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Using picture narratives to support equitable and informed  
participation in lung cancer screening

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## Abstract

**Background:** The use of pictures and narratives in print health communication has been successful in improving engagement, comprehension, and behavioural enactment. However, the use of these two modalities in an integrated way for health communication has been less extensively researched. Through the thesis, the term ‘picture narratives’ is used to refer to the portrayal of a narrative through a sequence of static visual images. Lung cancer is the third most common cause of death in Scotland – with some of the highest rates of lung cancer being in the most socioeconomically deprived areas of Glasgow. Lung cancer screening (LCS) is currently being trialled in the UK and, if expanded to a national screening programme, could greatly reduce the burden of lung cancer for individuals and for society. To be able to build understanding into the application of picture narratives in health communication, I developed and tested example picture narrative information in the context of LCS.

**Methodology:** A multidisciplinary approach was taken while developing the picture narratives to ensure they were well designed before evaluating their effectiveness. The first stage of the design process (Study 1) was content analysis of picture narrative use in current practice, looking at official information materials produced for invitees to cancer screening in the UK. The second design stage (Study 2) involved an analysis of the ways in which LCS related topics have been portrayed in comics. This study was used to identify culturally prevalent images, symbols and conventions used for picture narrative portrayals of cancer which could be adopted in the designs to increase recognisability and appropriateness. The third design stage (Study 3) was a community-based design workshop with twelve people aged between 50 and 75 who smoke and were living in a low-resource area of Glasgow. This workshop was used to explore LCS information design preferences and perceptions surrounding LCS within the target audience to make the picture narrative designs more engaging, acceptable, and supportive. Picture narrative LCS information was then created based on the findings of these studies alongside an expert review, the support of a professional artist and usability testing with eight members of the target audience (Study 4).

The picture narrative LCS information was then tested (Study 5) in a questionnaire study of randomised controlled trial design, with 311 people living in Glasgow aged between 50 and 75, to determine their effectiveness in supporting informed decision-making in an

equitable way in comparison to the same lung screening information provided as text with pictures and as text alone. Support of informed decision-making was measured via LCS knowledge acquisition, LCS eligibility self-assessment accuracy and LCS related beliefs.

Main findings: The picture narrative format was not found to support informed decision making when compared to the picture condition, producing lower knowledge scores and lower eligibility self-assessment accuracy. The LCS information provided as text with pictures was found to be most equitable, with the gap in knowledge scores between people with higher and lower levels of social economic deprivation being significantly smaller than when provided in text-only format. This thesis reaffirms the importance of using pictures that have been developed in a culturally sensitive way when producing health information materials that aim to both engage and inform.

Other avenues and opportunities for making use of picture narratives for supporting informed and equitable participation in lung cancer screening are considered.

## Table of Contents

|                                                                                               |    |
|-----------------------------------------------------------------------------------------------|----|
| Abstract.....                                                                                 | 2  |
| List of Tables .....                                                                          | 9  |
| List of Figures .....                                                                         | 10 |
| List of accompanying materials .....                                                          | 11 |
| Acknowledgements .....                                                                        | 13 |
| Author's declaration.....                                                                     | 14 |
| Abbreviations.....                                                                            | 15 |
| Chapter 1. Lung cancer screening information provision.....                                   | 16 |
| 1.1 Lung screening for early detection and improved cancer outcomes.....                      | 16 |
| 1.1.1 Lung cancer poses a serious threat to human life .....                                  | 16 |
| 1.1.2 Screening programmes for the early detection of cancer .....                            | 17 |
| 1.1.3 Screening for lung cancer .....                                                         | 18 |
| 1.2 Informing invitees about lung screening.....                                              | 21 |
| 1.2.1 Print information leaflets for providing information about cancer screening to invitees | 21 |
| 1.2.2 Defining LCS invitation success.....                                                    | 21 |
| 1.2.3 Deciding what information to provide to invitees to lung screening .....                | 24 |
| 1.2.4 Findings so far on the use of print information for cancer screening .....              | 25 |
| 1.3 Behavioural goals and communication targets of LCS information for invitees .....         | 26 |
| 1.3.1 Specifying the target behaviours.....                                                   | 26 |
| 1.3.2 Specifying the target communication outcomes .....                                      | 27 |
| 1.4 Review of factors involved in the communication of lung screening information .....       | 27 |
| 1.4.1 Source factors.....                                                                     | 27 |
| 1.4.2 Channel factors .....                                                                   | 30 |
| 1.4.3 Message factors.....                                                                    | 30 |
| 1.4.4 Receiver factors.....                                                                   | 35 |
| 1.4.5 Interactions between factors within the message components.....                         | 37 |
| 1.5 Summary .....                                                                             | 37 |
| Chapter 2. Using picture narratives in lung screening communication .....                     | 38 |
| 2.1 Properties of print communication.....                                                    | 38 |
| 2.1.1 Modality .....                                                                          | 40 |
| 2.2 Picture narrative form in health communication.....                                       | 40 |
| 2.2.1 Definition of picture narrative form.....                                               | 40 |
| 2.2.2 History of picture narratives in health communication .....                             | 43 |
| 2.2.3 Theories of picture narrative comprehension.....                                        | 45 |
| 2.3 Using picture narratives in lung cancer screening communication.....                      | 47 |
| 2.3.1 Affordances of pictures.....                                                            | 47 |
| 2.3.2 Affordances of narrative .....                                                          | 49 |
| 2.3.3 Affordances of picture narratives.....                                                  | 51 |
| 2.3.4 Constraints of picture narratives .....                                                 | 52 |

|                                                                                                 |    |
|-------------------------------------------------------------------------------------------------|----|
| 2.3.5 Current state of empirical research into picture narrative for health communication ..... | 53 |
| 2.4 Summary .....                                                                               | 55 |
| Chapter 3. Methodology, design approach, research questions and chapter summaries .....         | 56 |
| 3.1 Approach to the research .....                                                              | 56 |
| 3.1.1 Pragmatism .....                                                                          | 56 |
| 3.1.2 Mixed methods.....                                                                        | 57 |
| 3.1.3 Multi-disciplinary.....                                                                   | 57 |
| 3.1.4 Using design suggestions as a uniting principle .....                                     | 58 |
| 3.1.5 Research integrity .....                                                                  | 59 |
| 3.1.6 Researcher position.....                                                                  | 61 |
| 3.2 Approach to design .....                                                                    | 63 |
| 3.2.1 Target audience .....                                                                     | 64 |
| 3.2.2 Involving stakeholders .....                                                              | 65 |
| 3.2.3 Theory and evidence-informed .....                                                        | 67 |
| 3.3 Design stages followed .....                                                                | 68 |
| 3.3.1 Foundation .....                                                                          | 69 |
| 3.3.2 Exploration.....                                                                          | 69 |
| 3.3.3 Creation.....                                                                             | 70 |
| 3.3.4 Evaluation .....                                                                          | 71 |
| 3.4 Thesis chapters and research questions.....                                                 | 71 |
| Chapter 4. Analysis of picture use in print UK cancer screening information .....               | 75 |
| 4.1 Introduction .....                                                                          | 75 |
| 4.1.1 Background .....                                                                          | 75 |
| 4.2 Method .....                                                                                | 77 |
| 4.2.1 Sample.....                                                                               | 77 |
| 4.2.2 Analysis.....                                                                             | 78 |
| 4.3 Results .....                                                                               | 81 |
| 4.3.1 Overall Picture Prevalence .....                                                          | 81 |
| 4.3.2 Picture Function: Logos, Icons, Display and Message pictures.....                         | 81 |
| 4.3.3 Picture Content.....                                                                      | 81 |
| 4.1.2 Picture Style .....                                                                       | 84 |
| 4.2 Discussion .....                                                                            | 85 |
| 4.2.1 Picture Prevalence in Cancer Screening Information .....                                  | 85 |
| 4.2.2 Contributions to Theory .....                                                             | 87 |
| 4.2.3 Implications for Research .....                                                           | 88 |
| 4.2.4 Implications for Practice .....                                                           | 89 |
| 4.2.5 Limitations .....                                                                         | 90 |
| 4.2.6 Conclusions.....                                                                          | 91 |
| Chapter 5. Analysis of portrayals related to lung cancer screening in comics.....               | 92 |
| 5.1 Introduction.....                                                                           | 92 |
| 5.1.1 Background and aim .....                                                                  | 92 |

|                                                                                                                                                      |     |
|------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| 5.1.2 Analytic framework .....                                                                                                                       | 94  |
| 5.2 Method .....                                                                                                                                     | 96  |
| 5.2.1 Sampling strategy .....                                                                                                                        | 96  |
| 5.2.2 Analytical method .....                                                                                                                        | 96  |
| 5.3 Findings .....                                                                                                                                   | 97  |
| 5.3.1 Sample .....                                                                                                                                   | 97  |
| 5.3.2 Characteristics of the comics containing a cancer narrative .....                                                                              | 99  |
| 5.3.3 Representations of cancer .....                                                                                                                | 101 |
| 5.4 Discussion .....                                                                                                                                 | 108 |
| 5.4.1 Main findings .....                                                                                                                            | 108 |
| 5.4.2 Implications .....                                                                                                                             | 109 |
| 5.4.3 Sample and analysis limitations .....                                                                                                          | 110 |
| 5.4.4 Future consideration .....                                                                                                                     | 111 |
| 5.4.5 Conclusion .....                                                                                                                               | 112 |
| Chapter 6. Lung cancer screening information preferences and perceptions of the target audience:<br>A community-based design workshop approach ..... | 113 |
| 6.1 Introduction .....                                                                                                                               | 113 |
| 6.1.1 Background .....                                                                                                                               | 113 |
| 6.1.2 Design workshop .....                                                                                                                          | 114 |
| 6.1.3 Community-based workshop .....                                                                                                                 | 116 |
| 6.2 Community-based design workshop .....                                                                                                            | 116 |
| 6.2.1 Method .....                                                                                                                                   | 116 |
| 6.2.2 Results from the community design workshop .....                                                                                               | 123 |
| 6.3 Evaluation interviews of the design workshop approach .....                                                                                      | 135 |
| 6.3.1 Method .....                                                                                                                                   | 136 |
| 6.3.2 Results from the evaluation interviews .....                                                                                                   | 136 |
| 6.4 Discussion .....                                                                                                                                 | 138 |
| 6.4.1 Main findings .....                                                                                                                            | 138 |
| 6.4.2 Strengths and Limitations .....                                                                                                                | 141 |
| 6.4.3 Evaluation of the community-based design workshop approach .....                                                                               | 142 |
| 6.4.4 Conclusions .....                                                                                                                              | 143 |
| Chapter 7. Creating the picture narrative lung cancer screening test designs .....                                                                   | 144 |
| 7.1 Prototype development .....                                                                                                                      | 144 |
| 7.1.1 Design priorities .....                                                                                                                        | 144 |
| 7.1.2 LCS information selection .....                                                                                                                | 145 |
| 7.1.3 Development of an integrated list of recommendations for print health information that<br>support decision making and behaviour change .....   | 145 |
| 7.1.4 Expert review .....                                                                                                                            | 148 |
| 7.1.5 Creation of initial test designs .....                                                                                                         | 148 |
| 7.1.6 Working with artist .....                                                                                                                      | 154 |
| 7.1.7 Final design elements .....                                                                                                                    | 155 |
| 7.2 Usability testing .....                                                                                                                          | 158 |

|                                                                                                                                                                                                   |     |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| 7.2.1 Introduction and study aims.....                                                                                                                                                            | 158 |
| 7.2.2 Method .....                                                                                                                                                                                | 159 |
| 7.2.3 Results.....                                                                                                                                                                                | 163 |
| 7.2.4 Results.....                                                                                                                                                                                | 163 |
| 7.2.5 Discussion .....                                                                                                                                                                            | 168 |
| 7.3 Design modification.....                                                                                                                                                                      | 170 |
| Chapter 8. Outcome testing of the picture narrative LCS information designs: A randomised controlled trial .....                                                                                  | 171 |
| 8.1 Introduction.....                                                                                                                                                                             | 171 |
| 8.1.1 Background and study aims .....                                                                                                                                                             | 171 |
| 8.2 Methods.....                                                                                                                                                                                  | 173 |
| 8.2.1 Trial design .....                                                                                                                                                                          | 173 |
| 8.2.2 Recruitment.....                                                                                                                                                                            | 173 |
| 8.2.3 Measures .....                                                                                                                                                                              | 177 |
| 8.2.4 Sample Size.....                                                                                                                                                                            | 183 |
| 8.2.5 Randomisation .....                                                                                                                                                                         | 184 |
| 8.2.6 Statistical methods .....                                                                                                                                                                   | 184 |
| 8.3 Results.....                                                                                                                                                                                  | 188 |
| 8.3.1 Final sample .....                                                                                                                                                                          | 188 |
| 8.3.2 Outcomes .....                                                                                                                                                                              | 191 |
| 8.4 Discussion.....                                                                                                                                                                               | 195 |
| 8.4.1 Findings.....                                                                                                                                                                               | 195 |
| 8.4.2 Strengths .....                                                                                                                                                                             | 198 |
| 8.4.3 Limitations .....                                                                                                                                                                           | 198 |
| 8.4.4 Conclusion .....                                                                                                                                                                            | 201 |
| Chapter 9. Discussion .....                                                                                                                                                                       | 209 |
| 9.1 Justification for the thesis and summary of the research aims.....                                                                                                                            | 209 |
| 9.2 Summary of findings.....                                                                                                                                                                      | 211 |
| 9.2.1 What content and design characteristics should be used in picture narratives of lung cancer screening information for invitees within the target audience? .....                            | 211 |
| 9.2.2 Can picture narratives be used to support the effective communication of lung cancer screening information for invitees, in the interest of supporting informed and equitable uptake? ..... | 215 |
| 9.3 Strengths and Limitations .....                                                                                                                                                               | 216 |
| 9.3.1 Novel approach .....                                                                                                                                                                        | 216 |
| 9.3.2 Timely and valuable.....                                                                                                                                                                    | 216 |
| 9.3.3 Mixed method .....                                                                                                                                                                          | 217 |
| 9.3.4 Stakeholder involvement.....                                                                                                                                                                | 218 |
| 9.3.5 Study 1 .....                                                                                                                                                                               | 218 |
| 9.3.6 Study 2 .....                                                                                                                                                                               | 219 |
| 9.3.7 Study 3 .....                                                                                                                                                                               | 220 |
| 9.3.8 Study 4 .....                                                                                                                                                                               | 220 |

|                                                          |     |
|----------------------------------------------------------|-----|
| 9.3.9 Study 5 .....                                      | 222 |
| 9.3.10 Orientated towards comics.....                    | 223 |
| 9.3.11 Orientated towards white women.....               | 224 |
| 9.4 Implications of thesis for theory and practice ..... | 224 |
| 9.4.1 Theory .....                                       | 224 |
| 9.4.2 Practice.....                                      | 227 |
| 9.4.3 Future directions .....                            | 229 |
| 9.5 Concluding remarks .....                             | 231 |
| Appendices.....                                          | 232 |
| List of reference .....                                  | 329 |

## List of Tables

|                                                                                                                                                                |     |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Table 1-1. Summary of inclusion criteria for RCTs testing LDCT for lung cancer screening .....                                                                 | 20  |
| Table 1-2. Summary of the target communication outcomes for an information leaflet about lung screening mapped to target behaviours .....                      | 28  |
| Table 2-1. Conditions of each message dimension specific to print communication .....                                                                          | 39  |
| Table 3-1. Similar concepts across disciplines with discipline-specific terminology .....                                                                      | 58  |
| Table 3-2. Different stakeholder groups .....                                                                                                                  | 65  |
| Table 3-3. Key stakeholder matrix .....                                                                                                                        | 66  |
| Table 3-4. Double-Diamond phases mapped to final design stages followed .....                                                                                  | 74  |
| Table 4-1. Frequencies of style in display and message pictures in print cancer screening materials. ....                                                      | 85  |
| Table 4-2. Comparison of study findings between King (2015) and the current study. ....                                                                        | 87  |
| Table 5-1. Cancer-specific narrative characteristics of the identified comics .....                                                                            | 102 |
| Table 6-1. Summary of participant characteristics with anonymised participant identification numbers.....                                                      | 124 |
| Table 6-2. Interview participant characteristics .....                                                                                                         | 137 |
| Table 7-1. Information to provide to people before participating in lung cancer screening based on the UK National Screening Committee guidelines (2018) ..... | 146 |
| Table 7-2. Print health information evaluation tools .....                                                                                                     | 149 |
| Table 7-3. Gist-based messages covered in the test designs and their placement .....                                                                           | 156 |
| Table 7-4. Design decisions and justifications.....                                                                                                            | 157 |
| Table 7-5. Usability testing coding frame.....                                                                                                                 | 162 |
| Table 7-6. Participant characteristics .....                                                                                                                   | 164 |
| Table 8-1. Versions of the online questionnaire for identifying study condition and postcode level SIMD of the participants.....                               | 175 |
| Table 8-2. Intervention materials .....                                                                                                                        | 176 |
| Table 8-3. Knowledge measure items.....                                                                                                                        | 181 |
| Table 8-4. Response characteristics (i.e., returned questionnaires) by study condition and invitation modality .....                                           | 202 |
| Table 8-5. Response rate by study condition, SIMD and gender for participants recruited through posted invitation letter with questionnaire pack. ....         | 203 |
| Table 8-6. Respondent sociodemographic characteristics by study condition .....                                                                                | 204 |
| Table 8-7. Respondent smoking status and LCS eligibility by study condition .....                                                                              | 205 |
| Table 8-8. Confounding variables by study condition.....                                                                                                       | 206 |
| Table 8-9. Continuous primary outcomes by study condition .....                                                                                                | 207 |
| Table 8-10. Nominal primary outcomes by study condition.....                                                                                                   | 208 |

## List of Figures

|                                                                                                                                                    |     |
|----------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Figure 1-1. Logic model of the ‘problem’ .....                                                                                                     | 27  |
| Figure 2-1. Linear SMCR model .....                                                                                                                | 38  |
| Figure 2-2. Synergistic SMCR model.....                                                                                                            | 38  |
| Figure 3-1. Design stages followed through the project, mapped to the double diamond<br>model of design, with studies and chapters indicated ..... | 69  |
| Figure 3-2. Sections of the thesis and the included design steps .....                                                                             | 71  |
| Figure 4-1. Cancer screening topics present across Display and Message pictures .....                                                              | 83  |
| Figure 6-1. Workshop sections and activities .....                                                                                                 | 119 |
| Figure 6-2. Image produce by Cancer Research UK for the Be Clear on Cancer campaign,<br>2016.....                                                  | 120 |
| Figure 7-1. Picture narrative example 1 .....                                                                                                      | 150 |
| Figure 7-2. Picture narrative example 2 .....                                                                                                      | 151 |
| Figure 7-3. Picture narrative example 3 .....                                                                                                      | 152 |
| Figure 7-4. Picture narrative example 4 .....                                                                                                      | 152 |
| Figure 7-5. Picture narrative example 5 .....                                                                                                      | 153 |
| Figure 7-6. Picture narrative example 6 .....                                                                                                      | 153 |
| Figure 7-7. Picture narrative example 7 .....                                                                                                      | 154 |
| Figure 8-1. Flow diagram of the progress through the phases of a randomised trial.....                                                             | 174 |
| Figure 8-2. Interaction between socioeconomic deprivation and condition on knowledge<br>score .....                                                | 194 |
| Figure 9-1. Prototype used in usability testing .....                                                                                              | 221 |
| Figure 9-2. Design after usability testing.....                                                                                                    | 221 |
| Figure 9-3. Uniform panelled picture narrative sequence.....                                                                                       | 230 |
| Figure 9-4. Borderless picture narrative sequence .....                                                                                            | 230 |

## List of accompanying materials

|                                                                                                                  |     |
|------------------------------------------------------------------------------------------------------------------|-----|
| Appendix 1: Overview of thesis studies .....                                                                     | 232 |
| Appendix 2: Original plan for the design process.....                                                            | 233 |
| Appendix 3: Published paper from study 1 – Content analysis of UK cancer screening<br>information leaflets ..... | 234 |
| Appendix 4: Coding manual of picture content and style in print screening materials ...                          | 244 |
| Appendix 5: Catalogue of cancer comics identified and reviewed.....                                              | 249 |
| Appendix 6: Study 3 - Workshop schedule.....                                                                     | 251 |
| Appendix 7: Study 3 - Participant information sheet (short version) .....                                        | 252 |
| Appendix 8: Study 3 – Consent form.....                                                                          | 254 |
| Appendix 9: Study 3 - Demographic questions .....                                                                | 255 |
| Appendix 10: Study 3 - Participant information sheet (long version) .....                                        | 257 |
| Appendix 11: Study 3 - Discussion prompts .....                                                                  | 260 |
| Appendix 12: Study 3 - Example reference materials provided during design workshop<br>.....                      | 261 |
| Appendix 13: Study 3 - Participant's posters.....                                                                | 266 |
| Appendix 14: Study 3 - Example transcript poster .....                                                           | 270 |
| Appendix 15: Study 3 - Thematic maps.....                                                                        | 271 |
| Appendix 16: Study 3 - Participant and helper evaluation interview topic guide .....                             | 272 |
| Appendix 17: Study 3 - Artist evaluation interview topic guide .....                                             | 272 |
| Appendix 18: Study 3 - Table of workshop feedback interview extracts .....                                       | 273 |
| Appendix 19: Text information for test picture narrative lung screening designs.....                             | 275 |
| Appendix 20: All available guidance on using pictures in print health materials .....                            | 277 |
| Appendix 21: Identifying application of behaviour change techniques to print health<br>materials .....           | 278 |
| Appendix 22: Synthesis of guidance from print health materials evaluation tools.....                             | 280 |
| Appendix 23: Sketch of test designs v1 .....                                                                     | 283 |
| Appendix 24: Prototype designs (with letters identifying gist-based message content listed<br>in Table 7-3)..... | 284 |
| Appendix 25: Study 4 - Recruitment flier.....                                                                    | 288 |
| Appendix 26: Study 4 - Recruitment poster.....                                                                   | 289 |
| Appendix 27: Study 4 – Participant letter .....                                                                  | 290 |
| Appendix 28: Study 4 - Participant information sheet and privacy notice .....                                    | 291 |
| Appendix 29: Study 4 - Interview schedule .....                                                                  | 297 |

|                                                                                                     |     |
|-----------------------------------------------------------------------------------------------------|-----|
| Appendix 30: Study 4 - Example transcriptions around the designs .....                              | 301 |
| Appendix 31: Study 4 - Example section of completed coding frame for design elements<br>.....       | 302 |
| Appendix 32: Study 4 - Examples of usability test findings being applied to the designs<br>.....    | 303 |
| Appendix 33: Study 5 - Picture narrative LCS information .....                                      | 304 |
| Appendix 34: Study 5 - Text and pictures LCS information (study condition 1).....                   | 308 |
| Appendix 35: Study 5 - Text-only LCS information (study condition 1).....                           | 310 |
| Appendix 36: Study 5 – Invitation flier .....                                                       | 312 |
| Appendix 37: Study 5 – Invitation letter, participant information sheet and privacy notice<br>..... | 313 |
| Appendix 38: Study 5 - Questionnaire.....                                                           | 317 |
| Appendix 39: Project website .....                                                                  | 325 |

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## **Author's declaration**

I declare that, except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

### **Study 1 – Content analysis**

Dr Catherine Hanna and Lauren Fulton provided support as secondary coders on the content analysis for study 1.

### **Illustrations**

The first version of the picture narrative lung cancer screening information designs produced in this thesis were illustrated by Catherine MacRobbie. Catherine (M.Sc., MMAA, MIMI) is an award winning, professional Medical Artist working in Glasgow. Her freelance work primarily concentrates on illustration for publication of research in higher education, e-Learning, and on medical visualisation for healthcare industries. Catherine's research areas include visualising anatomical and pathological specimen collections in anatomy museums. She is fully accredited by the Academy of Healthcare Science and Medical Artists Association of Great Britain. You can contact Catherine at [catherinemacrobbie@hotmail.com](mailto:catherinemacrobbie@hotmail.com) or [@TheAnatomicalBotanist](https://www.instagram.com/TheAnatomicalBotanist) on Instagram

## Abbreviations

|          |                                                                                  |
|----------|----------------------------------------------------------------------------------|
| CDC      | Centers for Disease Control and Prevention                                       |
| CDV      | Community development worker                                                     |
| CT       | Computerised tomography                                                          |
| DANTE    | Detection and Screening of Early Lung Cancer with Novel Imaging Technology trial |
| Dépiscan | French Lung Cancer Screening trial                                               |
| DLCST    | Danish Lung Cancer Screening Trial                                               |
| ICD      | International Classification of Diseases                                         |
| ITALUNG  | Italian Lung Cancer Screening Trial                                              |
| LCS      | Lung Cancer Screening                                                            |
| LSS      | Lung Screening Study                                                             |
| LUSI     | German Lung cancer Screening Intervention                                        |
| MILD     | Multicentric Italian Lung Detection trial                                        |
| NCI      | National Cancer Institute                                                        |
| NELSON   | Dutch-Belgian Lung Cancer Screening trial                                        |
| NHS      | National Health Service                                                          |
| NLST     | National Lung Screening Trial                                                    |
| RCT      | Randomised Controlled Trial                                                      |
| SIMD     | Scottish Index of Multiple Deprivation                                           |
| UK       | United Kingdom                                                                   |
| UKLS     | UK Lung Screening trial                                                          |
| US       | United States                                                                    |
| USPSTF   | United States Preventive Services Taskforce                                      |
| WHO      | World Health Organisation                                                        |

# **Chapter 1. Lung cancer screening information provision**

## **1.1 Lung screening for early detection and improved cancer outcomes**

### **1.1.1 Lung cancer poses a serious threat to human life**

Morbidity and mortality rates for cancer remain troublingly high, while most other non-communicable diseases are on the decrease (World Health Organization, 2014). Global statistics from the World Health Organisation had cancer as the leading cause of death in 2020 (Ferlay et al., 2020). Cancer is the leading cause of death by a non-communicable disease in the UK (World Health Organization, 2018).

Lung cancer is the leading cause of cancer death worldwide (Ferlay et al., 2013). Malignant neoplasm of trachea, bronchus and lung (ICD-10 death certificate coding category C33-C34) was the third most common cause of death in the UK in 2018 (Office for National Statistics, 2020). In the UK, lung cancer is the second most common cancer for women (following breast cancer) and men (following prostate cancer), accounting for 13% of all cancers diagnosed between 2016 and 2018 (Cancer Research UK, 2022c). It is the most common cause of cancer mortality, being the cause of a fifth of all cancer deaths – killing more people than breast and colorectal cancer combined (Cancer Research UK, 2022a). The UK has a poor record for lung cancer survival compared to other countries, with a 5-year survival rate being the third lowest in Europe (Allemani et al., 2015). In 2018, Lung cancer mortality was significantly higher in Scotland than the UK average (Cancer Research UK, 2022c) and the third most common cause of death in Scotland (National Records of Scotland, 2018). Lung cancer mortality rates are also higher in areas with greater socioeconomic deprivation, within Scotland (ScotPHO, 2018a). High rates of incidence and mortality associated with lung cancer means carrying out work to increase lung cancer survival is of high priority, particularly for the Scottish population and for people experiencing greater socioeconomic deprivation.

### **1.1.2 Screening programmes for the early detection of cancer**

#### **1.1.2.1 Early detection of cancer improves outcomes**

Cancers found in the earlier stages (i.e., earlier in its progression) have greater chances of successful treatment and better survival rates. People diagnosed with lung cancer in its earliest stage of development, stage I (the earliest stage of progression), have the highest one-year net survival rates (88% for stage I vs 19% for stage IV; Office of National Statistics, 2019).

There are two paths to early detection of cancer, the diagnosis pathway and the screening pathways (World Health Organization, 2022). The diagnosis pathway involves the patient presenting with symptoms from which the medical staff make and test theories of what the cause could be, leading to a final diagnosis. Early detection via diagnosis is achieved by early presentation of the person with the cancer to a medical professional and quick identification of the disease by the medical professional. Due to lung cancer causing few discernible symptoms until it is at a late stage, this route to diagnosis is ineffectual. The second path to early detection is via screening.

Screening is the testing of asymptomatic individuals for a condition at a population level. In the UK, cancer screening is currently carried out through a centrally organised programme. Cancer screening improves cancer health outcomes and rates of survival, through early detection (Viguier, 2011). Cancer screening for breast, cervical and bowel cancer has been shown to reduce mortality for the particular type of cancer being screened for (bowel, Lin et al., 2016; cervical, Melnikow et al., 2018; breast, Nelson et al., 2016). Treatments are more successful when the cancer is in an earlier stage of development as cancers detected at an earlier stage require less aggressive and extensive treatment (Corradini et al., 2019). This also results in the patient experiencing reduced suffering and taking less time off work – reducing the financial burden on the patient and their employers. The treatments used when cancer is found earlier, rather than later, are also less costly for hospitals and the NHS (Birtwistle & Earnshaw, 2014). The earlier cancer is detected, the lower the costs for the person, as well as society.

#### **1.1.2.2 Cancer screening test results**

There are four main results a screening test will return: 1) the test detects the presence of cancer that, through further investigation, is confirmed (True positives), 2) the test

accurately detects the absence of cancer (True negatives), 3) the test detects the presence of cancer that is later found to not be present (False positives), 4) the test does not detect a cancer that is present (False negative). The frequency of false positives returned by a test is referred to as test sensitivity and the frequency of false negatives returned by a test is referred to as test specificity. Screening may also identify other health issues which are referred to as incidental findings.

There are additional benefits seen with cancer screening, alongside the early detection of cancer. These include reduction in overall mortality rates and finding other health conditions during the examination (referred to as incidental findings, Pinsky, 2014). People also report psychological benefits in light of receiving a negative result (Andrykowski, 2017; Hancox et al., 2022).

### **1.1.3 Screening for lung cancer**

With advances in medical technologies such as the improved body scanners and DNA sequencing alongside improvements in treatment options for lung cancer, the possibility of screening programmes for lung cancer has become viable. Lung screening is already available in the US (Krist et al., 2021). The European Union have encouraged the implementation of lung cancer screening via low dose Computer Tomography (low-dose CT) in a published position statement (Oudkerk et al., 2017). And, more recently, the European Society of Radiology and European Respiratory Society produced a joint statement saying that lung cancer screening should be implemented across Europe (Kauczor et al., 2020). On receiving encouraging results from RCTs run in the US and Europe, a number of implementation trials of lung screening at population-level are being run in the UK; 1) Liverpool Healthy Lung Project (LHLP), 2) Nottingham Lung Health MOT Pilot, 3) Manchester Lung Cancer Early Diagnosis service, 4) Lung Screen Uptake Trial (LSUT) in London, 5) Yorkshire Lung Screening Trial (YLST). A UK-wide lung screening programme is likely to be introduced following the findings of these trials (Grover et al., 2020).

#### **1.1.3.1 Screening modality**

Low-dose CT scans have so far had the greatest success as a method for detecting lung cancer in early stages. Based on the results of the US National Lung Screening Trial (NLST), screening via low-dose computed tomography could bring about 7,000 fewer

cancer deaths per annum (Aberle et al., 2011). Similarly, the Dutch-Belgian Lung Cancer Screening trial (NELSON; Yousaf-Khan et al., 2017) and the UK Lung Cancer Screening pilot (UKLS; Field, Duffy, Baldwin, Whynes, et al., 2016) have been successful and support the implementation of national lung screening. Pinsky (2018) concluded that the benefits of low-dose CT for lung screening outweigh the harms for individuals in the high-risk group to a moderate degree based on a global review of RCTs and ‘demonstration projects’. Additionally, the screening is likely to be offered both in clinics and in mobile low-dose CT scanner units as this method of provision has received good participation rates in the Yorkshire trial (Crosbie et al., 2019).

### **1.1.3.2 LCS Eligibility and Inclusion criteria**

Lung screening will be targeted at people who are at risk of getting lung cancer. The inclusion criteria used across the different trials of low-dose CT for lung cancer screening are detailed in Table 1-1. The following is a summary of the main inclusion criteria being used across these trials.

*Age.* The ages of the target population within the reviewed trials ranged from 49 to 75 years old. The reason given for excluding older participants, in the UK Targeted Lung Health Checks Programme was due to the programme’s duration (i.e., participants older than 75 will not benefit once cancer is identified and treated for; National Cancer Programme, 2019).

*Gender.* Almost all trials included both men and women. DANTE as well as the Netherlands arm of the NELSON trial included only men.

*Smoking history.* All trials, apart from UKLS, included participants based on smoking history determined by smoking frequency and time since smoking cessation. One of two measures were used for smoking frequency; either  $x$  number of cigarettes a day for  $x$  number of years or, smoking amount of cigarettes equivalent to one pack of cigarettes (20 cigarettes) a day smoked for  $x$  number of years (e.g., 1 pack a day for 20 years = 2 packs a day for 10 years). DEPISCAN had the lowest smoking frequency requirement (at 15 cigarettes a day for 20 years), while LSS and NLST had the highest (at equivalent to a pack a day for 30 years). If participants no longer smoked, quitting smoking must have happened no longer than  $x$  number of years ago (also known as, maximum time since

smoking cessation). This was at 15 years for two of the trials and at 10 years for the other trials.

*Table 1-1. Summary of inclusion criteria for RCTs testing low-dose CT for lung cancer screening*

| Abbreviated title | Gender                            | Age       | Smoking history                                                        |                                      |
|-------------------|-----------------------------------|-----------|------------------------------------------------------------------------|--------------------------------------|
|                   |                                   |           | Quantity                                                               | Maximum time since cessation (years) |
| UKLS              | Both                              | 50–75     | Risk score                                                             | Not applicable                       |
| NELSON            | Men (Netherlands), Both (Belgium) | 50–69     | $\geq 15$ cig/d $\times$ 25 years or $\geq 10$ cig/d $\times$ 30 years | 10                                   |
| DLCST             | Both                              | 50–70     | $\geq 20$ pack year                                                    | 10                                   |
| ITALUNG           | Both                              | 55–69     | $\geq 20$ pack year                                                    | 10                                   |
| DANTE             | Men                               | 60–74     | $\geq 20$ pack year                                                    | 10                                   |
| MILD              | Both                              | $\geq 49$ | $\geq 20$ pack year                                                    | 10                                   |
| LUSI              | Both                              | 50–69     | $\geq 15$ cig/d $\times$ 25 years or $\geq 10$ cig/d $\times$ 30 years | 10                                   |
| Dépiscan          | Both                              | 50–75     | $\geq 15$ cig/d $\times$ 20 years                                      | 15                                   |
| LSS               | Both                              | 55–74     | $\geq 30$ pack year                                                    | 10                                   |
| NLST              | Both                              | 55–74     | $\geq 30$ pack year                                                    | 15                                   |

*Candidacy over eligibility.* Caverly et al. (2018) introduce the idea of two candidate groups for screening; those with the best chance of benefit from screening for whom clinicians should recommend screening to the individual (‘best candidates’) versus candidates whose chance of benefitting is lower and so the individual should have a much greater involvement in the decision of whether they will participate in the screening (‘preference-sensitive candidate’).

*Impact of eligibility criteria on detection rate.* Ruparel and Janes (2016) provide a summary of the eligibility criteria and cancer detection rates of all Non-RCTs and RCTs of low dose CT for lung cancer screening prior to 2016. DANTE and UKLS had the highest detection rates (2.2 and 2.1, respectively). The higher detection rate in the DANTE trial can be attributed to the higher age (60-75yrs) and heavier smoking status (20 packs a year and above, quit less than 10 years prior) of the participants while success of the UKLS trial

in detecting cancer can be attributable to the stringent risk estimate (Liverpool Lung Project version 2; LLPv2) used to qualify eligibility.

## **1.2 Informing invitees about lung screening**

### **1.2.1 Print information leaflets for providing information about cancer screening to invitees**

In current cancer screening programmes, all invitees are sent information about the screening in the form of a leaflet alongside an invitation letter, designed by the screening programmes, such as ‘Bowel cancer: The Facts’ (NHS Cancer Screening Programmes, 2016), ‘NHS breast screening: Helping you decide’ (Public Health England, 2019a) and ‘NHS cervical screening: Helping you decide’ (Public Health England, 2019b). These leaflets are sent directly to screening invitees’ houses.

Using mailed leaflets allows for mass distribution of information, as well as the ability to target only those eligible for screening within a household. Production and provision of print materials is simple, and therefore, this method is relatively inexpensive and widely used for disseminating cancer screening information. Paper-based materials also have the assets of tactility, a level of permanence and do not require additional technology to be accessed. Additionally, print materials are suitable to be provided with a mailed invitation letter or by a health care professional if invited during an in-person consultation and can be used as a tool to facilitate communication between cancer screening attendees and providers at the clinic during the screening session.

### **1.2.2 Defining LCS invitation success**

A necessary condition, for any form of medical screening to be effective, is high rates of participation in the eligible population (Weller & Campbell, 2009). Screening programmes need to achieve high uptake to have high predictive power. In the case of cancer screening, predictive power is the programme’s ability to identify cancer in the population. Additionally, high uptake is needed for the benefits of screening to outweigh the financial costs. Higher uptake will mean more cancers being found early which will mean less extensive treatment is needed and therefore lower financial cost to society. However, high uptake rates are not the only measure of successful recruitment to cancer screening programmes (Raffle, 2001). Obtaining appropriate, equitable and informed participation

are also important and are conditions that an information leaflet for people invited to take part in LCS ought to achieve.

#### **1.2.2.1 Appropriate participation**

The first condition for successful recruitment into a cancer screening programme is ensuring that only the people who are eligible for the screening test are attending. Incorrect attendance to screening is unlikely to occur in the UK context as people are invited based on their eligibility which is determined through their GP records. However, appropriate participation also refers to achieving screening attendance from people who are at greater risk of having the condition and so, have greater need. In current screening programmes there is a trend for those with greatest need being least likely to take part (McCowan et al., 2019). This has been seen in some lung screening trials, with former smokers reporting greater interest and being more likely to attend LCS than current smokers (Aberle et al., 2011; Yousaf-Khan et al., 2015).

#### **1.2.2.2 Equitable participation**

Cancer screening programmes in the UK have encountered lower rates of participation from people experiencing greater deprivation compared to those living with greater affluence (Douglas et al., 2016; Solmi et al., 2015). The UK Lung Screening trial received lower uptake from people from lower socioeconomic groups (McRonaldd et al., 2014), with the final report on the trial advising that “strategies for increasing uptake and providing support for underserved groups will be key” for the success of a lung screening programme (Field, Duffy, Baldwin, Brain, et al., 2016, p. viii). This trend is particularly problematic for lung cancer screening in Scotland because people from less affluent areas are at much greater risk of getting lung cancer (Tweed et al., 2018). Therefore, to ensure the success of a future lung cancer screening programme in Scotland, a priority is to identify strategies for achieving equitable uptake across socioeconomic groups.

#### **1.2.2.3 Informed participation**

In healthcare, the term ‘informed choice’ has two uses. Firstly, the term refers to an ethical imperative to ensure that people have access to healthcare and are involved in decisions about their health. Secondly, referring to an individual making an ‘informed choice’ is to refer to a situation where the person has; 1) been made aware of the healthcare options available to them, 2) made an informed decision about the options and then, 3) carried out

the option they selected (Hersch et al., 2017). In this case, an informed decision is a decision that the person has participated in making while knowing the evidence surrounding the option/s and having considered their values and personal circumstances (Marteau et al., 2001). The UK National Screening Committee (2018) have asserted that personal informed choice, defined as making a decision “based on access to accessible, accurate, evidence-based information”, should be supported throughout the cancer screening programmes. Empowering people to make balanced and informed decisions about screening are two key ambitions set out in the Scottish Government Cancer Strategy, ‘Beating Cancer: Ambition and Action’ (The Scottish Government, 2016). Informed choice is particularly relevant in the context of lung cancer screening, as it is an elective medical test that carries some risks and potential harm. Therefore, it will be important for a LCS information leaflet to be able to support engagement with, understanding of, and consideration of, the cancer screening information. Rimer et al.’s (2004) definition of an informed decision also states that a decision is informed if the individual feels they have been involved in the decision-making process to the level they desire. This last point embraces the fact that people differ in how much they wish to be involved in the decision (Scholl et al., 2011) and maintains that the decision is still an informed one if the individual is satisfied with the degree to which they have been involved.

Studies in the UK have found that people wish to be informed in regards to cancer screening. Participants in a study by Ruparel et al. (2019) felt being informed about lung screening benefits and risks was a “human right” and that taking part should be an “individual choice”. However, other participants wanted the decision to be made at a population level. Crothers et al. (2016) and Kanodra et al. (2016). These perspectives suggest it would be suitable to provide expert guidance to everyone while, importantly, having sufficient information accessible for those who wish to partake to a greater degree in the decision-making process. There is a general agreement that people wish to maintain autonomy (Waller et al., 2012).

Informed decision-making is particularly important for lung screening where there are several risks, harms and costs associated with taking part. The risks and harm include exposure to radiation from the CT scan, overdiagnosis, which is the detection and unnecessary treatment of tumours that would not have caused the person harm, and with follow-up diagnostic tests bringing their own risk of harm (Pinsky, 2014). Undergoing lung screening can cause anxiety and increase in cancer worry (Wu et al., 2016). Receiving a

positive result, whether a false positive or a true positive can cause distress for the receiver (Kummer et al., 2020).

There are concerns that nationally led health agendas reduce evaluation to individualist outcome-based measures (Cross et al., 2017) and omit potential macro-ethical issues (Sindall, 2002) such as empowerment (Tengland, 2012). The goal of achieving informed participation presents an alternative framework to that of achieving high uptake rates and attends to these concerns.

In the UK, people often report high enthusiasm for cancer screening in general, believing it to be a positive thing (Petrova et al., 2015; Waller et al., 2016). This positive attitude has also been found towards lung screening (Greene et al., 2018; Quaife et al., 2017) and a national survey in England found intention to do lung screening was high (Quaife et al., 2018). Positivity toward screening programmes will support message acceptance. However, this generalised positive attitude is not necessarily supportive of informed decision making. Sharma et al. (2019) found participants had positive attitudes towards lung screening but had limited knowledge about it. Similarly, participants in Greene et al.'s (2018) interview study overestimated the benefits and underestimated or ignored the potential harms, with overdiagnosis not mentioned at all. This demonstrates that positive attitudes reflect something other than an informed consideration of screening as it relates to oneself. Information about lung screening must work to ensure invitees are aware of the 'less positive' aspects of screening (such as, overdiagnosis and potential harms), to ensure informed decision-making.

### **1.2.3 Deciding what information to provide to invitees to lung screening**

There are three approaches we can take when identifying what information would be most useful for the target population in making a decision about lung screening. The first approach is to use medical and expert consensus to identify key decision factors should be catered for in the information provided, which can include using guidelines already created by professional bodies. This usually ensures an ethical practise in health information provision, for example service users must be informed of any harms they may experience from using a service.

The second approach is to determine what key decision factors are valued by the target population and then provide information relevant to these decision factors. This approach

supports person-centred health information provision as it is guided by the preferences of the target population. To support decision making we may want to ensure that the information we are providing is able to resolve decision factors valued by the target population of the information. This might be of particular importance when attempting to eliminate disparities in LCS participation (Burnett-Hartman & Wiener, 2020).

Marteau et al. (2001) also suggest a third approach that considers the consequences of the inclusion versus the exclusion of different information on both psychological and behavioural outcomes such as anxiety, worry, acceptability, informed decision making, and screening behaviour. For example, Hersch et al. (2014) and Perez-Lacasta et al. (2019) have looked at the impact of providing women with information about breast cancer screening overdiagnosis on informed choice and worry. This approach is concerned with outcomes at a population-level. The strongest strategy will likely be to provide people with a culmination of the information identified as necessary through all three of these approaches.

#### **1.2.4 Findings so far on the use of print information for cancer screening**

Where the aim is to increase informed participation to lung screening, mailed information material presents an opportunity for intervention. There are relatively few studies looking into best practice for screening information material. Duffy et al. (2017) have reviewed studies testing interventions to increase cancer screening uptake published between 1990 and 2015. Within this review they have reported on a group of studies looking into the impact of using different invitation materials. The inclusion of an educational health brochure (Wardle et al., 2003) and an invite to a general health check (Mant et al., 1992) found an increase in colorectal screening uptake. On the other hand, Youl et al. (2005)'s study in Australia found inclusion of a brochure with the invitation letter did not increase screening for skin cancer. Wardle et al. (2016) found that simplifying the information material or supplementing it with a narrative-based leaflet did not increase colorectal screening uptake. Since Duffy et al.'s (2017) review, S. G. Smith et al. (2017) published a study which found inclusion of gist-based information alongside the standard information in a colorectal cancer screening leaflet did not increase uptake to a significant degree and did not reduce disparities in uptake across socioeconomic groups. However, the gist-based information was found to improve knowledge (S. G. Smith et al., 2015). Their adoption of theory and rigorous testing during the development (S. G. Smith et al., 2013) may account for why they found this improvement in knowledge. A study looking at leaflets for NHS

Health Checks incorporating messages framed in terms of gains, compared to those incorporating messages framed in terms of losses, found no impact on uptake (Gold et al., 2019). More recently, within the UK Lung Cancer Screening pilot, a tailored invitation leaflet developed to overcome barriers to screening by applying behavioural science theory to the design and content was tested within a randomised control trial and was found not to increase uptake overall compared to a control leaflet. However, the theory-informed leaflet did decrease disparities in uptake across participants from different socioeconomic backgrounds (Quaife et al., 2020). These studies demonstrate an increase in applying behavioural science principles to screening invitation leaflets and a range of success depending on the approach and context within which it has been applied.

## **1.3 Behavioural goals and communication targets of LCS**

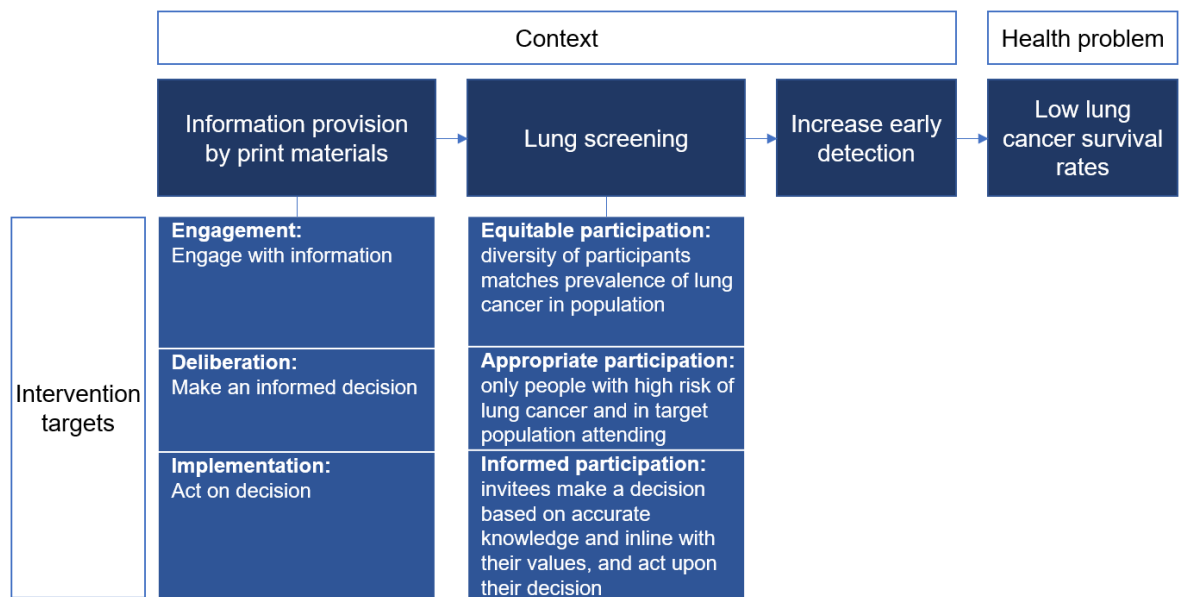
### **information for invitees**

The following sections attend to the first step for developing a theory-informed intervention for changing behaviour outlined in the intervention mapping approach (Bartholomew Eldredge, 2016). The first step of the approach is to produce a logic model of the problem and determine target behaviours for the intervention.

#### **1.3.1 Specifying the target behaviours**

For print information to have any impact on uptake to lung screening, it will need to be engaged with by the invitees (i.e., picked up and read; Engagement). Initial engagement will allow the invitees to become aware of the availability of the screening. Continued engagement will allow the invitees to receive the information necessary for making an informed choice. On the path to making an informed choice, invitees will need to engage in decision-making, using the information provided (Deliberation) and then act upon the decision made (Implementation). Figure 1-1 maps these targets onto the logic model of the problem. To ensure equitable uptake of lung screening, the intervention must support these three target behaviours for all invitees across different demographic identities. These target behaviours become the intervention targets when developing information materials to be provided to invitees to LCS.

Figure 1-1. Logic model of the ‘problem’



### 1.3.2 Specifying the target communication outcomes

The following table identifies the specific receiver actions necessary for the target behaviours as well as qualities a LCS information leaflet must achieve (i.e., the communication outcomes; Table 1-2). The inclusion of this third column, covering communication outcomes, is an attempt to ensure balance between focus on the individual and focus on the communication. This is in line with the interdisciplinary nature of our approach and avoids an individual-centric perspective.

## 1.4 Review of factors involved in the communication of lung screening information

The following section reviews factors that may have an impact on LCS message reception. The review is structured using Berlo’s (1960) message categories (source, channel, message, receiver; described further in chapter 2), for clarity and to ensure all aspects of the design of the print lung screening information is considered.

### 1.4.1 Source factors

Recipients of the information material will make judgments about the material (including the content, intentions and meaning) based on their perceptions of the *source*. The source, also referred to as sender, being the agent from which the message originates. Health communication research has often looked at the effects perceptions of the source has on

message reception (Wilson & Sherrell, 1993). In the cases of print sent information, perception of the source will be derived from the message content and channel as this is the only information the invitees will have access to regarding the source. Receiver's perceptions of whether the information being provided can be trusted is an important factor in message reception outcomes (Eagly & Chaiken, 1993) and this is tied to perceptions about the source (i.e., the spokesperson or provider) of the information (Priester & Petty, 2003).

*Table 1-2. Summary of the target communication outcomes for an information leaflet about lung screening mapped to target behaviours*

| Target behaviours                          |    | Target communication outcomes                  |                                                                 |
|--------------------------------------------|----|------------------------------------------------|-----------------------------------------------------------------|
|                                            |    | Receiver actions                               | Message qualities                                               |
| Engagement:<br>Engage with information     | 1  | Pick up and read information material          | Gain attention                                                  |
|                                            | 2  | Read all of information material               | Maintain attention (motivation to continue reading)             |
| Deliberation:<br>Make an informed decision | 3  | Comprehend the information*                    | Provides information in a way that it can be understood         |
|                                            | 4  | Acquire knowledge                              | Provides information for both gist and verbatim representations |
|                                            | 5  | Clarify values and personal circumstance*      | Supports with identifying and considering values and situation  |
|                                            | 6  | Engage in decision making                      | Supports decision making processes                              |
| Implementation:<br>Act on decision         | 7  | Know what actions to carry out and how         | Provides information on actions required                        |
|                                            | 8  | Remember the decision                          | Supports with recall of decision                                |
|                                            | 9  | Carry out actions in accordance with decision* | Supports completion of necessary action                         |
|                                            | 10 |                                                | Motivate engagement in the behaviour                            |

*Note.* \* reflects the conditions necessary for informed choice

#### **1.4.1.1 Perceptions of the message source**

The source of the information will be the NHS and will likely be signified by a logo, as is current practice. Perceptions about the NHS will be tied to beliefs about health care services or providers and may also denote authority figure, doctors, medical professionals,

scientists, experts, general practices and practitioners, public services, the government. Young et al. (2018) found ‘relationship with the health service’ as one of three main themes in their meta-ethnography of cancer screening attendance decisions, with trust being an important factor in the decision to do cancer screening. Trust of health service and providers has been found to be a key factor influencing engagement with LCS (Gressard et al., 2017). In a UK sample, Ruparel et al. (2019) found participants trusted their doctors’ recommendations and reported this to be their reason for doing screening. Draucker et al. (2019) found physician recommendations were key to participants’ decisions to take part in LCS, with participants who had decided not to do the screening reporting that it was not necessary for them as their physician had not mentioned it. Additionally, participants who were undecided said they would go for screening if recommended and participants who had done screening said they had done so based on a recommendation from a physician.

Lack of trust in the health care provider and their advice can be a result of previous trauma or lack of familiarity. Participants in Austin et al.’s (2009) focus group study reported a reason for not taking part in cancer screening was believing their cultural or religious needs would not be met, or that they would be made to feel uncomfortable due to these needs. Groups who have been mistreated by the health care system, or public services more generally (such as women, ethnic-, gender- and sexual minorities), and groups with language differences and inexperience with the health care system (for example, immigrant populations) will be most impacted.

#### **1.4.1.2 Power dynamics**

Power dynamics involved in the relationship between the public and medicine conflict with an individual’s ability to make an unbiased decision. Generally, medical knowledge is given greater prestige than lay knowledge. This means the message is given greater weight in a person’s decision to screen than their personal values and situation. This would seem acceptable under the guise that medical information is balanced and impartial (as is now the case with information leaflets about screening). However, an invitation letter is implicitly loaded with the message that medical professionals believe you should screen. For some people, the power dynamic will motivate them to comply – and agree to screening – while for other people this will motivate them to resist – and not agree to screening.

Studies have found a theme of compliance with invitees to screening, where doing screening is framed as the correct, sensible and proper thing to do (Bush, 2000). In some instances, compliance may be a result of feeling their future quality of care could be at risk if they were not to ‘obey’ (Jepson et al., 2007). Alternatively, it has also been found that people attempt to resist the control or surveillance perceived as associated with the screening programmes (Young et al., 2018). Both extremes undermine an informed decision, as response is based on feeling towards the source of the message rather than information about the options.

#### **1.4.2 Channel factors**

The *channel* is to be print medium suitable for mass scale printing and posting (i.e., leaflet). With this, the only thing to be decided is the physical format (shape, size, texture, folding) of the information material. This should be considered in terms of how the materials will be perceived by the invitees. As most health leaflets take a three-fold format, this may be what invitees expect of health information. We may wish to align with this expectation to support familiarity and ease of recognition or we may want to subvert these expectations to support novelty and gain attention. The format will also be constrained by the amount of information needing to be provided and the cost. For example, a gloss finish will make the material seem higher quality which could lead to higher perceived credibility (Metzger, 2007) but may be unaffordable.

#### **1.4.3 Message factors**

The following sections highlights that a lung screening message will likely be experienced as complex, uncertain, unfamiliar, threatening and with delayed benefit. These qualities are considered in terms of their impact on *message* reception and what might be done to supported desired communication outcomes.

##### **1.4.3.1 Complexity**

There is much to consider when deciding to go for screening; What is the likelihood of benefiting from screening (this involves considering a multitude of personal risk factors)? How and when to participate? What is involved during the screening test? What are the potential outcomes of the screening (including, learning about false positives and false negatives)? How would one respond if cancer were found? Additionally, the causal factors for lung cancer, as well as the factors determining eligibility for the screening, are multiple

and interacting. There is also the issue of screening statistics, with patients and practitioners finding it difficult to understand probabilistic numerical information (Han et al., 2009; Wegwarth et al., 2012). Consequently, it will be important for everything to be done to make the LCS information clear, coherent and easy to follow.

Providing gist-based information (the bottom-line ‘take-home’ message) has been posited as a way of supporting comprehension of cancer screening communications, that might be able to alleviate some of the screening disparities found across socioeconomic status driven by differences in health literacy (Wardle et al., 2016). This method is guided by the fuzzy trace theory and the assertion that gist-based reasoning can lead to better judgement and decision making when biases are minimal (Blalock & Reyna, 2016). Supporting this assertion in the context of cancer screening, S. G. Smith et al. (2015) found supplementing bowel screening information with a gist-based insert improved knowledge. A study by Cho et al. (2018) demonstrates how gist and verbatim information may be provided in a pictorial format, although their study found no significant difference between gist and verbatim graphics on acquisition of either gist or verbatim knowledge related to caffeine side effects.

#### **1.4.3.2 Uncertainty**

Following Han’s (2011) taxonomy of uncertainty, complexity is a source of uncertainty. In addition to this, the probabilistic nature of cancer risk and screening outcomes is another source of uncertainty. Future outcomes for the individual, at the point of being invited to screening, are indeterminable – there being no way of knowing if someone has cancer before being tested or if the person will be inadvertently harmed by the process (including overdiagnosis and risks of further testing). Additionally, the chance of benefiting from screening greatly differs even within the eligible population (Schneider & Arenberg, 2015). This ambiguity is another source of uncertainty. Based on a scoping review of recommendations for communicating uncertainty, Medendorp et al. (2021) “emphasizing the controllable elements of the situation” is needed to provide patients with a sense of control in the face of uncertainty (p. 1037).

#### **1.4.3.3 Unfamiliarity**

Lack of familiarity may be a particular challenge with print lung cancer screening information. Concepts surrounding medical screening are often unfamiliar to people, with

studies often finding people confuse screening with diagnostic testing (Hudson et al., 2017; Woof et al., 2020). The idea of testing people who are not showing symptoms conflicts with peoples' understanding of the usual diagnostic process. Similarly, concepts such as risk, within the context of health and illness, may be unfamiliar to invitees. People often conflate risk factors to mean direct causes of cancer, leading to the misinterpretation that 'scientists say everything causes cancer' (May et al., 2017).

#### **1.4.3.4 Threatening**

Due to the association of cancer with death and illness, the thought of lung cancer can be threatening to one's sense of personal safety and certainty and can increase feelings of existential vulnerability which is experienced as psychologically uncomfortable (Leventhal et al., 2016). A large population-based survey in England found 47.6% of participants endorsing the statement that 'Lung cancer is a death sentence' (Quaife et al., 2018). Dillard and Nabi (2006) provide examples of different types of cancer screening messages resulting in different emotional response based on Nabi's (1999) cognitive-functional model. In this model, appraisals of 'high probability of serious harm' leads to the general appraisal of 'danger' which leads to the emotion 'fear'. Lung cancer is repeatedly reported as something people fear (Greene et al., 2018; Ruparel et al., 2019), with fear being a main theme found in interviews with older smokers in socioeconomically deprived neighbourhoods in the UK (Quaife et al., 2017).

The common-sense model is helpful in considering the impact of personally threatening information on behaviour (Leventhal et al., 2016). The model poses emotions are experienced alongside the cognitive interpretation of a health threat, and that both lead to a coping response. One coping response for uncomfortable emotions, such as fear or worry, is to avoid information associated with the health threat. Within the model, avoidance (or 'selective exposure') is a type of 'expressive suppression' also referred to as emotion-focused coping, where the goal is to minimize the negative emotions (Gross & Levenson, 1993). Lung screening eligible participants in Carter-Harris et al's (2017) study in the US reported fear of lung cancer and fear of the treatment as reasons for having not attended LCS after being recommended by a clinician during a health visit.

Lung screening information will be most threatening to the people whom it is most relevant to, as increase chances of getting lung cancer is equivalent to a greater threat. This is reflected in the fact current smokers were most likely to report fear and the desire to

avoid lung cancer information as their reason for not taking part in the UKLS trial, compared to former smokers who are at less risk of lung cancer (Ali et al., 2015).

An alternative coping strategy is to change one's interpretation of the threatening event or condition, referred to as 'cognitive reappraisal'. For example, thinking of lung cancer as a treatable disease rather than a death sentence. This coping strategy has been shown to have better social, emotional and cognitive outcomes than expressive suppression such as avoidance (Cutuli, 2014). However, cognitive reappraisals can lead to biased judgement (referred to by Liberman & Chaiken, 1992 as defensive systematic processing) and can negatively impact engagement with healthy behaviour (van 't Riet & Ruiter, 2013). In the case of lung screening, a smoker might think 'I don't smoke that much' or 'smoking isn't actually a main cause of cancer', as to minimise perceived personal relevance and detach oneself from the health threat. Alternatively, the elements of uncertainty embedded in lung cancer screening might lend itself to high-risk individuals discounting the need for screening. This was indicated by participants in Quaife et al.'s (2017) interview study with older smokers in the UK, who focused on the unpredictability of risk in the context of LCS.

The most supportive coping strategies for engaging in decision making and health behaviours (such as screening) are problem-focused coping strategies. With lung cancer as the threat, a specific problem-focused coping strategy could be participating in lung screening or talking to health care providers about screening for further guidance, assurance and encouragement, as to reduce worry and uncertainty. Some participants in Quaife et al.'s (2017) interview study reported they would be motivated to do lung screening by the "potential for reassurance" of a negative result. In a semi-structured interview study, Schapira et al. (2016) found some participants considered lung screening as an opportunity to gain "a sense of control in the face of a threatening health condition" while other participants said they would prefer not knowing. There are individual differences in which coping strategy people have a propensity to adopt (Miller, 1995) when faced with health threats (Dillard & Nabi, 2006), which could explain why not everyone who expresses fear when encountering the cancer screening invitation goes on to avoid the information. The problem-focused coping strategy of using screening to combat uncertainty is only an option when invitees believe screening can bring certainty, which is undermined by false positives and occurrence of fast-growing tumours between scans.

To achieve successful LCS information provision, it will be essential to find ways to overcome defensive responses to the health threat of lung cancer. Giving clear recommendations on how the threat can be avoided or overcome (i.e., supporting a problem-focused coping response) may be one way to prevent or reduce defensiveness (Ruiter et al., 2001). Self-affirmation, first posed by Steele (1988), is the process of affirming the “perceived adequacy or integrity” (p. 262) of one’s self-concept and has been found to increase a person’s tolerance for considering threatening information, resulting in less defensive responses (Sherman & Cohen, 2006).

#### **1.4.3.5 Delayed benefit and psychological distance**

Health behaviours are the outcome of a trade-off between more immediate reinforcement (based on reward and cost such as, watching tv rather than reading a leaflet about lung screening) and more delayed reinforcement (such as, avoiding dying from lung cancer). This choice is ‘intertemporal’ due to being based on more than one timepoint (Urminsky & Zauberman, 2018). The main benefits of participating in cancer screening (including, engaging with the information materials and organising an appointment) are at a future time from the point that the invitation is received. Valuing immediate outcomes over delayed outcomes is known as delay discounting (Frederick et al., 2002; Logue, 1988). People who rate highly on delay discounting (i.e., value immediate reinforcement more) are less likely to engage in preventative behaviours (Story et al., 2014). A study by Whitaker et al. (2011) suggested individual differences in whether people are present or future orientated partially explained lower cancer screening attendance in people with lower socioeconomic status. J. Lee et al. (2020) found, in a LCS eligible population, rating higher on delay discounting (‘high time preference’ or ‘present bias’) was associated with being less likely to report intentions to take part in lung cancer screening.

Construal level theory provides a useful framework for considering the impact of the information characteristics of delayed benefit and uncertainty on people’s interpretations of the information and the impact on perception and action (Henderson et al., 2011). A delayed benefit has temporal distance between the persons present experience and the imagined scenario while an uncertain event can be thought to have hypothetical distance. The perceived distance of a phenomenon to oneself is also based on spatial distance and social distance. Trope and Liberman (2010) have found that people process information with “a broad and abstract mindset (high construal)” when they are psychologically distant from the perceived phenomena (e.g., lung cancer screening), while they process

information “at a concrete and detailed level (low construal)” when the phenomena is psychologically ‘close’ (Lee, 2019, p. 320). Affective forecasting can be used to strengthen association of future outcomes with present decision making (Ellis et al, 2018). One form of affective forecasting is increasing anticipated regret for the individual (Brewer et al., 2016) another is increasing their optimism (Briley et al., 2017).

#### **1.4.4 Receiver factors**

The *receiver* of the lung screening information materials in a future program will be anyone being invited to the screening. This is anticipated to be older adults (aged between 50 and 75) with a recent history of heavy smoking (smoking around 10 cigarettes a day for 20 years no more than 15 years previous).

Several qualitative studies conducted in the US have looked into LCS perceptions, that are implicated in LCS decision-making or participation, of people eligible (across varying criteria) for LCS (Carter-Harris, Brandzel, et al., 2017; Carter-Harris, Ceppa, et al., 2017; Draucker et al., 2019; Greene et al., 2018; Gressard et al., 2017; E. R. Park et al., 2014; Raju et al., 2020; Roth et al., 2018; Sin et al., 2016). Two qualitative studies (Ruparel et al., 2019; Tonge et al., 2019) and three mixed method studies (Ali et al., 2015; Quaife et al., 2017; Scobie, 2021) have been conducted in the UK looking into LCS perceptions of people with high risk of getting lung cancer. The studies report similar findings – that an individual’s likelihood to engage with LCS information or participate in the screening is influenced by perceptions surrounding the following: the benefits of screening, efficacy of the test, personal risk of cancer, practical barriers to taking part, the survivability and treatability of lung cancer as well as the willingness to receive treatment and stigma associated with smoking. It is also likely that confidence in one’s own ability to organise a screening appointment (based on the Social Cognitive Theory; Bandura, 1998) and perceptions about others (based on the integrated model of behavioural prediction, Yzer, 2012) will influence people’s likelihood of participating in screening.

The Extended Parallel Processing Model (Witte, 1992) asserts that perceived efficacy plays a key role in the type of coping-strategy an individual employs in response to a perceived threat, suggesting that defensive reaction to reduce fear (such as avoidance) will be used when efficacy is low while behaviour change to reduce the danger (such as preventative behaviours) will be used when efficacy is high. Hagger et al.’s (2017) meta-analysis found that, independent of illness type and context, greater perceived control leads to problem-

focused coping when cancer is believed to be treatable and thinking about cancer is not linked to strong negative emotions for a person. The meta-analysis results also showed, more severe perceived consequences lead to problem-focused solutions when perceived treatability is high and associated negative emotions are low but leads to emotion-focused coping when perceived treatability is low and associated negative emotions are high. Therefore, to increase engagement and participation (problem focussed coping), information needs to increase perceived control and perceived consequences at the same time as increasing beliefs around treatability and decreasing fear. Importantly, the factors leading to screening engagement are not independent.

#### **1.4.4.1 Differences across socioeconomic status**

Cancer screening awareness and knowledge has been found to be lower in populations with lower socioeconomic status (Zhu et al., 2021). A UK-based study looking into colorectal cancer screening perceptions found the association between socioeconomic status and intention to screen to be mediated by perceived risk, worry about bowel cancer, benefits, barriers, fears and fatalism (in order of strength of association in the model; Wardle et al., 2004). Smits et al (2018) conducted a population-based computer assisted face to face interview survey in Wales which found age, gender, smoking, social group (based on occupation of household's main income earner) and previous exposure to campaign messages were not associated with four key cancer belief statements, worry, fatalism or perceived benefit. A limitation with this study is self-selection bias, which could explain the high positive results found and the reason why no associations were found between variables. Additionally, 44% of participants had never smoked and participants under the age of 50- were included, making this sample unrepresentative of the target population. The lack of relevance (and therefore, threat) of the consideration of lung screening for this population was unlikely to reflect the experience of the LCS target population.

Studies in the UK, Denmark and the US have found that people in lower socioeconomic status groups are no less likely to endorse positive beliefs about cancer but are more likely to report negative beliefs (Hvidberg et al., 2019; Quaife et al., 2015; Sarma et al., 2021). These beliefs include 'A diagnosis of cancer is a death sentence', 'I would not want to know if I have cancer' and 'Most cancer treatment is worse than the cancer itself'. von Wagner et al. (2011) suggest many of the perceptions that predict lung screening non-attendance (such as low self-efficacy and negative beliefs about cancer) are more common

in people with low socioeconomic status due to conditions tied to socioeconomic deprivation (such as lack of access to health provision). The UK-based lung screening uptake trial found an invitation leaflet designed to minimise fear, fatalism and stigma improved uptake for the most deprived group. The leaflet reduced fear by framing screening as a UK vehicle check (M.o.T) and including no focus on cancer, while stigma was reduced by not mentioning smoking cessation (Quaife et al., 2020).

#### **1.4.5 Interactions between factors within the message components**

Factors across the message components are likely to interact in a synergistic way, having a unique effect when used together (Bol, 2015; Hinyard & Kreuter, 2007). Message components are often researched separately and so little is known about the synergic effects between the message components (Keller & Lehmann, 2008). Ultimately, the designer/design team assume the final responsibility to apply the design suggestions and should consider the potential impacts of using techniques in combination.

### **1.5 Summary**

This chapter maps the context of the problem to be tackled through this thesis– which is the equitable and informed uptake of lung cancer screening where high-risk individuals are provided print information. This chapter argues the value of a lung screening programme, considers the likely organisation of such a programme in the UK and then argues the value of ensuring print information materials can support equitable and informed uptake. Following this, a logic model of the problem is constructed, identifying the behaviours and communication outcomes to be targeted to achieve successful print lung cancer screening communication for invitees (Table 1-2). This chapter also considers the factors that will likely be implicated in the reception of communications about lung cancer screening.

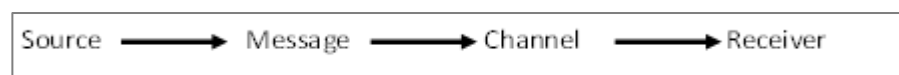
## Chapter 2. Using picture narratives in lung screening communication

In this chapter, picture narratives are presented as an opportunity to achieve the target behaviours and communication outcomes for a LCS information leaflet for invitees to a screening test.

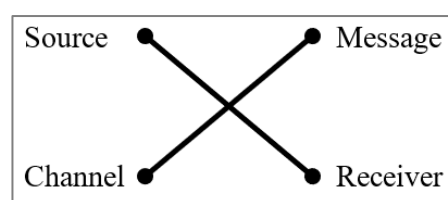
### 2.1 Properties of print communication

The different aspects of a communication event have been comprehensibly defined by Berlo (1960) and later tenants of the SMCR model of communication, with four components of communication; Source (sometimes referred to as sender), Message, Channel (the medium through which the communication is transmitted), and Receiver (or recipient). In the early SMCR model, the four components of communication were laid out in a linear way (Figure 2-1) but later models highlight that these are interacting factors that make up the communication (Figure 2-2).

*Figure 2-1. Linear SMCR model*



*Figure 2-2. Synergistic SMCR model*



In later adaptations of the model, the source and the receiver are both considered communicators, reflecting the turn to a transactional framework, which acknowledges that the roles of source and receiver are not static but reciprocal in a communication event (Barnlund, 1970). The linear version of the model could be suitable for print and posted communications as there is clear directionality from those producing the materials (the source) to those receiving the materials (the receiver). However, the highlighting of the interactivity across the components of any communication is still useful because any communication, even print information, is created and perceived through that interaction. For example, a recipient's perception of the source based on the channel used to

disseminate a particular message will have an impact on the communication outcomes. In an interactive model of communication, a reader's emotions and values are acknowledged as involved in the communication. This inclusion of the interactive nature of the communication components is a more accurate and informative description and is why this thesis refers to the LCS information materials as a method of communication rather than information transfer.

There are four main dimensions of the message component in the SMCR model that have been delineated: Elements, Structure, Code and Treatment. Message elements refer to specific sections within the message, such as sections of text or visual images. Message structure refers to the layout of the message (i.e., the way in which it is arranged). Message code refers to the mode through which the message is being sent (for example, what language is used). Finally, message treatment refers to the way in which the message is expressed (for example, a photo being in natural colours or in sepia-tone). In addition to these terms is Message content, which refers to the message in its entirety. To support a review of message characteristics that would be involved in print LCS information material, I have considered the conditions that sit within these dimensions that are specific to print communication (see, Table 2-1). By parsing these dimensions, we can see how graphic form and narrative rhetorical mode can be used in a complimentary way.

*Table 2-1. Conditions of each message dimension specific to print communication*

| <b>Message Content</b> | <b>Condition specific to print communication</b> | <b>Examples</b>                                                                       |
|------------------------|--------------------------------------------------|---------------------------------------------------------------------------------------|
| Elements               | • Pages                                          | cover page                                                                            |
|                        | • Sections of text                               | title                                                                                 |
|                        | • Images                                         |  |
| Structure              | • Layout                                         | position of elements across pages                                                     |
|                        | • Rhetorical mode                                | narrative                                                                             |
| Code                   | • Form                                           | written-text, graphic-images                                                          |
|                        | • Language                                       | English                                                                               |
| Treatment              | • Tone (of written information)                  | formal vs casual                                                                      |
|                        | • Style (of visual information)                  | hand drawn vs digital aesthetic                                                       |

### **2.1.1 Modality**

Print health communication information is multimodal as it uses written text (visible verbal mode) and still images, i.e., pictures (visible visual mode). Both text and pictures are perceived visually and, as such, will have visual qualities (such as colour or font). Many of the visual qualities will apply to both the text and the pictures (for example, colour). However, these two communication modalities differ with respect to perceptual and communicative processes (Geise & Baden, 2015). Due to this, many models treat text and images as distinct firstly and then propose how they are integrated, as is the case with Geise and Baden's (2015) model, which applies frame processing theory to visual and linguistic stimuli.

## **2.2 Picture narrative form in health communication**

All aspects of the message content are involved in communication reception and impact and will be considered when generating ideas for the print lung screening information. However, this thesis is primarily interested in the impact of using picture narratives when providing lung screening information to invitees. The rest of the chapter provides a definition for what is being considered 'picture narrative' and reviews why and how the picture narrative form might support lung screening communication.

### **2.2.1 Definition of picture narrative form**

Through this thesis, the term 'picture narrative' is used to refer to static visual portrayals of narrative created with intention using graphic techniques and with pictures as an essential mode of communication.

#### **2.2.1.1 Pictures**

The definition of a picture used in this thesis comes from Mitchell's (1986) taxonomy of images, where a picture is a graphic (perceivable through the senses) image (recognisable through likeness, resemblance and similitude) rendered on a 2D surface. It is important to avoid general use of the term 'image' as this can refer to anything from something perceived in the mind's eye to a written description of a visual thing. Other modes of communication in print media include text (recognisable through verbal language) and data visualisations (recognisable through mathematical conventions). It is important to recognise data visualisations (i.e., graphs, charts) and pictures as separate. Their modes of

representation are different and so the way they are perceived and understood will be different. Data visualisations represent data with abstract elements that do not visually resemble the thing being portrayed. Both the SAM+CAM (Helitzer et al., 2009) and the Health literacy INDEX (Kaphingst et al., 2012), two print health material evaluation tools, make the distinction between data visualisations and pictures. Meynell (2013) theoretical work also makes this distinction when applying Willat's (1997) demarcation of pictorial representations. Pictograms (a type of graphic that portrays numerical data using pictorial symbols), use a combination of these two modes of representation and have been referred to as 'pictorial statistics' in the past (Benus & Jansen, 2016).

Our definition of picture narrative holds that pictures must be an essential/integral aspect of how the narrative is portrayed to qualify. This definition is inclusive to any variations in the use of different communicative modes, provided pictures are fundamentally involved. For example, a picture narrative can, but does not necessarily, include text. Picture books would not qualify, as the narrative can be read and understood through the text alone (so the pictures are not fundamental to the recognition of the narrative).

#### **2.2.1.2 Graphic techniques**

Graphic techniques encompass all methods of capturing an image on a 2D surface. Originally reserved for printed surfaces (such as lithography, illustration, photography), but now also includes digital surfaces (such as digital illustration, digital photography and digital 3D modelling).

#### **2.2.1.3 Intentionality**

It is important that the element of intentionality is recognised in the definition of picture narrative. The 'object' must be created by a person with the aim to portray a narrative. If the narrative is consequential (such as laying out several photographs in a random sequence from which a narrative might be conjured by the viewer), rather than the objective of the creation of the 'object' (such as laying out several photographs in a specific sequence with an intended narrative in mind), this would not qualify as a picture narrative. To distinguish between these two manifestations of narrative, we might refer to these as narratives by interpretation and narratives by design, respectively.

#### **2.2.1.4 Narrative**

There are three main uses of the term ‘narrative’. One use of ‘narrative’ refers to a rhetorical mode in which information about a series of events is communicated by a narrator (i.e., narrative mode). Another use refers to the way a story has been told (i.e., narrative structure). Finally, the term can be used to refer to an artifact or experience that contains an account of connected events (i.e., narrative object). The definition of picture narrative applies this last use of the term. The connection between the described events may be causal, temporal or sequential (Pimenta & Poovaiah, 2010). The connection may be made through reoccurring objects, characters, scenes, or written description. Narratives may also, but do not necessarily, include place and narrators.

#### **2.2.1.5 Static**

A static form is one that does not contain moving parts (e.g., animatronics) and does not resemble visual perception of movement which occurs in a singular space and continues uninterrupted across a time (e.g., animation). For static media, any perception of movement or change is provided entirely by the audience’s mind. The narrative is composed of “frozen” intermittent moments. This concept of a static form comes from Pimenta and Poovaiah’s (2010) definitions of different ‘visual narratives’. Importantly, static visual narratives must provide visual cues to the viewer from which they are to build a narrative.

#### **2.2.1.6 Other terms**

The term ‘graphic narrative’ is often used to refer to materials that qualify under the proposed definition of picture narrative. However, the term ‘graphic narrative’ can also encompass non-static (i.e., dynamic) images, such as animation. The term also has close ties to graphic novels and comics (Chute & DeKoven, 2006). Other terms that have previously been used for formats similar to my description of picture narrative include Visual narrative illustrations, Narrative image/s, Picture stories, Narrative pictures, Illustrated narratives, Pictorial narratives, Graphic Storytelling, Visual Storytelling, Visual stories, Sequential art, Sequential images, and Sequential Text-Image Pairing.

#### **2.2.1.7 Comics**

McCloud’s (2009) definition of comics as “a deliberate sequence, intended to convey information and/or produce an aesthetic response in the viewer” is widely cited (p. 20).

Comics are a well-recognised use of static visual narrative form and sometimes the two are conflated. However, ‘comic’ refers to a cultural artifact rather than a form, meaning there are differences across culture (specific to time, place and people) in what is considered a comic as well as the graphic and narrative conventions used (Cohn, 2021). For example, European comics are read from left to right, while Japanese comics are read from right to left. Additionally, not all phenomena considered comics use pictures as an essential mode of communication or contain a narrative by design (see, Molotiu, 2009 for examples of abstract comics). Such comics are recognised as comics due to their use of conventional elements (for example, panels and speech bubbles). The following media are sometimes referred to under the umbrella of comics, depending on the elements used and interpretations made within a culture: Comic Strip; Collection of comic strips; Comic Book (Short Form, Serialised); Graphic Novel (Long Form, Independent); Web Comic photocomics, and Fotonovela.

### **2.2.2 History of picture narratives in health communication**

Comics are a popular media that use picture narrative form and there is a long history of comics being made about health and medicine and being used by public health educators<sup>1</sup>. There have always been comics dealing with “serious content [-] since comics’ inception in American newspapers around the turn of the nineteenth-century” and more and more comics are dealing with “the complex representation of illness and its effects” (Chute, 2007, p. 413). Additionally, comics are often provided as health communication tools with groups of people in low-access positions and has been found to have success equal to other health education interventions (Noe & Levin, 2020).

Using picture narrative, in the form of comics, is not a new idea in health education and promotion, with a skin cancer prevention comic being created and evaluated as a public health effort in 1985 (Putnam & Yanagisako, 1985). Wang et al. (2017) give other early examples of comics used in health communication and report that these examples cover almost every topic. They provide an example of a Korean education comic during World War II on avoiding health risks. There are modern examples of comics being used for a range of communication purposes; for contracts (Botes, 2017), research recruitment devices (Kearns et al., 2021), scientific journal abstracts (Hyndman, 2016) and news articles (for example, [thenib.com](http://thenib.com)) and behaviour change messaging (Collins, 2022). There

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<sup>1</sup> For examples of modern uses, see summary by Wahowiak (2014)

have even been different terms coined for different comics depending on their communication purpose. ‘Information comics’ are comics used to inform and educate the reader and are primarily concerned with knowledge transfer (Caldwell, 2012; Jüngst, 2010). Educational comics might be a broader term for comics that cover any educational purpose (Davidson, 2008). ‘Applied comics’ are comics used to achieve public-level project aims (Wysocki, 2018), and this includes public health comics (Li-Vollmer, 2022), public education comics (Herd et al., 2020), and public information comics (Murray & Nabizadeh, 2020).

#### **2.2.2.1 Cancer information specifically**

Rhode and Connor (2012) have produced a review of comic art in cancer narratives. They suggest that comics about cancer could be considered a literature or movement, with such comics being the greatest proliferation of cancer narratives in any popular media. They cite an educational comic about smoking and cancer produced in 1963 by the Department of Health and Welfare, Canada. This is a pamphlet that uses formal comic elements with the aim of cancer prevention. This comic provides a good example of the primarily didactic use of early comics about cancer. Similarly, Krakow (2017) presents a comic produced by American Cancer Society in 1963 encouraging women to get a pap smear test for uterine cancer – an early example of health communication using comic format with the aim to increase cancer early detection. However, comics became a medium through which people chose to create autobiographical accounts of the difficult experiences associated with cancer (along with other illness narratives) because of the tradition of comics in taking on challenging social issues, particularly comix (Rhode & Connor, 2012).

#### **2.2.2.2 Graphic medicine**

There is a relatively young, but rapidly expanding, unified discipline for the research and application of graphic narratives in the areas of illness, health and medicine, which is being referred to as ‘graphic medicine’ (Czerwicz et al., 2015; King, 2017). Within the discipline, graphic narrative is defined broadly and includes picture narratives, most frequently comics. In a similar vein, and with much crossover, there also exists; Graphic journalism, Graphic justice (comics used for activism), Graphic history, and Graphic social science.

### 2.2.3 Theories of picture narrative comprehension

Comprehension of picture narrative is interpretive and based on a learnt knowledge of visual conventions (Hatfield, 2009). The following processes are involved in perception and communication (as outlined by Barry, 1997), and are consequently involved in the comprehension of picture narratives: 1) perceptual and cognitive abilities shared across humans (e.g., visual information is received through light sensitive cells in the eyes); 2) perceptual and cognitive capabilities that differ across people (for example, colour blindness will impact colour perception, and differences in cognitive capacity will impact learning and recognition of symbols); and 3) cultural conventions and learnt understanding which differ across different groups of people (e.g., different languages or the meaning a culture attaches to a particular sign). These factors together influence the way a person will see and understand a picture narrative. Therefore, the experience will be unique to each person, while there remains some level of shared interpretation across people.

The discipline of social semiotics provides an explanation of the process of signification, and how it is possible that two people can interpret the same meaning from a picture narrative. Signs are the key phenomenon through which we make meaning. Following Peircean theory, a sign is the composite of three interacting components: the object (the referent that the sign signifies, e.g., there exists a fire), the representmen (the signifying element, e.g., you see smoke), and the interpretant (interpretations made, e.g., you interpret that the smoke indicates there is a fire). This is dealt with, in particular, in Peirce's essay *Nomenclature and Divisions of Triadic Relations, as Far as They Are Determined* (Peirce, 1998). Shared interpretation is made possible due to the fact communication skills and comprehension are learnt and built upon through interaction with other people (i.e., a social process). With this, people within a culture have shared signs and semiotic rules.

Pierce provides a widely used and useful classification of the semantic properties of signs for considering how meaning is made from both visual and verbal information. Iconicity refers to the quality of a sign where the signifying element is linked to the signified through resemblance. A realistic portrait can be described as having high iconicity (due to looking a lot like the thing being depicted) while a smiley face emoji has low iconicity (due to not sharing many visual similarities with the thing being depicted). Indexicality refers to the directness of causal connection between the signifying element and the signified, where a film photograph of an object has high indexicality and a written description of visual aspects of the object has low indexicality). Messaris (1997) asserts

that these two properties are major semantic features of visual images when compared to other modes of communication, including language.

Meaning is also construed from visual communication through spatial and temporal relationships (syntactic properties). Image content and the spatiotemporal relationship between images can imply many things, including time, place, analogy, similarity, and causality (Messaris, 1997). The static nature of picture narratives is heavily implicated in how these relationships can function, as the portrayal of each event or aspect must exist in a different physical space. Groensteen (2007) argues that narrative is signified in comics by the relational placement of the images and that meaning is primarily constructed from the relationship between one panel and the next<sup>2</sup>, with spatial information being substituted for temporal information. S. McCloud (1994) proposes that the particular spatiotemporal relationships of juxtaposition and sequence are key to how narrative meaning is perceived from static images, in the case of comics, and suggests the psychological phenomena of ‘closure’ (also referred to as Reification) is what allows humans to perceive connections between images to create a coherent interpretation. This principle is adopted from Gestalt psychology and finds that people unconsciously perceive things as ‘complete’. This concept is used to explain how people create meaning from the limited/bounded visual information available – including imagining what has occurred between a panel and the next, as well as information about the visual world<sup>3</sup> that exists beyond the panel frame.

Cohn (2021) outlines that comics are not universally understood phenomena. Comics are an example of shared signs, semiotic rules and syntactic rules being established for a picture narrative modality. Comics use symbolic signs<sup>4</sup> to communicate meaning (such as a speech balloon) which must first be learnt to be understood (Cohn et al., 2016). Consequently, there are examples of the conventions behind comics adapting and transforming over time and between different cultures (Cohn, 2014b).

An additional consideration is how the pictorial and textual elements are comprehended in an integrated way. Geise and Baden’s (2015) multimodal framing model integrates theories

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<sup>2</sup> McCloud (1994) refers to the way one panel moves to the next (panel-to-panel relationship) as ‘transitions’.

<sup>3</sup> J. J. Gibson provides a distinction between the “visual field” (the image as it would appear on the retina) and the “visual world” (the mental/imagined experience of an individual) cited in Barry (1997)

<sup>4</sup> In semiotics, this refers to a sign for which the representment is related to the object through social convention

in visual communication and media framing to explain how humans make meaning from words and visuals. This model follows dual coding theory in suggesting that visual and verbal information is processed separately, while each is appraised in relation to the other. The model also identifies both shared and unique characteristics of each system that are implicated in the perception of the combined use of visual and verbal information.

## **2.3 Using picture narratives in lung cancer screening**

### **communication**

Picture narrative form is suitable for printed and posted LCS materials due to its static and graphic nature. Blending pictorial and narrative modes of communication, picture narrative form benefits from the affordances of each mode. Therefore, before considering the strengths and challenges of using picture narrative form, the following sections first look at the affordances of pictures and narrative separately.

#### **2.3.1 Affordances of pictures**

Pictures are more engaging and expend less attentional energy compared to text (Levie & Lentz, 1982), improving the chances of information materials being read. Picture superiority is the property of visual images to grab people's attention before textual information. Giese and Baden's (2015) multimodal framing model proposes that this is due to the immediacy through which this modality is made recognisable, as the mental representations of visual images closely resemble the perceived information. The visual similarity between a picture and that which it is depicting (i.e., iconicity) will play a role in the pictorial superiority effect. The human brain is adapted to process pictorial information more efficiently than textual information (Barry, 1997), with a large portion of the human brain being dedicated to visual information processing (Snowden et al., 2006).

Pictures can improve the comprehension and recall of health information compared to presenting text alone (Houts et al., 2006; Schubbe et al., 2020). A review by J. Park and Zuniga (2016) found pictures used in health information materials supported learning for people with low health literacy. The multimedia effect is the finding that information received through multiple perceptual modalities (i.e. verbal and visual) is better remembered than when received through a single modality, and this is believed to be due to each mode being cognitively coded and stored through separate processing systems with

independent limited capacities (Mayer, 2005). The cognitive theory of multimedia learning proposes that visual images have an active role in the process of meaning making and that message comprehension is supported when textual information is accompanied by visuals that are consistent with the message (Mayer, 1999). Additionally, the inclusion of pictures is thought to help readers make connections between the text and mental images, which is implicated in learning (Mayer, 2001, 2005). By supporting readers with making such connections, the pictures can reduce cognitive load and improve understanding (Mayer, 2002). Where the goal is to increase understanding to support informed decision-making, it is important that the pictures in cancer screening materials are relevant to the leaflet messages and contribute to comprehension of those messages.

Messaris (1997) suggests that it is the ‘indeterminate’ nature of visual syntax (referring to this quality as ‘syntactic indeterminacy’ and a ‘lack of propositional syntax’) that makes visual images persuasive, as it allows the images to imply things that would be questioned by the viewer if said explicitly. For example, a picture of smiling people drinking a particular branded beverage can imply (or convey), rather than saying, ‘drinking this branded beverage will make you happy’. Horn (1998) promotes this sentiment, saying that visual communication is less restrictive than verbal communication allowing for "greater complexity, accuracy, and nuance" (p. 242).

Visual representations of data support comprehension of quantitative information (Fekete et al., 2008). Icon arrays, which visually display quantities by repeating icons, have been found to support comprehension of risk information (Petrova et al., 2015). Pictures can signal information as appropriate (i.e., relevant) to target populations by using images that are visually salient and can indicate this in a more immediate way than text. For example, participants in a study by Wang et al. (2017) suggested that the comic strips “could be made more clearly relevant” (p. 1267) to the target population (who were Asian Americans and Pacific Islanders over 50 years old) by including more visual indicators of relevance, such as chopsticks or rear view mirror decorations.

The inclusion of pictures in print material about gout, independent of style, has been found to make health information materials more visually appealing compared to text alone (Krasnoryadtseva et al., 2020). Visual appeal is predicted to increase likelihood of engaging with the material (Greenwald, 1968). Through increasing engagement with, and improving understanding of, written information, the use of pictures in cancer screening

information leaflets could support informed choice. In line with this, many guidelines, toolkits and assessment tools for print health education materials assert that pictures should be used in patient and public health information (Centers for Disease Control and Prevention, 2009; National Cancer Institute, 1994).

### **2.3.2 Affordances of narrative**

Narratives can help to communicate in a comprehensible and engaging way due to their familiar, emotive, and transportive nature (M. C. Green et al., 2002; Hinyard & Kreuter, 2007). Firstly, narrative structure is thought to mirror the way humans process information, and most verbal communication follows narrative structure, which means complex information can be more easily processed when provided in a narrative form (Wyer et al., 1995). This is supported by the finding that narrative text is more accurately recalled than other types of textual information (Graesser et al., 2002). Secondly, there are inherent processes through which stories influence and involve emotion, and emotions are a key system for motivating attitudinal and behavioural change (Nabi, 2002). Oatley (2002) proposes narrative fiction is experienced as a simulation (as an imagined reality or ‘a kind of dream’). Emotions are experienced as part of this simulation through enactment (where the reader both houses the experience of, and is an active agent in, the simulation) and are created from the reader’s memory. The simulation is experienced as a safe space where the emotions can be felt and explored without becoming threatening or harmful. This could be particularly helpful in the case of cancer screening information, where thinking about cancer is experienced as a health threat (Kok et al., 2014). Additionally, the emotions experienced contribute to the entertainment quality of the narrative which will engage readers and maintain their attention. Nabi and Green (2015) propose that the evolution of emotional experiences across the duration of engaging with the health message, the ‘emotional flow’, is important in persuasion. Narratives can manipulate emotional experience and are able to provide this emotional flow.

The experiences of becoming absorbed in, and pulled along through, a narrative has been theorised to play a key role in the ability of the narrative form to influence beliefs and behaviours. M. C. Green and Brock (2002) build on Nell’s (1988) consideration of the quality of narrative to absorb and entrance the readers and who refers to Gerrig’s (1993) ‘engulfing transportation’, terming this process ‘transportation’ and proposing a formalised model of narrative persuasion through transportation and imagery. A meta-analysis by van Laer et al. (2014) found narrative transportation can impact affective response, critical

thought, narrative thought, beliefs, attitude and intention. Transportation has also been found to lead to reduced decisional conflict (Osaka & Nakayama, 2017). The extended Elaboration Likelihood Model proposes that transportation minimises resistance to attitudinal change which leads to changes in motivation and behaviour (Moyer-Gusé & Nabi, 2010).

There have been several reviews into the use of narrative as health intervention, with M. C. Green (2006) and Hinyard and Kreuter (2007) specifically considering the use of narrative in the context of cancer prevention and control. M. C. Green (2006) proposes that, through transportation, narratives can support cancer communication efforts by reducing counter-arguing, facilitating “mental simulation of unknown, difficult, or frightening” situations, providing role models and resulting in “strong attitudes that are based on both cognition and emotion” (p. S163). Hinyard and Kreuter (2007) assert that narratives provide the following four capabilities applicable to cancer control, with the first two being particularly applicable to encouraging cancer screening participation: “overcoming resistance, facilitating information processing, providing surrogate social connections, and addressing emotional and existential issues” (p. 222). A meta-analysis by Shen et al. (2015) of 25 studies testing the impact of narrative health communication on attitudes, intention and behaviour found narrative messages about detection and prevention had a significant positive impact.

In an experimental study by Cox and Cox (2001), narrative information was more engaging for participants than statistical information in the case of a breast cancer screening message. The personal stories of others can make it easier for people to think about sensitive and emotive topics associated with cancer screening (Bennett et al., 2015). Hinyard and Kreuter (2007) suggest narratives can provide ‘para-social’ support through creating relationships between the reader and the characters. Narratives encourage the reader to suspend disbelief which can get people to think about things they would otherwise disagree with (‘suppress counter-arguing’; McQueen et al., 2011). Hinyard and Kreuter (2007) also suggests the reader’s desire to find out what happens next in the story means they continue to engage with the narrative even when it opposes their beliefs (‘counter-attitudinal’). A review by de Graaf et al. (2016) even suggested that narrative persuasion is not inhibited by overt persuasion.

In addition to overcoming resistance to the health message and making information more comprehensible, Hopfer and Clippard (2011) suggest narrative form is good for supporting an audience who are less involved and who have less knowledge, by including culture and experiences of the audience. Studies have also suggested that narrative information is more supportive for people with low literacy compared to other rhetorical modes (Volk et al., 2008).

### **2.3.3 Affordances of picture narratives**

The picture narrative form provides several capacities that could be particularly supportive for communicating health information, such as LCS information, in print format. The multimodal nature of picture narratives that integrate text with pictures can support comprehension by producing meaning not possible through a single mode (M. J. Green & Myers, 2010) and provide reinforcement of the message (McAllister, 1992). In addition, picture narrative might be thought of as not only using the linguistic and visual modes, but also that of audio, gestural and spatial (Jacobs, 2013). Comics have long been recognized as being effective in visualizing complex scientific issues (Farinella, 2018; Spiegel et al., 2013). The static and sequential nature of picture narratives is useful for presenting processes and demonstrating actions (McAllister, 1992). They are also read at a self-determined pace meaning information will less likely be missed.

Comics are often created in a way that is entertaining to read. This entertainment value can support engagement with the message and recall (Sones, 1944). Visual elements, such as “caricature and exaggerated body-language”, contribute to energy and drama (R. Palmer, 2016, p. 37). Triggering emotions, such as humour, can improve recall (Schmidt & Williams, 2001). Picture narratives can model behaviours by showing people carrying out actions. Viewing someone else successfully performing an activity that might have been perceived as challenging or intimidating can lead to adoption of that behaviour through increasing perceptions of one’s ability to cope and complete the behaviour (self-efficacy; Bandura, 1998). Symbolic modelling refers to when the modelled action is viewed through a medium rather than viewed directly, as would be the case if portrayed in a picture narrative. Similarly, picture narratives can result in the reader imagining events and experiences in a vivid way (referred to as mental simulation), which can help motivate behaviour by making consequences more tangible and can help increase self-efficacy by providing an opportunity for mental rehearsal (M. C. Green, 2006). The use of “direct speech” (in the form of speech balloon) and the use of “filmic techniques” make comics

more personal by bringing the reader closer to the characters (R. Palmer, 2016), which could encourage openness and engagement with the message. The inclusion of characters in the picture narrative also brings the focus to a personal level (McAllister, 1992), which means they can be humanising in the context of health conditions (McNicol, 2014). When picture narratives are hand-drawn, the indexical presence of the author-creator can create intimacy with the reader (Chute & DeKoven, 2006).

McAllister (1992) suggested that comics are able to “deal with frightening subjects in a very down-to-earth yet non-threatening manner” (p. 18). Comics are often seen as jovial (Botzakis, 2009) which might lead to them being perceived as non-threatening. The fact the message in picture narratives is perceived through a medium, rather than directly, provides the reader distance from the content. This allows a safe space to vicariously experience situations and events.

Some experiences are easier to depict through visual metaphor created through picture narrative than can be explained in text. Rhode and Connor (2012) give the example of “panels heavy with black ink” (p. 137) being used to depict the experience of lost time during the character’s seizures in David B’s *Epileptic*<sup>5</sup>. Not only can this help with understanding, but it also has the potential to alter experience through providing alternative framings (Semino et al., 2018).

Pictures and narratives used together in cancer information have been found to lead to greater improvement in comprehension compared to formatted text information for people with lower literacy, even when the text information was written at a lower reading level (Michielutte et al., 1992). The capacity of comics to be comprehensible for audiences independent of literacy level will help to avoid exacerbating communication disparities.

#### **2.3.4 Constraints of picture narratives**

Due to the stereotype of comics as jovial and created for entertainment and often being considered childish (Botzakis, 2009), audiences may perceive this style as unsuitable for health topics such as cancer (Alam et al., 2016). Extraneous aspects of the images or narrative can distract from the health message rather than support it (Barrera-Clavijo et al., 2016). Similarly, due to the multiplicity created through the visuals and narrative aspects, a

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<sup>5</sup> David B, *Epileptic* (New York: Pantheon, 2005)

comic can have multiple readings, which might not satisfy the aims of instruction and education. Additionally, with bringing the focus to a personal level, there is a risk of reducing an issue to a single story and stereotypes. This can impact the audience perceptions of the causes and risks associated with a condition (Hinyard & Kreuter, 2007).

### **2.3.5 Current state of empirical research into picture narrative for health communication**

Cohn (2014a) provides examples of research suggesting that “sequential images combined with text are an effective tool of communication and education” (p. 1). Noe and Levin (2020) have produced a scoping review of the use of comics in health and medicine. Their review considered the use of comics by three main target groups – students, patients, and consumers – as well as an ‘other’ group collecting studies with practitioners and active military, which is a practical and informative way of breaking down current uses of comics in health settings. Vuillème (2021) has created, and is maintaining, an open science review of randomised control trials of comics, which is planned to be updated and can be contributed to by anyone. This register can be searched for studies looking into cancer communication efforts.

Noe and Levin’s (2020) review concluded that comics are found to be appealing, but that more research is warranted looking at the impact of comics on knowledge transfer and behavioural change. They identified 22 studies (ten with children, ten with adult and two with families) testing the impact of providing comics as patient information. All the studies with adult participants were with people from underserved populations. Of these studies, comics were found to be liked and supported knowledge acquisition. More recently, Brand et al. (2019) found that providing consent documents in comic form to patients before a coronary angiography reduced anxiety, increased understanding, and satisfaction, compared to the same information in written form. Noe and Levin (2020) also identified 24 studies looking at the use of comics to persuade or encourage adults to engage in healthy behaviours, twelve of which either did not report on effectiveness or used other intervention components alongside the comic. In two cases identified that used comics for cancer-related information, effect was found to be only marginal and no more effective than other interventions (Putnam & Yanagisako, 1985; Risi et al., 2004). Barnett (2004) suggests several contextual reasons why evaluation of comic interventions has been lacking, including due to; responding to time-sensitive issues, lack of funding, prioritising

funding on intervention over evaluation, a funding culture where acceptance of technology as more important than whether it works, and reluctance to show a program did not work due to budget insecurity.

#### **2.3.5.1 Mixed results due to differing intervention characteristics and study measures**

Research into the combined use of pictures and narratives in print health communication is disparate. Although comics have frequently been used for supporting health communication and public health endeavours, only recently has there begun to be systematic and standardised investigation into the effectiveness of comic in health information provision (King, 2017; Noe & Levin, 2020) and empirical studies are scarce (Farthing & Priego, 2016). Use of comics has not been consistent - being used by different groups, at different times, for different purposes. Two main problems for the evaluation of comics in effectiveness studies is that the comics are often being used alongside other interventions, meaning the unique contribution of the comic is unable to be measured. Additionally, study articles often have not provided examples of the comics used, meaning reviewers cannot identify the characteristics of the comics that may have impacted their effectiveness. No guidelines on the most effective use of comics in health education can yet be made. Graphic medicine is the academic field widely covering the study and practice of graphic narratives (particularly comics) related to health, illness and medicine (Czerwicz et al., 2015). This is likely a fruitful area to gain insights for picture narrative health communication.

Theory-based empirical research into the use of pictures in cancer screening material is also minimal (King, 2015) as is true of research into narratives (McGregor et al., 2016). Further to this, there is not a substantial body of work looking at the conditions and characteristics impacting the effectiveness of pictures in health communication (Jensen, 2011) or narratives (Hinyard & Kreuter, 2007; Shaffer et al., 2018). To progress the use of comics in health education, the methods of development and evaluation need to be rigorous and transparent to be able to determine which picture narrative characteristics lead to effects and under which conditions – this means being systematic in the use of theory and past evidence during development and employing experimental design during evaluation.

## 2.4 Summary

This chapter identifies the utility of using picture narratives for health communication, in terms of impacting attitudinal change, motivating behaviour, and supporting behavioural enactment. An important condition for picture narrative comprehension, identified through reviewing theories of image and text comprehension, is that it requires that the signs, syntax and conventions used match those that are used by, and known to, the audience.

## **Chapter 3. Methodology, design approach, research questions and chapter summaries**

The aim of this thesis is to investigate whether picture narrative form could be used to improve equitable uptake of lung cancer screening (LCS) while enhancing informed decision-making. To carry out this investigation, I developed and evaluated example picture narrative LCS information, developed for people anticipated to be invited to lung screening (once rolled out as a national programme) and living in Glasgow in more socioeconomically deprived areas. The current chapter describes and justifies the approach taken to the research investigation and the approach taken to designing the example picture narrative LCS information.

### **3.1 Approach to the research**

To be able to build understanding into the application of picture narratives in health communication, I developed example picture narrative information for the context of LCS. Lung cancer screening information provision was used as a case study because the development of supportive LCS information was a valuable and timely goal. A mixed research approach was used for the development and evaluation of the picture narrative LCS information, traversing epistemological positions and academic disciplines.

#### **3.1.1 Pragmatism**

For this project, different methods have been used to build a comprehensive and multi-perspective understanding of the various phenomena relevant to picture narrative LCS information provision (including picture narrative form, receiver factors, and print communication). This adopts pragmatism as its research philosophy, where the methods of data collection and analysis used are guided by the research questions being answered – the aim being to use the most suitable methods for each question. With this philosophy, claims are not made about the nature of reality, instead truth is held relative to the goals and context behind an investigation (Bishop & Yardley, 2017). The aim is to build a fuller understanding rather than seeking to find a universal, objective truth, as is the case with positivist philosophy. This paradigm is particularly appropriate when designing an intervention or communication strategy (such as LCS information materials), where there

are predefined goals and where the study of a variety of phenomena (such as knowledge, perceptions, culture, visuals, and narrative) may best serve the development process.

The pragmatism philosophy does not make claims about the nature of reality. However, this paradigm also does not assume the researcher, or the methods used, stand outside of socio-political influences on the construction of the problem/s being investigated (Hickman & Alexander, 1998). The researcher holds personal understanding and this will impact decisions made through the research process. These influences are considered in the research position section below.

### **3.1.2 Mixed methods**

Mixed-methods refers broadly to the combined use of qualitative and quantitative methods. The pragmatism paradigm supports the use of different methods of inquiry (across and within qualitative and quantitative approaches), where what is considered most important is that methods are selected based on their suitability in responding to the aims of each study (Bishop & Yardley, 2017). Following this, several different methods of data collection and analysis have been used through this thesis. The questions asked through this thesis, and the methods used to answer them, have been undertaken to supplement one another. This facilitates the generation of a broader multi-perspective understanding of picture narrative cancer communication and informs the design process in a holistic and appropriate way. However, it is not believed that any two methods can be unproblematically mixed and matched. The combined use of different methods and the integration of their findings is not a straightforward matter, as different methods are underpinned by different ontological positions and research traditions (Giddings, 2006). Instead, careful consideration has been given to the questions pursued and methods applied in this thesis, and in how they fit together.

### **3.1.3 Multi-disciplinary**

This thesis draws on knowledge from multiple disciplines, to build a broader understanding of the subject of picture narrative health communication as well as identifying the most appropriate approaches to the design process. This is to be expected, as the issue of creating picture narrative lung screening information is relevant to the areas of communication, people, health and design. Health communication and information design are both cross-disciplinary by nature (Thompson & Harrington, 2021).

Additionally, Mitchell (1994) has suggested scholarship around the visual arts is interdisciplinary and approaches to studying visual narratives have been interdisciplinary (Cohn, 2016). A key challenge of working across disciplines is the lack of a common terminology or a frame of reference (for example, information being target versus behaviour being target). Table 3-1 identifies repeating concepts found across some of the disciplines.

*Table 3-1. Similar concepts across disciplines with discipline-specific terminology*

| <b>Concept</b>                                                                          | <b>Behavioural science/psychology</b>                                                                             | <b>Communication studies</b>             | <b>User design</b>                    |
|-----------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------|------------------------------------------|---------------------------------------|
| The tool being designed                                                                 | Behavioural Intervention                                                                                          | Communication strategy                   | Product                               |
| The people for whom the tool is being designed                                          | Target population                                                                                                 | Target audience                          | User/end-user                         |
| Factors that increase or decrease a person's likelihood of meeting the designer's goals | Behaviour change: facilitators/enablers (+) or barriers (-)<br><br>Decision making: encourage (+) or confront (-) | Amplifiers (+) or noise (-) <sup>a</sup> | Desirable or undesirable <sup>b</sup> |

Note. <sup>a</sup> For example, used by McGuire (1989) <sup>b</sup> for example, used by Preece et al. (2015)

### **3.1.4 Using design suggestions as a uniting principle**

Design suggestions became a centralising concept used to bridge across the different approaches taken through this project. The findings from each study were used to inform or support design suggestions which could then be used to inform the designs of the picture narrative lung screening information. This was necessary due to the vastly different ontological and epistemological positions being adopted within each investigation. The concept of *design suggestions* allowed for a consistent way of interpreting the diverse findings across the different disciplines and different approaches to investigation (e.g., aesthetic, narrative, qualitative and quantitative), which allowed for their synthesis into a set of design recommendations that could be applied to the picture narrative LCS information designs.

### 3.1.5 Research integrity

The quality of the research will determine whether there can be confidence in the claims made. The standards of what determines quality in research differs across different methods, both between and within qualitative and quantitative approaches, as what is considered good research is dictated by the epistemology and tradition underpinning each method.

Many have suggested principles for achieving high quality research that apply across the different methods and based on this body of work, Levitt proposed ‘methodological integrity’ as an overarching principle for high quality qualitative research, that is equally applicable to quantitative research. Levitt et al. (2017) proposed two conditions through which methodological integrity is achieved: “(a) fidelity to the subject matter” which is to maintain consistency with how a phenomena is being conceptualised and how it is being investigated relative to the tradition through which it is understood, and “(b) utility in achieving research goals”, which is to use research design and methods that can effectively achieve the research goals (in keeping with the pragmatism philosophy). Levitt et al. (2017) provide a list of items to consider to ensure both fidelity and utility during data collection and data analysis stages.

Rigour, which is not highlighted by Levitt et al. (2017), is also fundamental for achieving research integrity. Rigour is the degree to which the research has been carefully and thoroughly carried out, and this applies to all steps of the research endeavour, including adherence to the conditions of fidelity and utility. To attain and demonstrate research integrity, it is necessary to be systematic and transparent through all phases of the research, as well as explicate and justify all decisions made. Each chapter in this thesis reporting a study (chapters 4 to 8) has a methods section substantiating the integrity of the research. Reaching for these three qualities will ensure the research approach and resulting evidence are considered valid and meaningful by reviewers and future users of the findings.

*Data collection.* Morrow (2005) provides a list of different strategies for ensuring quality data in qualitative research: Data saturation or redundancy, where data collection stops once no new information relevant to the research question is being found (which requires being sensitive to the nature of the question under investigation, see Braun & Clarke, 2021c); Purposive sampling, where participants are selected based on whether they may best answer the research question; Good interview strategy, where the interview format,

questions and length are selected based on ability to answer the research question; triangulation, where a variety of data sources are used to expand the breadth and richness of the data; Preliminary immersion, which is immersion of the researcher in the research setting to “ground the study in the culture and context of the participants” and build “sufficient trust and rapport with the participants” (p. 256); and, Disconfirmation, which is searching for disconfirming evidence and comparing these with cases being used to justify the existing interpretations and ensure the investigation is not swayed by the researcher’s initial interpretations. In quantitative research, the primary strategies for ensuring quality data are sample size, sample selection, measure validity and measure reliability (Liu, 2017).

*Data analysis.* For high quality data analysis in qualitative research, Morrow (2005) recommended the following activities: Immersion, where the researcher becomes intimately acquainted with the data through repeat exposure (referred to by others as familiarisation; Braun & Clarke, 2021b); Analysis framework, where the researcher articulates and follows a systematic approach to bringing meaning to the data; and Analytic memos, where the researcher leaves a trail of notes to themselves as they are working through the data, including “hunches, interpretations, queries” (p. 256). In quantitative research, this involves following statistical protocols set out prior to the investigation and using appropriate calculations of effect sizes and significance.

*Subjectivity and representation.* In qualitative research, the issues of subjectivity and representation are dealt with through reflexivity, which is “making one’s implicit assumptions and biases overt to self and others” (Morrow, 2005, p. 254). How this awareness is then used differs across qualitative approach (for example, phenomenologist aim to nullify their subjectivities, whereas critical researchers aim to include their subjectivities within their analyses). In quantitative research, the presence of the researcher’s subjectivity and influence on research findings is considered a limitation in that it biases the true result. Different strategies are used to minimise this bias, including treating all participants the same and using statistical methods that minimise the impact of difference across the sample.

These strategies have been attended to through this thesis to ensure research integrity. The application of each strategy differs, not only between a qualitative or quantitative approach, but also within each of these approaches depending on the particular

epistemological position of the study. Therefore, how I have applied these strategies is described within each chapter.

### **3.1.6 Researcher position**

In this section, I describe factors that are implicated in how I conducted the different studies, and in the data generated.

First, I outline the justifications for the research as well as what is being considered ‘successful’ lung screening information, in chapter 1. In chapter 2, I justify the assumption being taken through this thesis that there will be some level of shared visual understanding and common icons used within a community which can be identified and generalised across the community. Crucially, I took the position that there is a level of predictability in the way people will perceive and interpret visual-textual information but that this is context-bound (e.g., differs across culture, communities, time, and personal experience), comparable to a bounded relativism ontology. I followed Barry’s (1997) consideration of visual perceptions as true for all human perception.

Through the thesis and during the studies, I have referred to the participants, researcher, facilitator and artist using these terms. I took this into account within my reflexive practice, as these terms are laden with implicit meaning. In all studies where data were produced through interaction between the author and other people (Studies 3, 4 and 5), I have been considering and referring to the people involved as participants - as people who are taking part in my study and are participating in the production of knowledge. In referring to the artist as such, participants may have perceived a power imbalance and be less inclined to draw when being watch by a professional. To account for this, during the workshop, the artist took turns at each table and would crouch beside the participants, asking them for their thoughts and providing encouragement.

The following characteristics about myself were implicated in the workshop and interviews. I am younger than the target population, young looking and sounding, not originating from Glasgow, with an English accent, somewhat posh sounding, a student and a researcher, university graduate, white, female, in a heteronormative relationship<sup>6</sup> and

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<sup>6</sup> This became relevant as participants often me questions related to my romantic relationship as a way to get to know me.

quiet<sup>7</sup>. My age (even on the phone, I sound young) and accent were noticeably different from the participants. When on the phone with people interested in taking part in the usability interviews or the evaluation questionnaire, I had people ask about where I lived (reflecting on why I did not have a Scottish accent). People also often wished me luck on my course and some asked me how I was getting on with my studies (reflecting on my student status and I think also how old I sounded). From spending time with the community groups and speaking with workers at the community centre, I found members were suspicious of, and reluctant to take part in research with any ‘outsiders’. However, community group members were very willing to help a student in any way, if it was to help them pass their course. Therefore, my status as a student greatly helped in recruitment. However, I had concerns that this desire to help me ‘pass my course’, led people to evaluate the workshop positively during the interviews. Similarly, during the usability testing, participants gave general positive comments about the designs. These were not directed at particular aspects of the designs, and I believe the participants were trying to be encouraging to me, the researcher, who made the designs, rather than expressing their genuine reactions.

I was concerned that, due to my dissimilarities with the participants, I would be considered an outsider who was just ‘passing-through’ and that this would make it difficult to build trust and rapport. I therefore spent time at the community centre, meeting people who might take part in the workshop, before organising it.

When establishing the aims of the project with the workshop co-organiser and facilitator, I told him that I wanted the workshop to be the best that it could be in order to improve the quality of my research and that I believed his expertise and knowledge of the groups at the community centre were essential for making the workshop good – this was to encourage him to speak openly and critically when we were coming up with ideas for the workshop. I believe this was achieved because during our workshop planning meetings he would disagree with my ideas, and we had fruitful debate. During our first planning meeting, we discovered that we had both been diagnosed with dyspraxia as adults. This provided a common ground and an immediate sense of commonality that I believe helped in building a friendly and trusting relationship. Additionally, the facilitator was a past graduate of the University of Glasgow and I was studying there, which allowed for another shared

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<sup>7</sup> Which was something commented on by several participants

perspective. It was particularly helpful that we shared these experiences because we differed in age, gender, social position, smoking status and were from different devolved nations.

I joined the participants' group meet-ups several times in advance of the workshop, which was important to build a relationship with the participants, and to build trust and familiarity. The workshop facilitator was already known at the community centre and by many of the participants, meaning there was already trust and rapport between them. Additionally, he shared more in common with the workshop participants than the researcher (closer to 50 years old, Scottish, living in Possil, working class upbringing, and a current smoker), which helped to bridge the distance created by our differing social identities. This was invaluable for recruiting participants to the workshop, as well as encouraging engagement during the workshop.

It was notable that there were differing knowledge systems between the research team and participants, during the workshop. Participants appeared not to have often been given control to dictate or create knowledge and this was noticeable in the amount of encouragement people needed to make suggestions. The workshop had an explicit goal which was focussed on generating design ideas to inform the final designs. By making this goal explicit to the participants, they were made aware of the orientation to knowledge being adopted by the researcher and that this was an orientation they were being invited to take part in.

### **3.2 Approach to design**

Within this thesis, the picture narratives developed are considered a behavioural intervention, as they were developed to support people in attending to, and reading, the information (engagement), making a decision (deliberation) and enacting that decision (implementation). Therefore, this thesis followed the stages for developing an intervention set out by the Intervention Mapping (IM) approach which has been informed by behavioural science theory and research in practice (Bartholomew Eldredge, 2016). The IM approach outlines well-established stages to cover in the development of an intervention programme in order to increase the success when applied in a 'real world' setting. The following three principles for developing an intervention are included in the

IM approach and were adopted when designing the picture narrative LCS information: tailoring, involving stakeholders and using theory and evidence.

### **3.2.1 Target audience**

The concept of cultural sensitivity comes from health communication and refers to the condition of ensuring that communication efforts respect the practices and values of the people within a certain audience (Brooks et al., 2019). Additionally, cultural specificity can be thought of as ensuring the communication tools are appropriate to the needs and communication conventions used by the audience. Achieving these two conditions will be necessary if the LCS information being developed is to be considered relevant by the audience and comprehensible to them. Making sure the designs are appropriate to the communication conventions used by the audience is no less important when developing visual communication as it relies heavily on shared understanding (V. Hoffmann, 2002).

Based on a need to achieve cultural sensitivity and specificity, the picture narratives were developed for a smaller target audience than the target population for a future LCS test. The target audience was chosen based on the desire to develop LCS information that was supportive for those with the greatest need for LCS and who experience the greatest inequity in the present cancer screening programmes. Therefore, the target audience for the picture narrative LCS information developed in this thesis were people living in areas of Glasgow with high levels of socioeconomic deprivation and who would be eligible for LCS. Between 2018 and 2020, there were more lung cancer deaths in Glasgow City (138.63) than any other council areas in Scotland (90.58; ScotPHO, 2018b). Glasgow has some of the highest rates of lung cancer mortality in the UK (British Lung Foundation, 2016), with higher rates in areas with high levels of socioeconomic deprivation (Tweed et al., 2018). The criteria used for LCS eligibility in this thesis were people aged between 50 and 75, with a history of heavy smoking (equivalent to 10 cigarettes a day for 20 years), and who currently smoke or have done so within the previous 15 years. This was based on the broadest criteria derived from those used in the LCS trials previously conducted (Table 1-2, Chapter 1). The current UK implementation trial is targeting people aged between 55 and 75 (Grover et al., 2020). Including people aged 50 to 55 in this project was appropriate as they would likely be eligible by the time a LCS programme is implemented in Scotland.

### 3.2.2 Involving stakeholders

The second principle for developing an effective intervention is including key stakeholder in the development process. The term ‘stakeholder’ is used to refer to anyone involved in the delivery of a product or who will be affected by the release of the product. Table 3-2 lists the different possible stakeholder groups as outlined by NHS improvements guidelines on stakeholder analysis (NHS, 2009). Involving stakeholders in the development of a product ensures it is suitable for the people delivering or using it and provides an opportunity to secure their investment in the product. This will lead to the developed product being more likely to be accepted and adopted.

*Table 3-2. Different stakeholder groups*

| Design stage                | Stakeholder group | Stakeholder description                                                                   |
|-----------------------------|-------------------|-------------------------------------------------------------------------------------------|
| Intervention development    | Commissioners     | people commissioning the development of the intervention                                  |
|                             | Contributors      | people who provide content for the intervention                                           |
|                             | Collaborators     | people involved in developing and delivering the intervention (includes ‘Creatives’)      |
| Intervention implementation | Channels          | the people and networks through which the intervention will be able to be implemented     |
|                             | Customers         | the people who will use the intervention                                                  |
| Intervention adoption       | Commentators      | people who share their views about the intervention and influence others                  |
|                             | Competitors       | people developing or delivering similar interventions                                     |
|                             | Champions         | people advocating for the development and delivery of the intervention                    |
|                             | Consumers         | people who will receive the intervention i.e., those who are targeted by the intervention |

Not all stakeholders need to be engaged with to the same degree and, for a successful intervention programme, it will be necessary to determine how we will involve the different stakeholders. The NHS improvements guidelines suggest four qualitatively different ways of engaging with your stakeholders depending on the level of power they

have in affecting changes (i.e., the group's inherent ability to influence the design of the intervention) and how much stake they hold in the project's outcomes (i.e., amount of impact the intervention would have on a group). I have expanded upon the matrix by adding a third level that takes into account the group's inherent ability to influence the adoption of the intervention. Stakeholders with high power over adoption need to be consulted over the implementation strategies for the intervention, while it will be less important to involve stakeholders with low power over adoption. I used this matrix to identify and organise potential stakeholders in the LCS information provision intervention being developed (Table 3-3).

*Table 3-3. Key stakeholder matrix*

|                                                                                           | <b>High stakes</b><br>Involve through consultation and regular communication |                                                                              | <b>Low stakes</b><br>Consultation and regular communication will not be necessary |                                                                                                                                                  |
|-------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                           | <b>High power over design</b><br>Identify and meet their priorities          | <b>Low power over design</b><br>Give support to increase their influence     | <b>High power over design</b><br>Identify and meet their priorities               | <b>Low power over design</b><br>Give support to increase their influence                                                                         |
| <b>High power over adoption</b><br>Give them control in the design phase                  | (A) Future screening program organisers                                      | (B) Future invitees to lung screening (particularly underserved communities) |                                                                                   | <ul style="list-style-type: none"> <li>Health communication educators and practitioners</li> <li>People in social circles of invitees</li> </ul> |
| <b>Low power over adoption</b><br>Giving them control in the design will not be necessary | (C) Cancer screening leaflet designers                                       | (D) Lung screening practitioners                                             | <ul style="list-style-type: none"> <li>Project funders</li> </ul>                 | <ul style="list-style-type: none"> <li>Lung cancer specialists</li> <li>Health communication students</li> </ul>                                 |

Several key stakeholders were involved while developing the research programme followed in this thesis. First, I met with a general practitioner working in an area of Glasgow with high levels of socioeconomic deprivation. I described my project plan to her, and she gave advice based on her experience of working with people in the target

population (relevant to group B in stakeholder matrix). I participated in two public engagement events as a stallholder while in the planning stage of the project: one at an evening science fair for the general public in Glasgow centre, and the other during the day at a community fair held in a community centre in a low-resource area of Glasgow. I told attendees that I was planning a project to improve cancer screening information leaflets and asked for their thoughts and ideas for conducting the research (group B in matrix). I had a meeting with a professor with experience of developing cancer information leaflets, to receive further advice on the methods planned (relevant to group A in matrix).

Stakeholders were also included in the development and organisation of the studies that included human participants (Studies 3, 4 & 5). For the design workshop (Study 3), a community development lecturer with ties to the target population gave advice on the study plan, community groups were consulted on the plan for the workshop and a community group volunteer helped organise the workshop. For the usability interviews (Study 4): a community development worker was consulted on the recruitment plan; the interview schedule was piloted with a member of the target population; and advice and support in recruiting participants was received from Community Connectors (who are coordinated through Glasgow Community Planning Partnership's Thriving Places programme) and Community Link Workers (who are coordinated through Glasgow City Health and Social care Partnership, as part of a programme established by the University of Glasgow's Scottish Deep End project). For the evaluation questionnaires (Study 5), a community development worker reviewed the questionnaire, and it was piloted by community group members in the target population.

### **3.2.3 Theory and evidence-informed**

The third principle for developing an effective intervention is to employ theory and evidence to guide the intervention and implementation strategy. The IM approach gives clear guidance on how to incorporate theory and evidence into the development of an intervention and provides steps on how to accomplish this (Bartholomew Eldredge, 2016). The first step is to produce a logic model of the problem and determine target behaviours for the intervention. The second step is to map the context of the proposed solution to the problem (which in this case is the use of picture narratives). The third step calls for collecting and building theory to apply in the intervention. The fourth step calls for planning, uniting, and combining context and theory.

Additionally, I took a mechanisms-focused approach to reviewing communication factors in Chapters 1 and 2, in order to identify design suggestions that were supported by theory and empirical evidence. Within the behavioural sciences, a mechanism is a general explanatory construct or process theorised to influence a person's likelihood of engaging in a behaviour (Fishbein, 2009). The concept of mechanism is based on the desire to find and distil the 'active ingredients' within a behaviour intervention or communication strategy, to improve the chances of success of future interventions and strategies (Onken et al., 2014). Behaviour change intervention developers are interested in finding specific expressions of a mechanism that results in an individual being more likely to carry out a desired behaviour or less likely to carry out an unwanted behaviour (Fishbein, 2009). Once the mechanism expressions that are critical to the behaviour have been identified (for example, the belief that screening can reduce suffering), they are mapped to techniques through which they can be manipulated (for example, education into the ways screening can reduce suffering). Within the design approach of this thesis, these techniques become the design suggestions.

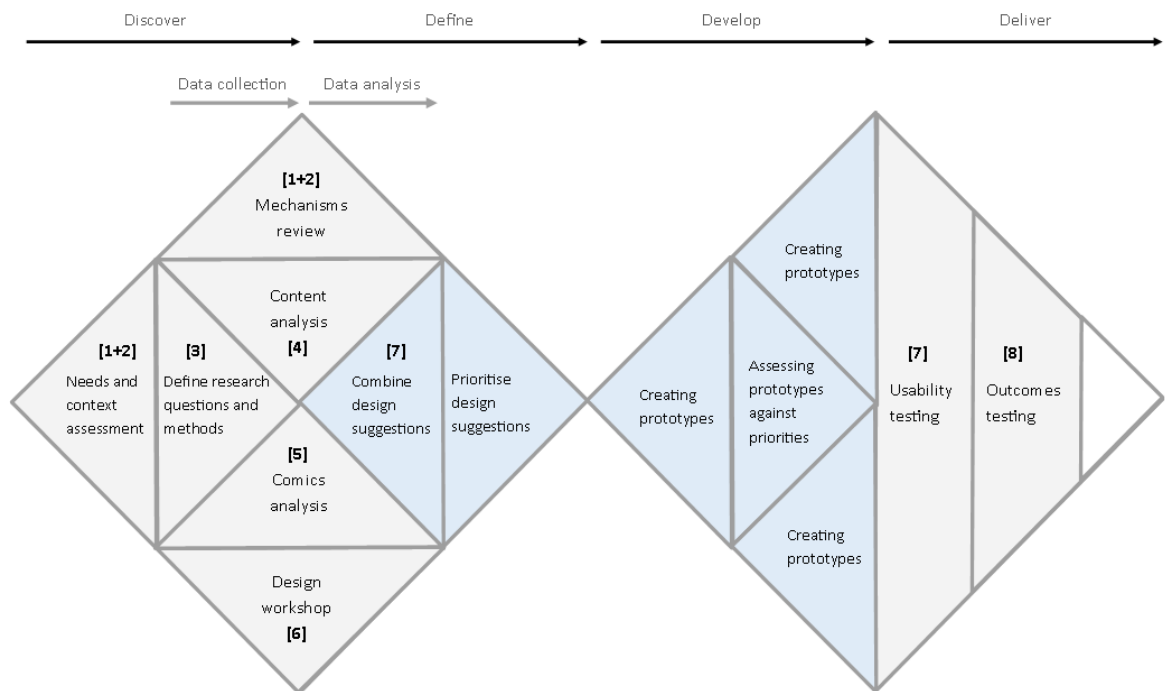
### **3.3 Design stages followed**

The British Design Council's Double-Diamond model of design was drawn upon when planning the development stages of the picture narrative lung screening information. The Double-Diamond is a visualisation that simplifies the main phases of design and provides a helpful method for understanding the progression of any design project (Figure 3-1).

The model starts with a phase of expanding knowledge (referred to as divergence), followed by a condensing of knowledge (referred to as convergence) through research and synthesis, creating the first 'diamond' shape. The model then has a phase of expanding product ideas (divergence), followed by refinement of the product (convergence), through prototype generation and testing.

I present this thesis in four sections (Foundation, Exploration, Creation and Evaluation), which follow the four phases of design-orientated research methods laid out by Martin and Hanington (2012). Figure 3-2 shows a summary of the thesis sections and design steps followed in this thesis.

*Figure 3-1. Design stages followed through the project, mapped to the double diamond model of design, with studies and chapters indicated*



*Note.* Chapters indicated in square brackets. Processes from ‘define’ through ‘develop’ (as indicated with blue) are all described in Chapter 7.

### 3.3.1 Foundation

#### Stage 1. Map the context

The first stage of the design process was to outline the context and constraints of the project and to define the goals. In line with step 1 of the IM approach, I produced a needs assessment of the health problem (poor lung cancer outcomes), from which I created a logic model of the problem and opportunity for intervention (Figure 1.1, Chapter 1). This logic model outlined the ‘program goals’, which were the behaviours to be targeted by the intervention and the priority population to be targeted. In this stage, I also proposed an intervention method (picture narrative format) and assessed the context surrounding this as a solution to the health problem. Chapters 1 and 2 present a summation of these considerations.

### 3.3.2 Exploration

#### Stage 2. Build knowledge

The main aim of this second stage of the design process was to expand knowledge relevant to the development of picture narrative lung screening information developed for the target

audience, building a broad perspective of the challenge and associated phenomena. This is in line with step 3 of the IM approach. The route of enquiry was directed by the following question: What content and design characteristics should be used in picture narratives of lung cancer screening information for invitees within the target audience? This question is investigated in Chapters 4 to 6.

### **Stage 3. Synthesise knowledge**

The third stage of the design process was concerned with synthesizing the knowledge produced through the studies in stage 2. This is in line with step 4 of the IM approach. Synthesis began at the point of data analysis, followed by developing design suggestions based on the results of these analyses. All design suggestions identified through Chapters 2 to 6 were then collected together in a table alongside the evidence supporting the suggestions (this included the following different types of information; empirical, qualitative and practice-based). Chapter 7 presents the priority design suggestions taken from this synthesis.

### **3.3.3 Creation**

#### **Stage 4. Generate prototypes**

The next design stage was to develop prototypes based on knowledge generated and synthesised through the previous stages. Chapter 7 describes how the priority design suggestions were incorporated into the development of prototypes of picture narrative information about lung screening tailored to the target audience.

#### **Stage 5. Usability testing and redesign**

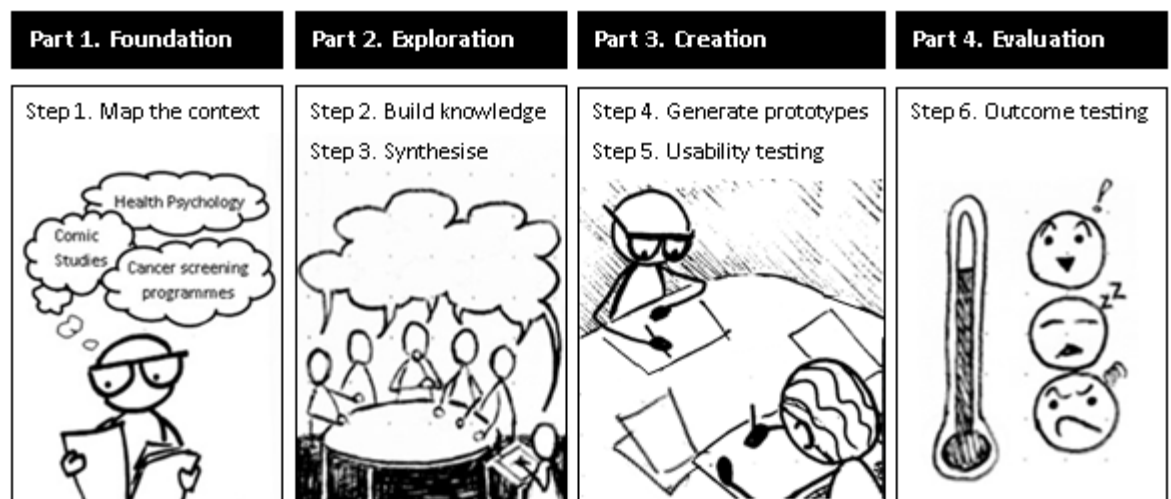
The fifth stage of the design process was to evaluate the prototypes and make revisions. Chapter 7 summarises an interview study with members of the target population used to assess the accessibility and acceptability of elements of the LCS picture narrative prototypes [*Study 4*]. Popular design models suggest this phase should be iterative. Initially, it was planned that the usability tests would be staggered with modifications to the designs occurring between each couple of interviews. However, due to a desire to maintain rigour in the method and to approach the phenomena of accessibility in an appropriate way, all usability interviews were conducted in a single stage and from the analysis of these, modification were made to the prototypes.

### 3.3.4 Evaluation

#### Stage 6. Outcome testing

The final design stage involves testing the product that has been created against project specific measures of success to determine whether the product is ready, or suitable for, dissemination or implementation. The following question was used when evaluating the picture narratives created through this project, corresponding to the program goals: Can picture narratives be used to support the effective communication of LCS information to invitees to support informed and equitable uptake?

*Figure 3-2. Sections of the thesis and the included design steps*



### 3.4 Thesis chapters and research questions

To investigate whether picture narrative form could be used to support equitable and informed uptake of LCS, this thesis first determines design suggestions for ensuring the picture narratives were suitable for the context of LCS and for the target audience. To take a holistic approach to determining these design suggestions, several studies attending to unique research questions were carried out. The overarching question guiding these studies was:

Question 1. What content and design characteristics should be used in picture narratives of lung cancer screening information for invitees within the target audience?

Chapter 4 reports a content analysis of pictures present in print information materials produced for the UK cancer screening programmes [*Study 1*]. This study was conducted to build insight into current practice, and to identify the context within which the designs would be situated. The content analysis was also used to identify instances where picture narrative are being used in current practice and to investigate the characteristics of these, looking at their function, content and style. This chapter attends to the following question:

*Question 1.2* How is picture narrative form being used in print cancer screening information in current practice?

Chapter 5 reports the analysis of a sample of comics portraying cancer narratives to build insight into LCS related portrayals in picture narrative form [*Study 2*]. This study investigates the extent to which depictions of lungs, cancer, and screening are present in comics, by looking at comics portraying a narrative about cancer and available in English. This is followed by a qualitative content analysis of picture narrative portrayals of cancer within a selection of the comics identified. This study was conducted to build insight into the formal conventions and aesthetics available for picture narrative portrayals of lung screening. This chapter attends to the following question:

*Question 1.3* What are culturally prevalent portrayals of lung cancer and cancer screening information in picture narrative form (for the target audience)?

Chapter 6 describes a community-based design workshop run with members of the target audience in which LCS and design suggestions were explored [*Study 3*]. This workshop was carried out to ensure the design suggestions for the picture narrative LCS information were culturally sensitive and appropriate for the target audience. This chapter explores to the following question:

*Question 1.4* What are the target audiences' preferences and perceptions relevant to the presentation of lung cancer screening information in picture narrative form?

Chapter 7 describes the development of the picture narrative designs, including; the synthesis of the design suggestions identified through Studies 1 to 3, the selection of the lung screening information to be made into a picture narrative format, the review of best practice guidelines for print health information materials and behaviour change techniques,

consultations with a lung health expert, the initial development of designs through a reflexive creative practice, the development of prototype designs with the support of a professional artist, and the usability testing of these prototypes to identify any elements or aspects of the designs that were not accessible or acceptable to the target audience [Study 4]. Final picture narrative LCS information designs were then developed based on the findings from the usability testing.

Chapter 8 describes a questionnaire study carried out to evaluate the acceptability and effectiveness of the final picture narrative designs created through the previously described phases of the project. This study used a quantitative questionnaire survey with a parallel randomised controlled design to test the impact of the picture narrative LCS information on important communication outcomes (LCS knowledge; LCS eligibility self-assessment accuracy; LCS attitudes; and design appeal) compared to the same LCS information in a text with pictures format and in a text-only format [Study 5]. This chapter aims to answer the following questions:

Question 2. Can picture narratives be used to support the effective communication of LCS information to invitees to support informed and equitable uptake?

Question 2.1 Was the picture narrative LCS information developed through the project perceived as acceptable to the target population, able to increase lung cancer screening knowledge and able to reduce psychological barriers to lung cancer screening?

Question 2.2 Were effects of the picture narrative LCS information on communication outcomes equal across people from different socioeconomic groups?

Chapter 9, the final chapter, reflects on the results of the studies carried out and on the design process followed, considering both the strengths and limitations of these. The chapter also considers what contributions the thesis makes towards theory and practice.

The following table outlines each chapter and study and how these map to the design phases and stages followed in this thesis (Table 3-4).

Table 3-4. Double-Diamond phases mapped to final design stages followed

| Phases of the double diamond methodology       | Stages of design followed in the current project | Thesis sections, chapters, and studies                                              |
|------------------------------------------------|--------------------------------------------------|-------------------------------------------------------------------------------------|
| <i>Phase 1.</i> Discover through Research      | <i>Stage 1.</i> Map the context (IM step 1 & 2)  | Foundation<br><i>Chapter 1:</i> LCS background<br><i>Chapter 2:</i> PN background   |
|                                                | <i>Stage 2.</i> Build knowledge (IM step 3)      | Exploration<br><i>Chapter 4:</i> Factors review                                     |
| <i>Phase 2.</i> Define through Synthesis       | <i>Stage 3.</i> Synthesise knowledge (IM step 4) | Chapter 5: <b>Study 1</b><br>Chapter 6: <b>Study 2</b><br>Chapter 7: <b>Study 3</b> |
| <i>Phase 3.</i> Develop through Ideation       | <i>Stage 4.</i> Generate prototypes              | Creation<br>Chapter 8: <b>Study 4</b>                                               |
| <i>Phase 4.</i> Deliver through Implementation | <i>Stage 5.</i> Usability testing and redesign   |                                                                                     |
|                                                | <i>Stage 6.</i> Outcome testing                  | Evaluation<br>Chapter 9: <b>Study 5</b>                                             |

*Note.* LCS = Lung cancer Screening, PN = Picture Narratives, IM = Intervention Mapping. For a simple overview of the different studies and how they work together, see Appendix 1.

## Chapter 4. Analysis of picture use in print UK cancer screening information

### 4.1 Introduction

This chapter investigates the extent to which picture narratives have been used in recent UK cancer screening information materials (Study 1). The study identified that few picture narratives were used and so a broader investigation into the use of pictures was carried out to better understand the characteristics of pictures used in current practice. The pictures are considered in terms of visual communication theory which is something that has not been done before for cancer screening materials produced in the UK. The contents of this chapter were published in *Health Communication* during the completion of this thesis (Gatting et al., 2022; see Appendix 3).

#### 4.1.1 Background

There is limited guidance on what types of pictures to use, and under which conditions, to best facilitate different desired communication outcomes (Jensen, 2011). This reflects a lack of available or consistent research findings. Most research into picture use in a health information context has not distinguished between different types of pictures, their effectiveness to communicate different types of message or their use in different health contexts (Jensen, 2011). Lack of clarity between types of pictures, as well as heterogeneity across study samples and contexts, are likely the reasons why reviews of pictures in health information materials (Houts et al., 2006; Schubbe et al., 2020) have concluded mixed results and why studies have difficulty replicating the results in applied settings. Jensen (2011) determines that a more systematic investigation into the visual element of health information communication is needed. To be able to investigate how elements within a picture impact the way that health messages are received and consequent behaviour change, it is necessary to have precise and shared ways of categorising and describing these elements. This will also improve the communication of recommendations made to designers and providers of health materials.

In response to calls for more systematic investigations of pictures in health information, King (2015) conducted a content analysis of pictures present in cancer information materials produced in the United States of America (US) from four key health and cancer

organisations. King (2015) found visual images were used more often in materials targeted at minority populations and materials about cancer prevention and detection. Also, pictures most often depicted people and behaviours being modelled/demonstrated. King (2015) considers these variations in picture use in terms of relevant theories, but concludes that more theory-based research into the use of visual information in cancer screening material is required. A comparison between the US and UK context will be valuable as, although similar in many ways (in culture, economics, politics and industry; Henrich et al., 2010), they have very different approaches to health care provision; healthcare is a nation-wide universal public service in the UK, but not in the US. In addition, replication of King's (2015) study would provide an opportunity for testing and refinement of the original coding frame.

Question 1. To what extent have pictures (including picture narrative) been used in print cancer screening materials in the UK?

Content and style are key qualities to analyse when attempting to describe the technical elements of a picture (Willats, 1997). Picture content refers to what is being depicted within the picture and style refers to the methods of expression used to produce the picture. Additionally, picture function is an important quality to capture. Picture function refers to the quality of the information provided by the picture (i.e., what the picture is doing as part of the information material). To identify the most appropriate system for classifying pictures in cancer screening information materials, this study will therefore investigate the content of pictures being used in recent UK cancer screening information materials, what style they are in, and what functions they have.

Question 2. What are the characteristics of the pictures used in these materials (in terms of content, style and function)?

Question 3. Are there any patterns in the way different picture characteristics have been used?

## 4.2 Method

### 4.2.1 Sample

#### 4.2.1.1 Identifying and selecting the sample

The sample included any materials designed to be printed and paper-based, intended to be posted or handed to targeted readers, concerning any of the UK cancer screening programmes in operation at the time of the study (breast, bowel and cervical screening) and, produced within the ten years preceding the search date (i.e., 2009 or later). Only materials that had a version available in English were included. Prostate cancer screening was not in operation and a lung screening programme was being trialled but not yet available as a UK-wide screening programme. The sample did not include ‘Easy-read’ materials designed specifically to be read with the support of another person, or posters. Where different versions of the same material were identified, the most recently published version was included in the sample.

Materials were identified through a hand search of the websites of seven UK cancer charities and public health organisations (National Health Service, [nhs.uk](https://www.nhs.uk); Macmillan, [macmillan.org.uk](https://www.macmillan.org.uk); Cancer Research UK, [cancerresearchuk.org](https://www.cancerresearchuk.org); Bowel Cancer UK, [bowelcanceruk.org.uk](https://www.bowelcanceruk.org.uk); Public Health England, [gov.uk/government/organisations/public-health-england](https://www.gov.uk/government/organisations/public-health-england); NHS Wales, [bowelscreening.wales.nhs.uk](https://www.bowelscreening.wales.nhs.uk), Health & Social Care, [cancerscreening.hscni.net](https://www.cancerscreening.hscni.net)). These seven organisations were selected due to being the main providers of advisory board approved and publicly trusted information about cancer or medical screening across the devolved nations (England, Wales, Scotland, Northern Ireland) in the UK (which differ slightly in the running of their cancer screening programmes). All materials were indicated on the websites as designed to be printed (e.g., described as leaflet/booklet or being in PDF print-ready format). The search was conducted during November 2019.

#### 4.2.1.2 Final sample

There were 44 cases found during the search period that satisfied the inclusion criteria. Of these, five were materials that included only instructive and procedural information, all of which related to bowel cancer screening. Characteristics of the sample, including cancer and test types, providers, location, years produced and number of pages for all the

materials, have been reported in an openly available data file via Figshare (doi: 10.6084/m9.figshare.14483589).

### **4.2.2 Analysis**

A content analysis was used to give a systematic description of the prevalence and characteristics of pictures in our sample of cancer screening information materials produced in the UK. This method of analysis was suitable because it provides a systematic and replicable approach to summarising the content of a sample of documents (Stemler, 2001), such as print information materials. The method for running a basic content analysis involves identifying the units of analysis within the sample materials and then methodically applying a coding scheme to those units (Drisko & Maschi, 2015).

#### **4.2.2.1 Units of analysis: Pictures**

Within the materials, the unit of analysis was pictures. The definition for a picture was based on Mitchell's (1986) definition of an image; information portrayed through visual resemblance, with pictures categorised as graphically rendered images. Most types of data visualisation, such as data graphs, do not satisfy this definition as they rely on abstract visual representation of mathematical information (e.g., size representing quantity or location representing numeric relationship; Meynell, 2013). Therefore, unlike King's (2015) analysis that included all visual images, the current analysis of pictures did not include data graphs.

Further to this, Meynell's (2013) consideration of Willats' (1997) description of pictures was used to define the boundary of a picture. Meynell determines the minimal elements required to qualify as a picture are 'picture objects' (e.g., lines and shapes created from marks) and that a picture is singular (i.e., separate from background or other pictures) where these 'picture objects' exist within a distinct space (also referred to as 'picture scene'). In short, a picture is defined here as any self-contained image that visually resembles that which is being depicted.

#### **4.2.2.2 Coding manual development**

A literature review was conducted to identify categories analysed in previous studies of pictures in health communication that fell within one of the three picture elements being analysed; function, contents, and style. In addition, the primary researcher viewed, and

made notes on, each picture as presented in its information material and in comparison to the other pictures. These notes were used to adapt, and add to, the categories identified from the literature to be suitable for the current study sample and to identify any additional categories where appropriate.

The coding manual was trialled and updated twice, with two randomly selected pictures from the sample, coded by both LG and CH in the first round, and three pictures in the second. The validity of the final version of the coding manual was then tested by comparing the coding of a separate sample of pictures by the main researcher (LG) and an uninitiated coder (LF). Fifteen pictures were double coded for the contents and style categories, while 34 pictures were double coded for the function category. Cohen's Kappa was used to test inter-rater reliability for the dichotomous codes. For the continuous codes, intra-class correlation estimates were calculated based on an absolute-agreement, 2-way mixed effects model. A full description of the coding categories and their related interrater reliability can be found in supplementary file 1. Most coding achieved good ( $n = 7$ ) to moderate ( $n = 11$ ) agreement based on Altman's (1991) guidelines to interpreting kappa coefficients. Twelve codes had too few occurrences, across their variables, for Kappa score to be calculated.

#### 4.2.2.3 Calculated Variables

To determine the prevalence of picture use across the materials, the study recorded how often (frequency) pictures were used and how much surface space was dedicated to pictures (coverage), as was previously done by King (2015). Picture frequency was calculated across the entire sample (total number of pictures) and by case (number of pictures per print material).

Picture coverage was calculated using the Nvivo 12 Pro region selection tool, which allows for the coding of rectangular regions (parallel to the document) and automatically provides a percentage for the size of the region containing the picture relative to the size of the document containing the selected picture.

$$\text{Mean Document coverage} = \frac{\sum \text{Coverage in each case}}{\text{number of cases}}$$

$$\text{Mean coverage per picture} = \frac{\sum \text{Coverage of each picture}}{\text{number of pictures}}$$

The data were managed in SPSS v26.

#### 4.2.2.4 Coding Categories

*Picture Function.* The development of the coding manual was used as an opportunity to determine what types of pictures were being used based on their function. The following four types were identified; Logos (pictures identifying a brand or organisation), Icons<sup>8</sup> (simple symbols that indicate the content of the text that follows), Display pictures (pictures not used to communicate a coherent message, e.g., pictures used to decorate the page, set the scene or show what something might look like), and Message pictures (pictures used to communicate a coherent message, e.g., pictures explaining how something works or a sequence of actions involved in completing a task). Logos and Icons are commonly used design terms, while the terms Display pictures and Message picture were developed for this analysis.

*Picture Content.* The following categories of content were recorded for each picture; what the main depiction was (scenery, a subject, an action or speech, as well as, no depiction – which would be meaningless lines and shapes), the number of people, the types of objects (ranging from medical equipment to plants), the background setting (whether indoors, outdoors, medical, home, unclear or blank), what cancer screening topics were covered (ranging from anatomy to benefits of screening, as well as, no topic – indicating an entirely decorative picture), what cancer screening messages were included (ranging from procedural instruction to emotions experienced), the viewer's position within the picture's world (as part of it, as outside observer or having no presence) and whether the picture portrayed a narrative (a narrative being a sequence of connected events involving an actor and an action).

*Picture Style.* The following methods of expression were recorded for each picture; how the picture had been produced (digitally, photographically, by hand or a mix), whether it was in colour, what types of marks had been used (outline, fill, or a mix) and how words had been used (as labels, sounds, part of objects, parallel to the picture or within the picture).

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<sup>8</sup> Not to be confused with the use of the term in semiotics. Here, to support communication with a wider readership, I use the term *icon* from the field of computing, where *icon* refers to a graphic representation.

#### 4.2.2.5 Exploratory Analyses

To answer question three (Are there any patterns in the way different picture characteristics have been used?), pictures were coded based on the presence or absence of; (1) screening topic, (2) background scenery, (3) one or more objects and, (4) one or more people. This produces 16 permutations, and these permutations were explored to determine what the most frequent combinations of content were present for each picture based on their function.

### 4.3 Results

#### 4.3.1 Overall Picture Prevalence

A total of 406 picture extracts were identified, within the 44 print cancer screening materials examined in this study. Each document had between two and 44 pictures, with the average being 9.23 ( $SD = 7.19$ ) pictures. After excluding logos, there were 283 pictures and an average of 6.43 ( $SD = 7.30$ ) pictures per document. Each picture covered a mean average of 1.10% ( $SD = 2.25$ ) of a document's surface and each document had an average of 6.83% ( $SD = 5.67$ ) surface area covered by pictures.

#### 4.3.2 Picture Function: Logos, Icons, Display and Message pictures

The most common type of picture based on function were display pictures ( $n = 129 / 406$ ), followed by logos ( $n = 123 / 406$ ) and icons ( $n = 101 / 406$ ). The least common type of picture were message pictures ( $n = 53 / 406$ ). However, pictures of this type were the largest relative to document size ( $M = 2.15\%$ ,  $SD = 4.21$ ), followed by display pictures ( $M = 1.50\%$ ,  $SD = 1.85$ ). Icons and logos covered an average of 0.16% ( $SD = 0.20$ ) and 0.03% ( $SD = 0.06$ ), respectively.

#### 4.3.3 Picture Content

This section reports the frequency of notable depictions present in pictures used in cancer screening information materials, looking at the pictures separately based on their function (logo, icon, display or message).

The most common type of logo depicted no subject or action ( $n = 89 / 123$ ), followed by having a subject as the main depiction ( $n = 34 / 123$ ). No logos contained people,

background settings or screening topics, and more often did not contain an object ( $n = 92 / 123$ ). Logos did not position the viewer within the image world and were not narrative.

Icons are simple symbols that indicate the content of the text that follows. The most common types of icons contained only an object ( $n = 40 / 101$ ) or shapes ( $n = 44 / 101$ ), with no people, background setting or screening topic. Icons either had a subject as their main depiction ( $n = 60 / 101$ ) or did not contain a depiction ( $n = 41 / 101$ ). Sixteen icons (15.8%) portrayed a cancer screening topic, and these were all of the signs and symptoms of cancer. Icons did not position the viewer within the image and were not narrative.

#### **4.3.3.1 Display pictures**

Display pictures are pictures that provide visual information without communicating a coherent message or functioning as a logo or icon (for example, to decorate the page, set the scene or show what something might look like). The most common type of display picture portrayed at least one screening topic (such as, how to do the test) and included an object while having no people and no background setting ( $n = 43 / 129$ ). The second most common type of display picture did not portray a screening topic but did include people, objects and background settings ( $n = 23 / 129$ ).

Display pictures either had a subject (e.g., a person or a laptop;  $n = 90/129$ ) or an action (e.g., a person typing on a laptop;  $n = 39/129$ ) as their main depiction. Under half of the display pictures had a person in them ( $n = 59$ ). The largest number of people in a picture was eight ( $n = 1$ ). The most common objects depicted in display pictures were body parts and anatomy ( $n = 58$ ), medical and scientific items ( $n = 48$ ) and household items ( $n = 33$ ). Display pictures covered the whole range of different setting types. A little over half did not depict a setting ( $n = 68/129$ ), while those that did depict a setting were most often of the indoors ( $n = 40/129$ ).

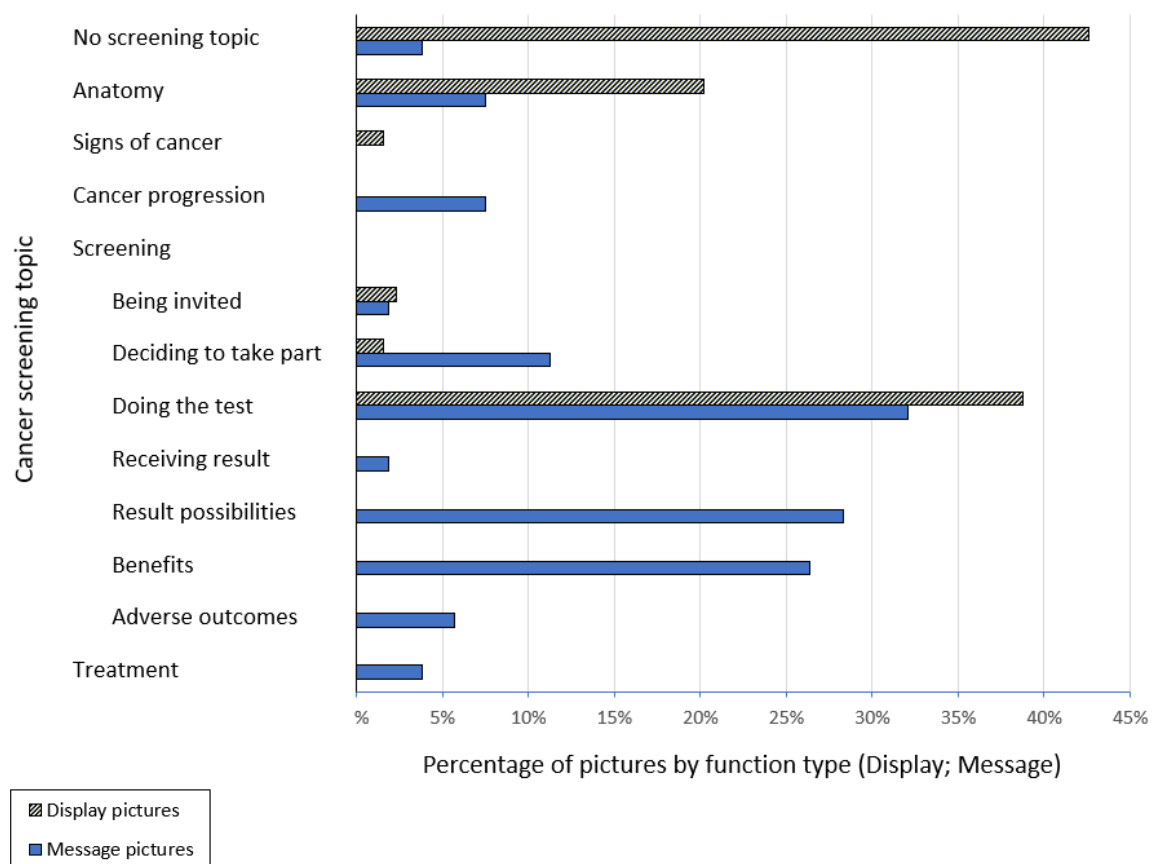
Where display pictures portrayed a cancer screening related topic ( $n = 74/129$ ), most were about doing the test ( $n = 50$ ) or anatomy ( $n = 26$ ). No display pictures portrayed cancer progression, receiving results, possible test results, adverse outcomes or treatment (see, Figure 4-1). Use of the different viewer positions varied roughly equally between the viewer having no presence in the picture ( $n = 47$ ), being positioned as an outside observer ( $n = 47$ ) and, being positioned as part of the picture's world ( $n = 35$ ). Only one display picture was a picture narrative.

#### 4.1.1.1 Message pictures

Message pictures are pictures used to communicate a coherent message. The most common type of message picture; was not narrative, portrayed a screening topic, contained no setting, contained no people and either contained objects ( $n = 26 / 53$ ) or did not (i.e., lines and shapes not forming an object;  $n = 10 / 53$ ).

Message pictures most often had either a subject ( $n = 28/53$ ) or action ( $n = 12/53$ ) as a main depiction or contained no depiction (i.e., meaningless lines and shapes, not representing a perceptible thing;  $n = 10/53$ ). Most message pictures did not have a person in them ( $n = 42/53$ ). For those message pictures that did contain people, the largest number of people in a picture was three ( $n = 2$ ). The most common object depicted in the message pictures were body parts ( $n = 22$ ), followed by medical or scientific equipment ( $n = 15$ ) and household items ( $n = 15$ ). Most message pictures did not have a setting in the background ( $n = 44/53$ ).

Figure 4-1. Cancer screening topics present across Display and Message pictures



Nearly all of the message pictures ( $n = 51/53$ ) portrayed a cancer screening topic. The most frequent topics portrayed were doing the test ( $n = 17$ ), the possible test results ( $n = 15$ ) and the benefits of screening ( $n = 14$ ; see, Figure 4-1). The only cancer screening topic not portrayed was the signs of cancer. The types of messages being communicated were mostly about procedure ( $n = 27$ ) or outcomes ( $n = 20$ ), while decisions ( $n = 5$ ) and experiences ( $n = 3$ ) were also covered. Several messages were recorded that did not fit into these four types. These were related to cancer progression ( $n = 2$ ), where to find more information ( $n = 1$ ) and personal data protection rights ( $n = 1$ ). The viewer was most often not positioned as part of the picture's world ( $n = 30$ ). There were twelve message pictures that portrayed a narrative, with eight about procedure, one about procedure and outcomes, one about procedure and experiences, and two about decisions.

#### 4.1.2 Picture Style

Logos were either digital illustrations ( $n = 107 / 123$ ) or digital illustration in combination with analogue illustration ( $n = 16 / 123$ ). They were more often in colour ( $n = 76 / 123$ ) and most often created with only fill markings ( $n = 88 / 123$ ), with 23 being outline only and 12 having both marking styles. All logos had a word or words in them, such as the organisation's or campaign's name.

Icons were entirely digitally illustrated ( $n = 101 / 101$ ) and more often in colour ( $n = 76 / 101$ ). Icons were created with an even range of marking styles (Outline only = 34; Fill only = 32; Outline and Fill = 35). Only 15 (14.9%) icons contained words, and all were used as labels.

Display pictures were most often; photographs ( $n = 74 / 129$ ), followed by digital illustrations ( $n = 44 / 129$ ), produced in colour ( $n = 114 / 129$ ), created without outline markings (fill only = 94 / 129) and contained no words ( $n = 80 / 129$ ). Where words were used, they were for labelling ( $n = 28$ ), were part of objects ( $n = 21$ ), or were part of text ( $n = 4$ ). There were no words used to portray sound or speech. When text was included ( $n = 4$ ) it was situated parallel to the pictorial images (Table 4-1).

Message pictures were most often digital illustrations ( $n = 35 / 53$ ). Most message pictures were produced in colour ( $n = 44 / 53$ ). There were 31 (58.5%) message pictures created with blocks of colour (only fill markings) and 21 (39.6%) created in combination with an outline (outline and fill markings). Only one (1.9%) message picture was a line drawing

without solid sections of colour. Most message pictures included words ( $n = 44 / 53$ ), with many ( $n = 28$ ) containing text. The only type of words not used were sound words. The text was integrated with the pictorial images in 16 of the cases and parallel in the other 12 (Table 4-1).

*Table 4-1. Frequencies of style in display and message pictures in print cancer screening materials.*

|                       | Display ( $n=129$ ) |       |               |           | Message ( $n=53$ ) |      |               |           |
|-----------------------|---------------------|-------|---------------|-----------|--------------------|------|---------------|-----------|
|                       | Frequency           |       | Mean Coverage |           | Frequency          |      | Mean Coverage |           |
|                       | <i>n</i>            | %     | <i>M%</i>     | <i>SD</i> | <i>n</i>           | %    | <i>M%</i>     | <i>SD</i> |
| Production            |                     |       |               |           |                    |      |               |           |
| Photograph            | 74                  | 57.4  | 1.56          | 1.75      | 6                  | 11.3 | 3.52          | 2.72      |
| Digital illustration  | 44                  | 34.1  | 1.06          | 1.04      | 35                 | 66.0 | 2.18          | 5.01      |
| Analogue illustration | 7                   | 5.4   | 1.44          | 0.50      | 2                  | 3.8  | 1.37          | 0.01      |
| Analogue & digital    | 1                   | 0.8   | 0.94          | -         | 2                  | 3.8  | 0.22          | 0.01      |
| Photograph & digital  | 3                   | 2.3   | 6.78          | 6.11      | 8                  | 15.1 | 1.71          | 1.19      |
| Colour                |                     |       |               |           |                    |      |               |           |
| Yes                   | 114                 | 88.4  | 1.56          | 1.95      | 44                 | 83.0 | 2.33          | 4.58      |
| No                    | 15                  | 11.6  | 1.02          | 0.63      | 9                  | 17.0 | 1.31          | 1.27      |
| Marks                 |                     |       |               |           |                    |      |               |           |
| Outline               | 2                   | 1.6   | 1.26          | 0.76      | 1                  | 1.9  | 1.24          | -         |
| Fill                  | 94                  | 72.9  | 1.66          | 2.08      | 31                 | 58.5 | 2.27          | 5.31      |
| Outline & fill        | 33                  | 25.6  | 1.05          | 0.95      | 21                 | 39.6 | 2.02          | 1.95      |
| Word use              |                     |       |               |           |                    |      |               |           |
| None or separate      | 80                  | 62.0  | 1.45          | 1.36      | 9                  | 17.0 | 1.40          | 1.71      |
| Labelling             | 28                  | 21.7  | 0.99          | 1.00      | 8                  | 15.1 | 1.76          | 1.11      |
| Sounds                | 0                   | 0.0   | .             | .         | 0                  | 0.0  | .             | .         |
| Speech                | 0                   | 0.0   | .             | .         | 5                  | 9.4  | 2.32          | 1.27      |
| Object                | 21                  | 16.3  | 2.35          | 3.50      | 9                  | 17.0 | 4.83          | 9.74      |
| Text                  | 4                   | 3.1   | 3.84          | 5.65      | 28                 | 52.8 | 2.77          | 5.66      |
| Integrated            | 0                   | 0.0   | .             | .         | 16                 | 57.1 | 2.09          | 1.78      |
| Parallel              | 4                   | 100.0 | 3.84          | 5.65      | 12                 | 43.0 | 3.69          | 8.52      |

## 4.2 Discussion

### 4.2.1 Picture Prevalence in Cancer Screening Information

There were very few pictures that portrayed a narrative across the screening information materials. Despite the low number of pictures used to portray a narrative across the cancer screening material analysed, there were picture narrative examples for all the types of topics relevant to making and acting on a decision to screen (i.e., procedure, outcomes,

experiences and decision dimensions). There were also picture narratives that included more than one type of topic, demonstrating the capacity and potential for picture narratives to communicate the entire range of cancer screening information within future leaflets. This content analysis identified that cancer screening information materials have under-utilised picture narrative form.

Most of the print materials produced for the purpose of communicating UK cancer screening information to invitees followed health communications guidelines by including visual information, with the materials containing an average of 6 pictures and 7% surface area dedicated to pictures (when discounting logos). Health communication guidelines stipulate using pictures wherever they may support or facilitate communicating a message within a document. The materials in our sample contain very similar messages, following guidelines on what information should be told to invitees of a screening programme (National Quality Forum, 2016; Public Health England, 2009). Therefore, it could be expected that similar numbers of pictures are used across the sample. However, the number of pictures used, and the size of the surface area dedicated to pictures, varied greatly across the materials.

King's (2015) study found a similar, but slightly greater, percentage of materials surface area to be covered by visual images in information materials about cancer detection in the US (11% vs 7%; Table 4-2), while both studies found the same average number of pictures per case ( $M = 6$ ). The larger surface area taken up by pictures in the US sample may be accounted for by the inclusion of data graphs in the unit of analysis and would suggest data graphs require more space. The similarity in picture prevalence suggests that picture placement across cancer information leaflets is similar across the two contexts. This may potentially come down to principles of composition, where designers in both countries are aiming for the same ratio of pictures to text and white space. King's (2015) sample had more pictures with people in them (57% vs 39%) and more photographs (57% vs 50%), suggesting US cancer organisations are more reliant on pictures of people and on photographs than providers of information about cancer screening in the UK when developing information materials. Taken together, this perhaps reflects different tones used in healthcare messages between the US and the UK. The private healthcare system of the US means that most healthcare needs to 'sell itself' to the public, leading to US healthcare information having a tone of product advertisements that rely on images of attractive, healthy and happy-looking people. The national healthcare system of the UK positions

health as a social responsibility (Brookes, 2021), leading to UK healthcare information having a tone of an instruction manual with educational diagrams and images of the tests, equipment and procedure.

*Table 4-2. Comparison of study findings between King (2015) and the current study.*

|                    | <b>King, 2015</b>                                                                                                                          | <b>Current study</b>                                                                                                                                              |
|--------------------|--------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Picture prevalence | Average of 6 pictures per case.                                                                                                            | Average of 9 pictures per case (6, when logos excluded)                                                                                                           |
|                    | Pictures covered an average of 9.4% surface area of each case. (10.6% for cancer detection materials)                                      | Pictures covered an average of 7.3% surface area of each case (6.8%, when logos excluded)                                                                         |
| People             | People were the predominant feature of 57% pictures (496 vs 228 object and 134 data).                                                      | People were in 38.7% (70 vs 112 no people) of display (45.7%) and message (20.8%) pictures.                                                                       |
| Object             | Food or drink were the most common type of object in pictures predominantly featuring object (31.2%), followed by parts of people (22.6%). | Parts of people were the most common type of object (44.0%) in display (45.0%) and message (41.5%) pictures, followed by medical or scientific equipment (34.6%). |
| Production         | Photographic production was used for 56.8% (487 vs 371 illustrative).                                                                      | Photographic production was used for 50% (91 vs 91 illustration) of display (59.7%) and message (26.4%) pictures.                                                 |

#### **4.2.2 Contributions to Theory**

Firstly, this analysis described picture characteristics across three categories; content, style, and function. These categories remained a stable way of grouping the different variables that were analysed. Working to capture each of these categories gives a holistic assessment of individual pictures that integrates a description of the informational (content) and aesthetic (style) qualities and the picture's relationship to the leaflet message (function).

This study determined four useful distinctions (logo, icon, display, message) to describe the different functions of pictures present in cancer screening materials. Firstly, the

acknowledgement of logos and icons as pictures with unique functions is an important contribution to the analysis of pictures in print information material. These visual images can often be overlooked in health communication research, as was the case with King (2015). However, their presence will contribute to a viewer's overall interpretation of an information leaflet (for example, Pieters & Wedel, 2018), as well as contribute to the visual complexity of the material. Visual complexity being both the objective feature and subjective perception of visual information related to the quantity, variety, arrangement and regularity of the visual elements (Berlyne, 1958; Pieters et al., 2010). Therefore, icons and logos are also worth recognising and accounting for in descriptions of print health information.

Secondly, the classification of display pictures versus message pictures is a novel approach to describing types of pictures in health communication. A strength of the two categories is that they depart from the affect and cognitive dichotomy promoted by some recent health communication research (Bol et al., 2014; Cho et al., 2018) and bring the focus on the properties of the information being provided. The categories of affective and cognitive pictures are suitable as experimental conditions. However, during coding scheme development it was identified that when used to describe pictures in a naturalistic context, these categories create a false dichotomy, as a single picture can both facilitate learning and induce an emotional response, and such cognitive and emotional information is processed in an integrated way (VanRullen & Thorpe, 2001). Therefore, these two qualities should be kept separate when assessing picture use in health information. The two categories of display and message function categories allow for the comparison between two meaningfully different types of information communicated by pictures in health information materials – showing the features of a thing (display) versus providing an explanation into how something works (coherent message). Additionally, information about pictures with a decorative quality is not lost within the coding scheme, as any display pictures coded as having 'no topic' can be considered as entirely decorative in nature.

#### **4.2.3 Implications for Research**

In addition to describing pictures used in cancer screening print materials, this study also set out to provide empirically useful categories for describing such pictures.

The coding scheme and questionnaire developed in this study achieved high inter-coder reliability rates between the primary researcher and a second coder who had not been

involved in the development of the coding scheme and had never formally analysed pictures before. Therefore, the coding scheme was a valid and understandable way of describing the pictures, giving support for the use of the coding questionnaire (Appendix 4) in future studies and could be used to replicate the research in different contexts (e.g., with other health leaflets or repeated in the future to measure changes in practice) to build the field of visual health communication research.

The coding scheme developed in this study provides scaffolding for the development of a standardised classification system for the study of pictures in print health communication. Such a system would enable a more systematic investigation into pictures used in health information communication – a need highlighted previously (Jensen, 2011). The categories could be used as the starting point for deciding and describing which picture characteristic are being manipulated in a study, to be able to untangle the impact different manipulations have on communication outcomes (such as, viewer awareness or understanding).

#### **4.2.4 Implications for Practice**

A large proportion of the pictures did not connect directly with messages within the materials as they did not include a cancer screening topic. Health leaflet developers may have easier access to stock images that are not specific to cancer screening or tend to use pictures for affective-elicitation and appeal rather than utilising them as a resource to support comprehension. With visual images being the initial point from which viewers make a judgement about the leaflet (due to the picture superiority effect), it will be important for the pictures to indicate the type of information being provided or the relevance to the viewer. Pictures that do not connect with the target audience and do not communicate the relevance that the information has to them will discourage people from reading the materials. Accordingly, many existing print health information guidelines advise keeping leaflets (Charnock et al., 1999; Kaphingst et al., 2012; Moody & Rose, 2004; Shoemaker et al., 2014) and pictures (Centers for Disease Control and Prevention, 2019; Kaphingst et al., 2012; Moulton et al., 2004; Shoemaker et al., 2014) clear of irrelevant content. Current practice was found to be inconsistent with the advice to keep pictures entirely relevant to the leaflet message.

Topics that were particularly missing from the pictures were being invited, deciding to take part, receiving result, result possibilities, screening benefits and potential adverse outcomes (Figure 4-1). Future design work could focus on balancing the portions of pictures across

these different screening topics. Shaffer and Zikmund-Fisher's (2018) taxonomy of screening narratives – identified while developing the coding scheme – was helpful in determining a broad range of screening topics capable of capturing the nuance of people's cancer screening experiences and decisions.

The pictures included in the cancer screening materials analysed for the purposes of this study often did not portray an action and they seldom included people. Considering most of these pictures were about doing a screening test, we should be seeing more pictures that show an action being carried out, as modelling behaviours is an important mechanism for learning and adopting new behaviour (Bandura, 1998). Where the goal is to support informed choice (acting in line with one's decision), it is important that pictures of people modelling screening-related behaviours are used in cancer screening materials.

A clear finding from this analysis is that cancer screening information materials include fewer, and have less surface area dedicated to, pictures that perform a message function compared to pictures that perform a display function, indicating that pictures are predominantly used to highlight or support the written messages rather than as a conduit of the message themselves. In some situations, display pictures are the most suitable type of picture to use, as with anatomical drawing used to show what parts of the body look like. However, most messages within screening information materials go beyond showing what something looks like, from describing the process involved in doing the screening to the potential positive and negative outcomes of taking part. Therefore, cancer screening material designers should look to use a larger portion of pictures that convey coherent cancer screening messages. Many of the display pictures were photographs of people. Such pictures do not need to be limited to a display function and future design work could focus on conveying relevant cancer screening messages through photographic pictures of people (for example, photos illustrated with symbols such as arrows and crosses or sequences of photos depicting speech, thought and behavioural enactment).

#### **4.2.5 Limitations**

On reflection, there are some picture characteristic categories that could be useful for cancer screening picture researchers that were not included in the coding scheme in this paper. Although we coded whether any action was depicted in the picture and what screening topic was being portrayed, we did not specifically code for instances where a picture was modelling cancer screening behaviour. This specificity may be necessary for

studies considering the interaction between different picture characteristics (such as ethnicity cues and behaviour being modelled) on communication outcomes (such as raising awareness or changing behaviour). Details were not kept about people's skin tones or how recognisable the household objects would be to different cultures. Researchers ought to measure these factors if looking into the presence of diversity of people in cancer materials or evaluating if there is a match between the ethnicity of the target audience and the models in the material. King (2015) demonstrates a way of measuring this. Picture structure (such as positioning) was not coded for. Structure is a key message feature (Shen & Bigsby, 2012) alongside the contents and the style of a picture but was not within the scope of the current analysis.

This study did not evaluate the characteristics of the picture portraying a narrative present as there were so few in the sample. A future analysis of the contents of health communication pictures could include a qualitative description of the picture narratives used. The sample included only materials that were publicly available online. Any materials developed locally by individual clinics have not been included. Therefore, the findings reflect the standards of the centralised screening programmes.

#### **4.2.6 Conclusions**

This study provides a description of the types of pictures being used in current UK cancer screening information materials, and their prevalence. This has allowed for a reflection on current practices, with a consideration of where best practice guidelines are not being followed. This study has highlighted that the following types of pictures have been underused in recent cancer screening information materials produced in the UK: pictures that communicate a coherent message, pictures that portray a narrative, pictures modelling a screening-specific behaviour and pictures conveying experiences or decision dimensions involved in cancer screening participation.

## **Chapter 5. Analysis of portrayals related to lung cancer screening in comics**

### **5.1 Introduction**

This chapter reports an investigation into the culturally prevalent narrative visualisations of cancer screening by looking at a selection of comics that contain cancer as a main aspect of the narrative (Study 2). This investigation was carried out in order to identify ways to communicate about lung screening in picture narrative form that would be recognisable to the target audience and support the target communication outcomes for LCS information material (supporting engagement, decision-making, and behavioural enactment, as identified in Chapter 1). First, I review the number, and characteristics, of comics portraying cancer narratives, to give an account of such comics and contextualise the proceeding analysis. Then, I report an image analysis, informed by comic theory, of the identified comics which was conducted to build understanding around prominent cultural portrayals of cancer in picture narrative form. These findings could then be used to inform designs of the picture narrative LCS information.

#### **5.1.1 Background and aim**

For the target audience to be able to understand and make use of the information provided in the picture narratives being developed, it is important that the picture narrative depicts images and symbols known to, and used by, the target audience. There is no formal knowledge base of visual symbols and imagery of cancer screening from which to make decisions about the designs of the LCS picture narratives. One way to ascertain the images and symbols that are used within a community is by looking at visual materials created and consumed within that community (Leeuwen & Jewitt, 2001).

##### **5.1.1.1 Comics as object of analysis**

In this chapter, I am looking at comics that fit the following description: a medium that employs static visual image and words (i.e., text) in a blended way to communicate a message, and which uses classic comics elements, such as panels and gutters (further description given below). Most comics (not including abstract comics) are created with intention to communicate a narrative, via visual images and words, in a way that will be understood (Eisner, 2008). Comics have a wide readership and have been used for

educational and informational purposes in health communication (Czerwiec et al., 2015). To be understood, comics have well-established/sophisticated visual language and apply culturally recognised symbols (Caldwell, 2012; Cohn, 2016). Therefore, an analysis of cancer comics should provide insight into acceptable and recognisable ways of describing lung screening information in a picture narrative format. Additionally, comics have traditionally received less attention in anthropological and medical scholarship into narratives of cancer than other mediums (McMullin, 2016). Analyses of cancer comics often focus on the narrative aspects of content, characters and plot and on a close reading of a small selection of cases, such as Chute's (2007) review of *Our cancer year*<sup>9</sup>, *Janet and Me*<sup>10</sup>, *Cancer Vixen*<sup>11</sup> and *Mom's Cancer*<sup>12</sup>, and Squier's (2007) comparison of *Our cancer year* and *Mom's cancer*. Alternatively, Lo-Fo-Wong et al. (2014) have conducted a thematic content analysis on the comic *Cancer Vixen* identifying the extent to which different types of distress have been portrayed.

Comics can be created for the following three reasons, which make them fruitful sites of analysis when concerned with cultural representations surrounding cancer screening. Firstly, comics may be created as a means of expression, being used by the creator to share their story with others<sup>13</sup>. The form is suitable for making visible the personal and internal experiences that may be otherwise invisible to, or unrecognised, by others (Williams, 2015). For example, the comic *Fibromyalgia and us* which depicts internal, or often hidden, experiences of the condition (Jindal-Snape et al., 2017). Secondly, creating comics can provide a way of processing experiences, feelings and challenging situations<sup>14</sup>. The drawing process gives distance between the creator and the topic being drawn, both through physical distance from the environment or the people that may be unsafe, and through writing the experience as happening to the character rather than oneself. Comic layout also provides structure through which one can organise thoughts and reinterpret an experience. There is linearity as well as flexibility provided by the comic convention, with the creator deciding the ordering and positioning of their panels, choosing what to show and what not to show. Having the power to determine panel layout can also give a sense of control over the experience. Finally, comics are often created collaboratively and have

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<sup>9</sup> Joyce Brabner, Harvey Pekar and Frank Stack, *Our Cancer Year* (New York: Four Walls Eight Windows, 1994)

<sup>10</sup> Stan Mack, *Janet and Me: An Illustrated Story of Love and Loss* (New York: Simon & Schuster, 2004)

<sup>11</sup> Marisa Acocella Marchetto, *Cancer Vixen: A True Story* (New York: Alfred A. Knopf, 2006)

<sup>12</sup> Brian Fies, *Mom's cancer* (New York: Abrams ComicArts, 2006)

<sup>13</sup> I see this as the outward facing capacity of comics.

<sup>14</sup> I see this as the inward facing capacity of comics.

been used as a means of building understanding around an issue (for example, Barker & Scheele, 2016). There is a high level of intentionality behind how the content within comics has been depicted by the creator/s, as each element must be created (i.e., written and drawn) and the creator/s must select the moments (captured by each panel) that they wish to present to the reader. This means materials are rich with constructed and reflective meaning. Therefore, comics make for a rich resource of socially embedded meaning.

Question 1. What comics have been produced in English that contain cancer within the main narrative and what are the characteristics of these in relation to messages about lung cancer screening (i.e., cancer type, early detection, and type of cancer narrative)?

Question 2. How has cancer been represented in these comics (in terms of repeating images and depictions)?

### **5.1.2 Analytic framework**

An underlying assumption of this study is that repeating images and symbols found across cases can indicate what will be recognisable to the target audience. This assumption is supported by the culturally embedded nature of comics (Cohn, 2021). While analysing the comics, the following aspects of comic were recognised as playing an important role in representation:

*The story world and reflection outside of the story world.* Comic creation is both a rhetorical act, in which the creators both consciously select representation to produce an intended message and affect as well as unconsciously adopt culturally available images and tropes. Symbols and icons are selected both consciously and unconsciously, based on the creator's desire for the comic to be understood and rooted in the creator's fluency in a culture's lexicon of visual cues. Hermeneutic images are images that add further meaning 'outside' or separate to the diegesis (which is the world created by the narrative; Duncan, 2012). Hermeneutic images are most useful to look at if you wish to analyse the creator's thoughts and ideals, as this is what these images are often included to convey and is done so in a self-aware manner. On the other hand, diegetic images provide insight into the less deliberate selection of symbols and icons, as they function to carry the narrative.

*Interpretative.* The analysis was also carried out with an awareness that my understanding of the comics will be experienced through my own “perceptual filter”, which will have an impact on my analytic interpretations (Duncan, 2012, p. 44).

*Formal elements of comics.* An investigation of comics requires an awareness of the following techniques and formal elements that have become commonly used in comics and have become “established as conventions during the first half of the 20th century” (R. Palmer, 2016, p. 37): 1) ‘panels’ which are self-contained sections of a comic page, distinguishable from other panels, enclosed either by a border or blank space, that portray at least one image (visual or verbal) of an event or aspect; 2) the ‘gutter’ which is the space between two panels; 3) ‘effects’ which include speech balloons, movement lines, and enamata (emotions depicted as emanating from a character), 4) visual encodings related to size, shape, colour and texture, and 5) the organisation of contents on the page (i.e., page layout). Keegan (2013) distinguishes the following types of text used in comics; neurolinguistic, sound effects, narrative and printed. Edwards (1997) identifies the following four compositional elements of narrative common in all narrative theories across disciplines; characters, place, plot and narrator (cited in Goodnow, 2020).

#### **5.1.2.1 A both/and approach**

Comics use both the visual (i.e., images) and linguistic modes (i.e., text), which are produced, presented and read in combination. Therefore, comics must be analysed in a way that can connect the visual and linguistic elements (i.e., an intermodal reading). To do this, I adopted the approach of first analysing the text and images as one, then separately, and then in comparison to each other.

#### **5.1.2.2 A Panel-within-page approach**

There are different frames through which the meaning in comics is perceived. Baetens and Frey (2014) parse these different frames, which are Panels, Strips (panels in a row), Pages, and Container (e.g., book, website). Groensteen (2007) argues that panels are the smallest useful unit for studying comics. Panels work together to produce the narrative and are viewed simultaneously on page. Therefore, in this analysis I focus on individual panels while considering them in relation to the page.

## 5.2 Method

### 5.2.1 Sampling strategy

Rhode and Connor (2012) have published a comprehensive review of comics used in cancer narratives and cancer communications prior to 2012. However, due to the proliferation of the use of comics to share illness narratives dealing with difficult topics (including those about cancer), it was anticipated that more comics about cancer would have been released since this review was conducted. Therefore, I conducted my own search for examples of cancer comics. I conducted database searches through ProQuest, Ovid and EBSCOhost, and searched the online collections of the *U.S. National Library of Medicine*, *The comics grid* and *graphicmedicine.org*. I conducted a broad search using a range of search terms that could be used for comics: Comic, Graphic novel, Picture narrative, Static visual narrative, Visual narrative illustration, Narrative image, Visual-, Graphic, or Pictorial-storytelling, Sequential images, and Sequential text image pairing.

#### 5.2.1.1 Eligible cases

Cases were included if they were comics (defined as multi-panel sequence of visual images depicting a narrative), if they had cancer as the main topic (i.e., that one of the main narrative threads through the comic is about cancer) and if the comic was available in English.

### 5.2.2 Analytical method

The identified comics were collected into a spreadsheet and coded for the following categories: title, source (author, publisher, publication date, publication country), format (comic book, defined as short form and serialised; graphic novel, defined as long form and independent; book collecting series of comic strips; web-comic strips; comic strip pamphlet). The following dimensions were coded for regarding the cancer narrative: 1) 'What primary part of the body was affected' (cancer type), 2) 'Is information about early detection included', 3) 'Who has the cancer' (author, author's relation, main character, secondary character, cancer is a character, no one), 4) 'What is the narrative based on?' which was grouped into 'creator's own experience of having cancer', 'creator's experience of a significant other having cancer', 'clinical/medical knowledge' or 'other/unknown', and 5) 'What type of narrative is portrayed?' (i.e., genre), which was grouped into 'Biographic' (in the style of a personal narrative, memoir or journaling),

‘Naturalistic’ (in the style of slice-of-life or drama), ‘Speculative fiction’ (for example, fantasy, superhero or sci-fi), ‘Explanation’ (these comics were of a character giving an explanation to either the reader or another character and did not include plot or place). These categories were developed through a top-down followed by bottom-up approach, first guided by prior knowledge (for example, popular comic genres, such as slice-of-life and superhero) then, while reviewing the included comics, the categories were modified to better capture/fit the characteristics of the comics in the sample.

*Selecting extracts.* I searched within all available cancer comic cases within the sample ( $n = 32$ ) for reference to cancer, either visually or verbally. The whole page was captured for each extract (in line with the panel-within-page reading of comics) and collected into a single Word document.

*Analysis of extracts.* Following contemporary visual semiotics, analysis focussed on both the figurative (i.e., visual symbols) and non-figurative (i.e., artistic style) elements of the visual imagery (Aiello, 2020), which were considered alongside the verbal content (i.e., written text), in line with an intermodal reading of comics. I produced a written description for each extract, reflecting on the depiction of cancer by considering visual symbols, artistic style and written text. Observations that repeated across cases were explored further and formed the analysis finding.

## 5.3 Findings

### 5.3.1 Sample

The search identified 53 cases of comics with cancer as a main aspect of the narrative (see, Appendix 5 for the catalogue of collected comics). Throughout the following sections, I will be referring to the case by ‘case number’ which corresponds to those used in the catalogue. The comics were predominantly published in the US ( $n = 34$ ), followed by Canada ( $n = 10$ ) and the UK ( $n = 5$ ). There was one comic produced by a global syndicate to be used in Nigeria, one produced in Australia and two produced in Belgium. Eight of the cases were produced before the year 2000, eighteen during the decade following, and 25 after 2010. There were 26 books, 13 comic books, four comic strips, three pamphlets, six webcomic strips and one minicomic.

Sixteen of the comics identified were produced by Jumo Health, an organisation based in the USA that creates age-specific health information and resources. Twelve of these were part of the *Medikidz* series, in which superhero-type characters help one or more young characters to understand a specific disease. The superheroes take the children and the reader on a journey inside the body to explain the disease. There is a comic for each of the following cancers: Brain, Breast, Colorectal, Leukaemia, Liver, Lung, Non-Small Cell Lung, Melanoma, Osteosarcoma, Multiple endocrine neoplasia type 1, and type 2, and Prostate. The remaining four comics by Jumo Health were produced as part of a more recent series that use the same scenario. These comics are slightly shorter and cover the social and emotional effects of cancer that were somewhat missing from the earlier editions, covering *Leukaemia*, *Osteosarcoma*, *Lung Cancer* and *Childhood Cancer*. The comics in this series have been considered as a single case through the analysis, as they share very similar visual and narrative elements.

The following graphic narrative cases were identified that were not considered as comics in the current review; Anders Nilsen & Cheryl Weaver's *Don't go anywhere I can't follow*<sup>15</sup> (Hodgkin's lymphoma, illustrated book), Nancy Miller's *My multifocal life*<sup>16</sup> (Lung cancer, online collection), *Super Clara* by Robert Martin with Keira Ely<sup>17</sup> (brain cancer, illustrated book) and Annie Smith's *Bearing up with cancer*<sup>18</sup> (breast cancer, illustrated book). Teva Harrison's *In-between days* (Case 41) and Stan Mack's *Janet & Me: An Illustrated Story of Love and Loss* (Case 8) are illustrated books that include comics within the pages, so have been included in the review. The following comics were identified as potentially eligible but have not been included in the review due to being unavailable; Steve Gould's *Thank god it's only cancer*<sup>19</sup> and Peaco Todd and Dany Adam's *A mild case of cancer*<sup>20</sup>.

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<sup>15</sup> Drawn & Quarterly, 2012

<sup>16</sup> <https://nancymiller.com/my-multifocal-life/> Accessed 27 March 2022. Although not traditionally comic form, this work could be considered a comic as pieces are framed as panels by their placement on the blog pages and are ordered by date, so allow for a sequential reading.

<sup>17</sup> DreamChaser Publishing, 2018

<sup>18</sup> Second Story Press, 2004

<sup>19</sup> Mondays, 1995

<sup>20</sup> Cited in Todd (2013), unpublished

### 5.3.2 Characteristics of the comics containing a cancer narrative

#### 5.3.2.1 Cancer type

*Lung cancer cases.* There were three cases found in which a character in the story has lung cancer. Brian Fries' *Mom's Cancer* is a non-fiction biographic account of the author's mother having lung cancer (Case 16). The book is a collection of webcomic strips that Fries created during the time that the accounts were taking place. His mother defies the odds (of 5% survival rate) and goes into remission, to the surprise of the author and his sisters. *The death of captain marvel*, authored by Jim Starlin, was the oldest comic about cancer found that did not have an educational purpose (Rhode & Connor, 2012; Case 1). In this fantasy superhero comic, the character Captain Marvel dies from an incurable lung cancer. There were three comics about lung cancer in the Jumo Health series; *Medikidz Explain Non-Small Cell Lung Cancer*, *Understanding Lung Cancer* and, *What's Up with Sam's Grandma? Medikidz Explain Lung Cancer* (Case 68). One of which was published by American Cancer Society and Health Promotions in 2013. Additionally, Jennifer Hayden's *The story of my tits* (Case 30), which is about both her mother and herself having breast cancer, includes a peripheral character being diagnosed and later dying from lung cancer.

*Other cancer types.* Breast cancer was the most commonly represented cancer in the comics reviewed ( $n = 18/53$ ). Not including the Jumo Health comics aimed at kids, the following types of cancer were portrayed in the cases; prostate ( $n = 5$ ), Bowel ( $n = 3$ ), Hodgkin's Lymphoma ( $n = 2$ ), non-Hodgkin's lymphoma ( $n = 2$ ), testicular ( $n = 2$ ), bile duct ( $n = 1$ ), brain ( $n = 1$ ), cervical ( $n = 1$ ), Ewing sarcoma ( $n = 1$ ), larynx ( $n = 1$ ), leukemia ( $n = 1$ ), bone ( $n = 1$ ), skin ( $n = 1$ ), throat ( $n = 1$ ) and uterine ( $n = 1$ ).

#### 5.3.2.2 Early detection

The following cases were found which included content related to cancer early detection practices. A comic produced by the American cancer society, promoting the use of yearly pap tests (a test used in cervical cancer screening) and produced in 1969, was one of the earliest examples of cancer comics found (Case 69). Krakow (2017) has analysed the plot development in this comic and has identified that perceived barriers to participating in pap tests play a key role in the narrative. There were three comic strips from the series *Between friends* by Sandra Bell-Lundy promoting participation in mammograms, which were sponsored by the Canadian Cancer Society (Case 23). *Lisa's story* is a story arc in the

series *Funky Winkerbean* which was later collected and published in a single book, included resource material about early detection and one of the strips carried an early detection message (Case 18, p. 196). In this strip, Lisa has terminal cancer and is recording a video of herself to be given to her daughter on her 16<sup>th</sup> birthday. She says, “and you should start getting regular medical check-ups... because a cancer caught early can be a cancer cured”.

Two comics have been developed to inform young men about testicular cancer and self-examination, produced by Brame et al (2011). One of these comics is longer and follows a narrative about a couple’s experience of one of them being diagnosed with, and treated for, testicular cancer (Case 25). The other comic is shorter and more didactic in its approach, with a character explaining the prevalence of testicular cancer and how to do a self-examination (Case 13). Both comics were evaluated and supported the use of the comics for promoting the early detection of testicular cancer (Brame et al., 2011). However, the evidence was limited to opinion and behaviour change was not measured. Paul Miller’s comic about prostate cancer, *A cartoonist’s guide to prostate cancer*, describes the use of Prostate Specific Antigen testing for early detection of prostate cancer alongside treatment decisions and outcomes (Case 12).

A recent comic, *John: Life is worth fighting for*, has been produced by the organisation vzw STOP DARMKANKER to raise awareness of bowel cancer and was connected to a wider awareness raising campaign (Case 39). This comic was informed by a collaboration of medical professionals and an artist. The story follows the character John, starting at his 50<sup>th</sup> birthday, from first experiencing symptoms of bowel cancer through to being diagnosed, treated, and recovering. This comic contains a two-page spread after the end of the story, providing information about colon cancer screening using images from the story. *The domino effect*, produced by University of Leicester Health Matters project and The Centre for BME Health, has been similarly created as part of an awareness raising campaign. This comic is for people in Caribbean communities, to encourage conversations about, and check-ups for, prostate cancer (Case 80). This comic also includes descriptions of the other activities of the associated campaign.

Lili Sohn’s web-comic series about her experience of breast cancer includes a strip about going for a mammogram (Case 28). This was in response to changes in her nipple rather than as part of an annual screening programme, with Sohn being younger than the

screening age when she found she had cancer. In most of the biographic comics, cancer was not discovered through screening, but incidentally by a doctor (Case 15), by the character noticing a physical sign (e.g., a lump, Case 11, Case 74; puckering nipple, Case 28), or being seen by a doctor due to ill-health as a result of having cancer (seizure, Case 16; collapsed with pain, Case 39).

### **5.3.2.3 Type of cancer narrative**

The following table outlines which character within the comic has cancer (separating author-characters from fictional character), what type of knowledge or experience with cancer informed the development of the picture narrative within the comic and what type of narrative is portrayed (Table 5-1).

### **5.3.3 Representations of cancer**

Overall, cancer was not often graphically rendered across the cases and, in the instances where it was, this was very rarely a depiction of cancer as a tumour. More often, when cancer was depicted or being referred to, it was as text (i.e., the word ‘cancer’), as an anthropomorphic character or as part of an x-ray image. There were even examples of an intentional absence of both visual and verbal description of cancer in instances where cancer was introduced into the narrative (for example, a character receiving a diagnosis) followed by panels that were ‘silent’ (i.e., had no text in them; for example, Case 1 p. 18, Case 3 p. 78 & 80, Case 16 p. 8). Creating this silence after having introduced cancer into the narrative leaves the reader thinking about the character and there is heightened awareness of what the characters are doing, their facial expressions and their surroundings. A sequence of silent panels also extends time and causes the reader to sit with the thought of cancer (and the characters’ emotions).

Visualisations of a tumour were particularly absent from bibliographic comics. This is not surprising, as the comics are long and focus on the personal experience of having cancer rather than cancer itself. Although, Matt Freedman, who was receiving treatment for cancer at the time of drawing his comic, does frequently visualise his cancer and its location within his body (Case 40). It is also possible that the authors of the graphic memoirs wish to not permit cancer any space within the comics pages, as a way of attaining control over the disease. An illustrative example can be found in a panel in Case 16, which depicts a doctor pointing at a “cancer-bloated lymph node” on a character’s

chest that is not visible to the reader due to the position of the characters (p. 53). On the proceeding panel, the lymph node is visible but almost too small to see, making the cancer inferior to the people and speech within the panel.

*Table 5-1. Cancer-specific narrative characteristics of the identified comics*

|                                                           | Frequency | %    |
|-----------------------------------------------------------|-----------|------|
| <b>Who has the cancer <sup>a</sup></b>                    |           |      |
| Character                                                 | 18        | 34.0 |
| Author                                                    | 16        | 30.8 |
| Author's significant other                                | 8         | 15.4 |
| No one                                                    | 5         | 9.4  |
| Cancer as character                                       | 2         | 3.8  |
| Various characters                                        | 3         | 5.7  |
| <b>What is the narrative based on</b>                     |           |      |
| Creator's own experience of having cancer                 | 24        | 45.3 |
| Creator's experience of a significant other having cancer | 7         | 13.2 |
| Clinical, medical or anecdotal knowledge                  | 10        | 18.9 |
| Other/unknown                                             | 12        | 22.6 |
| <b>Type of narrative <sup>b</sup></b>                     |           |      |
| Biographic<br>(includes memoir, journaling)               | 19        | 35.8 |
| Naturalistic<br>(includes slice of life, drama)           | 15        | 5.7  |
| Speculative fiction<br>(includes superhero, sci fi)       | 12        | 28.3 |
| Explanation<br>(includes didactic, instruction)           | 4         | 7.5  |

*Note.* <sup>a</sup> Missing data on one case, <sup>b</sup> Missing data on three cases.

The remaining results of the analysis are described through the following themes: The word cancer, Anthropomorphised cancer, X-ray images, Drawing cancer, Shape and colour, and Symbolic representations. These themes collect the common ways cancer was represented within the analysed comics.

### 5.3.3.1 The word ‘cancer’

Across the cases, the word ‘cancer’ was often used as a hermeneutic image, and this was the most frequently used graphic representation of cancer. This is to say that the word ‘cancer’ was drawn with visual characteristics that imbued particular meanings to the word. For example, in the strip ‘work above all’ in Case 14, the character is at work on a computer waiting for biopsy results, the word “cancer?” is repeating in the background, filling the panel. This conveys that the character is struggling to think while being ‘crowded’ by the words (both metaphorically and with visual literality) and her thoughts, portrayed in a thought bubble, trail off. The words are a separate entity outside from the characters own thoughts, giving cancer a presence in the panel and the narrative without affording it figural value nor, consequently, physical space within the diegetic. The consequence of portraying cancer as text is that the meaning is left open to interpretation depending on what the word signifies to individual readers. For example, the word ‘cancer’ might connote ‘malignant tumour’ to one person and ‘death sentence’ to another or, indeed, the same person. Instead, an image of a tumour is more specific in its representation as it is linked to a singular visual object. Therefore, to limit varying interpretation and negative association, it may be relevant to depict cancer as a figural form in the LCS information.

Different visual encodings (i.e., shape and colour) of font have been used across cases to attach different meanings to the word ‘cancer’. For example, in Case 3 when a nurse is telling the main characters that “the CAT scan will show his doctor any places where there’s more cancer” (p. 80). The word ‘cancer’ then ‘falls’ out of the speech balloon, with the text repeating, morphing and over-laid. This suggests the idea (of cancer) is becoming jumbled and taking on different meaning. In the proceeding panel, the words “more cancer” follow and surround the couple as they are leaving the hospital. The font for these words also signify additional meaning through the following encodings: 1) the words differing in sizes, 2) the letters within the word differing in size, 3) “more’ being in bold then “cancer’ being in bold, then in squiggly lines, and 4) the ordering of “more’ and “cancer’ swapping and then becoming unclear. These work together to suggest different accentuation is being placed on each word, as if thinking through the different meanings behind the words is similar to trying out a word not heard before. What is clear is that using verbal symbols for cancer allows for clear distinction of what is a part of the sensory diegetic and the non-sensory diegetic, while still allowing an opportunity to convey alternate or additional meaning through the use of different graphic encodings.

*Design suggestion box 5-1*

Visually represent cancer as a figural form to restrict interpretations

### 5.3.3.2 Anthropomorphised cancer

Another way cancer was visually represented in the comics was as an anthropomorphic character. By doing so, the creator can represent characteristics of the cancer, and the character's experience of it, through analogy with the character traits ascribed to the anthropomorphic cancer. For example, Case 15 depicts "possible cancer cells" as green circles with eyes closed, frowning and tongue out, with a single arm and hand with the middle finger up (p. 4). With this image, the cancer cells are rude and maybe petulant, uncaring, and troublemakers. Alternatively, cancer has been portrayed as a large aggressive and frightening monster, which the main character is fighting (Case 18, p. 136). Case 75, aimed at a young audience, depicts healthy cells as round eyed and smiling, while cancer is as a single mass with multiple angry looking faces with yellow teeth. Case 76, which is a line-drawn four-page comic explaining the biochemical process of cancer growth, depicts cancer cells as having more than two eyes and having different characterisations depending on what the panel is intending to explain. For example, on page 3 the author uses symbols for the devil (horns and a pointy goatee) to portray the cancer as being "even craftier". This comic achieves a visualisation of cancer growth and mutation that is unintimidating, by drawing the cancerous cells with basic shapes and with facial expressions that are void of malice. This divide between malicious and unmalicious depictions of cancer is something the author reflects on in Case 71, "I also don't like the way cancer is described as 'evil' and 'malign', like the mutated cells have a villainous gender. I find it easier to deal with if I just think of them as stupid, and doing what they're doing by accident." (p. 92). The first statement is associated with a depiction of two cancer cells that have protrusions, frowns and spiked toothy smiles. The second is associated with a depiction of two cancer cells that also have protrusions, but are not frowning and have smiles without spikey teeth.

Other than instances of characters fighting an anthropomorphic cancer, Case 11 was the only case I found where the character interacts with the cancer-as-character. In this instance, the cancer is informing the character about what is going on in her body while they walk through a representation of the inside of her body. The author uses metaphor (both visual and narrative) to describe qualities and behaviour of the cancer (such as, the cancer moving to, and populating, different 'territory' in the body).

*Design suggestion box 5-2*

Use anthropomorphic representations of cancer as unthreatening

**5.3.3.3 X-ray images**

Another way cancer was visually represented was as a scan picture in the form of radiographs (the images produced by an x-ray, often viewed on a light box) and ultrasounds. This was a regularly used image through the cases, across drawing styles and narrative types. Additionally, the image of a patient and doctor looking at the x-rays scans was common. An abstracted watercolour of a radiograph is on the first page of the prologue in Case 42. This image is used again through the comic. Case 16 not only uses scans to show tumours but also uses the sequential nature of comics to portray cancer growth (p. 7) and shrinking (p. 54). In Case 30, lung cancer is depicted on an x-ray (p. 135) and the author uses an interesting visual metaphor of the character trapped in a screen between the x-ray images of the lungs (p. 163).

One instance was found of an ultrasound image being used to depict the cancer, with an arrow pointing at “the tumour” (Case 16). Another instance was found of cancer visualised on a screen from an endoscopy (Case 39). However, these images were not found in other cases.

Within the instances where radiographs are depicted, there is a direct association between the x-ray image and the cancer-as-object. For example, in Case 14, which is a simply drawn comic, there are four panels in which a doctor is looking at x-ray negatives and the character is asking “how big is the tumor?”. In this example, the x-rays are drawn as two framed squares, within which are sections of round shapes shaded into a lighter degree than the other sections of the squares. Even in this very simple format, it can still be recognised as a radiograph.

This finding suggests x-rays are the main image available to comic creators for drawing cancer. The x-rays provide a way of depicting cancer while maintaining a diegesis based in reality. Another reality-appropriate depiction of cancer would be images under a microscope, but this image was less frequently used across the cases. Frequent use of the radiograph icon suggests this could be recognisable to the target population.

*Design suggestion box 5-3*

x-ray negatives could be used as a symbol for cancer

**5.3.3.4 Drawing cancer**

An alternate, and less frequently used, way of depicting cancer without pulling the reader out of the diegesis was to depict a character drawing the cancer. This is used in Case 39 to explain cancer growth and the different diagnosis stages (p. 22) and Case 69 to show where cancer of the uterus most commonly occurs (p. 12). Case 42 uses a page of six panels to depict someone drawing a simple anatomical cross-section of a human head and where the character's tumour is located (p. 8). This method of depicting cancer helps when portraying aspects of anatomy that may not be recognisable to the reader, as it guides the reader through the image as it is being drawn. However, this approach maintains a didactic style.

**5.3.3.5 Shape and colour**

There was inconsistent use of colour across depictions of cancer. However, cancer was consistently drawn in a darker colour or shade to non-cancerous cells or areas of the body. For example, dark purple compared to light blue in Case 75 (p. 7). There were some instances where the cancerous area was in colour while the rest of the illustration contained no colour, this was to highlight the location of the cancer in the body while being described in the text (Case 40). In Case 40 the cancerous area is red (throughout) and in Case 71 the cancerous cells are mottled pink and grey (p. 92). There were a limited number of cases from which to draw inferences about colour use because many of the comics in the sample were monochrome. There were two cases where cancer is green. In these cases, the cancer is depicted as a tadpole-shaped with a face (Case 15) and as a large frightening looking creature which the character is using superpowers to fight (Case 18). This suggests green should only be used for 'unrealistic' portrayals of cancer.

Cancer was often visualised with an irregular shape compared to non-cancerous which had a more uniform and regular shape. For example, in Case 14's strip 'you look good', the author depicts herself as having "visible tumours" and has drawn the character as having lumps and a wavy irregular outline. Case 16 uses a circle to indicate a brain tumour and a lumpy shape to indicate lung cancer (page 13). An illustration of a tumour on page 81 of Case 11 is drawn as being folded and lumpy, similar to human tissue viewed through a

microscope. This image is similar to ones used in Case 74 (p. 14) and Case 69 (p. 9). Both of these instances are contained within their own panels and only accompanied by extradiegetic text (i.e., external narration).

*Design suggestion box 5-4*

|                                                                           |
|---------------------------------------------------------------------------|
| Signify cancer with darker colours or more shading than other areas       |
| Avoid green as associated with mean or scary fantasy portrayals of cancer |
| Signify cancer with irregular shape with lumps and protrusions            |

### 5.3.3.6 Symbolic representations of cancer

The comics were found to represent cancer using the following symbols: a crab, personification of death, and walking a tightrope.

*Crab.* The crab symbol is associated with the western astrological sign for cancer and was used in some of the cases. The first instance was in an old pamphlet about the association between smoking and cancer, which might not match current trends. The second was in a predominantly silent (i.e., having no narration or speech depicted) comic that used stylised and abstract visuals, making use of less usual imagery that may not be clearly identifiable. There is also a minor appearance in Case 11, which has a surreal drawing and narrative that is often difficult to follow (p. 9). Therefore, the use of crabs as a symbol for a cancer screening information leaflet was not supported.

*Death personified.* Another symbolic representation for cancer was of either a skeleton or cloaked figure, representing death or the character's mortality. This image was frequently used across cases. In Case 15, the author has portrayed themselves as interacting with a figure in a black cloak who represents cancer. On the front cover, the author-character is facing the cloaked figure, which has the same silhouette as her and is mirroring her posture, and is shouting "cancer, I am going to kick your butt...". In this comic, the cloaked figure is used as a site for creating humour out of something frightening, giving the figure comic eyebrows, having the figure literally waiting around the corner for the unsuspecting character (p. 63) and involving the figure in a version of a knock-knock joke where the word 'cancer' is used as a pun for 'cancel' (p. 64). This instance demonstrates

how picture narrative could be used to overcome negative emotions associated with thinking about cancer through adding humour.

In Case 42, the image of a skeleton is used to signify two meanings, that the character who has cancer is skeletal from weight loss associated with being ill and that another character is imagining that they are dead. This association of cancer with death, through the use of a symbolic image for death, reflects the real possibility of dying from cancer but also represents the associated fear of cancer. It is interesting that there are more instances of this representation, of a skeleton or cloaked figure than representations of a tumour.

*Tightrope.* The visual metaphor of the characters walking a tightrope was used several times across the cases. Within this metaphor, the depiction of what lies below the tightrope connotes the potential consequence of the cancer. In most instances, this was death by falling into a canyon (Case 29, p. 2), an “abyss” (Case 40, p. 193 & 199) or pool with crocodiles (Case 16, p. 60 & 61). This conveys both the chance of death and the uncertainty that comes with a cancer diagnosis, without requiring an explicit description. Case 11, which has multiple surreal elements running through it, shows a net under the tightrope, suggesting safety, but the net is about to be cut by a mouse with scissors, suggesting the character (and the author) feels safe while possibly not being safe.

## 5.4 Discussion

### 5.4.1 Main findings

This study catalogued fifty-three examples of comics that contained narrative portrayals of cancer that have been produced in English. Only three cases were found that included a main narrative about lung cancer. Kaptein and Thong (2018) similarly found very few instances of lung cancer in novels, films, music and poems. More examples were found of comics promoting an early detection message ( $n = 7$ ). These were often produced as part of, or accompanied, early detection awareness raising campaigns. I did not find any portrayals of people having cancer found through routine screening in the biographic comics. Instead, in these comics, cancer was either found incidentally or after taking action due to finding a sign of cancer or having symptoms. In most cases, there was a fictional character ( $n = 18$  and  $n = 3$ ) or author-character with cancer ( $n = 16$ ). In only two cases the cancer was its own character within the diegesis (i.e., not including examples where characters are imagining interacting with an anthropomorphic cancer). Many of the comics

were based on the creator's own experience of having cancer ( $n = 24$ ). The types of narrative covered in the comics were predominantly biographic ( $n = 19$ ), closely followed by naturalistic ( $n = 15$ ) and speculative fiction ( $n = 12$ ).

Within the comics, cancer was rarely depicted as a tumour (or similar physical form). In addition to this finding, the current analysis determined several ways in which cancer was represented across the comics. Firstly, the word 'cancer' was often visualised in a way that attached different meaning to the word and conveyed additional information about the character's or author's feelings towards cancer.

Another way additional meaning was conveyed through the representation of cancer was through the use of anthropomorphism, where the concept of cancer becomes imbued with the way the character has been characterised (for example, "crafty" or "stupid"). Some of these anthropomorphic representations of cancer were used as part of a visual metaphor for the trope of 'fighting' cancer. However, this was not the only use, with one instance of the character and the cancer having a discussion and others where the cancer is a cell with facial features.

A key image that repeated across cases, independent of visual or narrative style, was that of x-ray images (i.e., radiographs). The cancer was also depicted through the image of a drawing (i.e., having a character within the story drawing the cancer). These two icons, that of a radiograph and of a drawing, demonstrate two techniques for depicting the presence of cancer within the diegesis (the world of the story) without impacting the story's realism.

Across these different types of images, cancer was represented as having a darker colour and being irregular in shape. Three symbolic representations associated with cancer were found within the comics – that of a crab, the personification of death, and walking a tightrope.

#### **5.4.2 Implications**

A large proportion of the comics found were about a breast cancer experience ( $n = 18/53$ ) and from a biographic perspective ( $n = 11/18$ ). Breast cancer incidence for women are similar to the incidence of prostate cancer for men, have similar rates of survival and are

diagnosed at similar ages (Cancer Research UK, 2021), yet only 3 comics were found about prostate cancer. I believe breast cancer is disproportionately represented in the biographic cases because of different gendered experiences in health and medicine.

The comics identified were most often autobiographical (biographic and about the author having cancer), which is true of most graphic medicine comics published and follows the movement after 1990's towards narratives being non-fictional and autobiographical (Rhode & Connor, 2012). Tumours were not often represented, and cancer was not often being depicted as a character other than as metaphor. This reflects that the comics within the sample were focused on the personal experience of having cancer rather than cancer as an object.

The categories developed while reviewing the comics were helpful for appreciating the context within which the representations of cancer were being used. In particular, 'What is the narrative based on?' was chosen as a useful characteristic of cancer comics to record, as this quality is implicated in the narrative. The groups developed for this category ('creator's own experience of having cancer', 'creator's experience of a significant other having cancer', 'clinical/medical knowledge' or 'other/unknown') align with Lewis' (2019) categories of cancer comics, 'Experiential', 'Familial', 'Clinical' and 'Fictive', respectively.

#### **5.4.3 Sample and analysis limitations**

Due to only three cases being found that included a portrayal of lung cancer, it was necessary to conduct an analysis of all cancer types included. There may be differences in the symbols and images that people associate with different types of cancer. However, the sample was unsuitable for an analysis comparing depictions of lung cancer to another type of cancer because the sample was too small to capture shared ways of portraying lung cancer specifically.

The usefulness of the analysis relies on the assumption that the comics analysed are applying conventions and symbols recognisable to, and understood by, the target audience for the lung screening information being developed within this thesis. Therefore, during the analysis, the comics were appraised based on the country in which they were produced. The age of the intended readers of the comics was also considered, with the belief that the visual and verbal language used by an adult artist for an adult audience may be different to

that used by or for children or adolescents. Only two cases included within the analysis were aimed at a young audience (Cases 68 & 75) and none were created by children. The year in which the comics were first produced was also considered, as the LCS designs ought to align with modern representation of cancer. For example, the symbolic visualisation of cancer as a crab was found in an old comic. As such, this symbol was not carried forward as a design suggestion for the LCS information being developed. The data may have been limited by the fact that most comics found were from the USA ( $n = 34/53$ ), with only five produced in the UK. However, media from the US is often distributed and consumed within the UK. Therefore, it was believed that the symbols and conventions used in the US should not differ greatly from those used in the UK.

The sample analysed in this study included 14 biographic cases that were about the creator's own experience of having cancer and five biographic cases that were about the creator's experience of a significant other having cancer (mother, Case 16; father, Case 27; wife, Cases 8 & 79; husband, Case 43; friend, Case 61). This diversity of perspectives increases the richness of the data analysed. The fact the analysis findings are based on portrayals of cancer that repeated across different types of narrative and different types of perspective, increases the likelihood of the identified images and visual conventions being recognisable to the target audience. However, only two of the biographic comics included in the analysis were about a man's personal experience of cancer, linked to the fact that most of the biographic comics were about breast cancer. Therefore, particular images and symbolic representations that men associate with cancer may be missing from the analysis.

A trend was found in the increasing production of comics. However, this may reflect the search method used. The search was conducted primarily through online databases. It is likely that older comics would not have been digitised or available through my search strategy. However, this does not undermine the aims of the current study as we were interested in modern portrayals of cancer in comics – based on the assumption that these would more likely be recognised by the target audience (of the picture narrative LCS information being produced through this thesis).

#### **5.4.4 Future consideration**

The current study only considered comics with the topic of cancer as a main narrative thread. Cancer has also been used as a narrative hook in comics, where the story is premised on cancer in some way but is not a thread running through the narrative. Rhode

and Connor (2012) identify several superhero comics using cancer as a narrative hook (p. 116-7). These cases were not considered pertinent to the current analysis because it was believed that representations of cancer would be minimal, overshadowed by the main narrative unrelated to cancer. However, future work could be done looking at these comics. There is also scope for future work looking into comics with more minor role occurrences of cancer within a certain genre or even series. This work could illuminate more lay and culturally embedded portrayals of cancer because the necessarily short and condensed appearance of a minor role would result in the creator using readily available symbolism and imagery that they believe their audience would readily understand.

It could be useful to do a discursive analysis of the text, considering that cancer was most often “talked about” rather than visualised. This was not in the scope or the aims of the current study. For example, Case 18 comic strip has a child asking “what's cancer?” with the affected person saying “cancer is when the cells in your body get sick”. Many of the comics in the sample were primary sources (i.e., written and drawn by one individual without input of editors) making them prime material for investigating social discourses and cultural understandings.

Comics within the study sample were created by a variety of creative teams, from individual creators to multidisciplinary teams (Case 39). How might the composition of the creative team, and style of collaboration, impact the stories told and the way elements are depicted? Duncan et al. (2016) considers the impact when the creator is the character with the illness and when the artist is bearing witness to the collaborator’s experience of an illness. In putting the story, pictures, panels and pages together, the creators have a role in curating the cancer experience being portrayed.

#### **5.4.5 Conclusion**

This study identifies ways in which topics relevant to lung cancer screening (i.e., lung cancer and early detection) have been portrayed in modern comics. This study also provides a repertoire of common images and tropes used to represent cancer in comics about cancer or a cancer experience, which can be used to inform the picture narrative LCS designs to improve their suitability for the target audience. Additionally, carrying out this investigation has helped me to build an understanding of the techniques available for describing cancer and cancer screening in a picture narrative format, which I could apply to the picture narrative LCS information being developed.

## **Chapter 6. Lung cancer screening information preferences and perceptions of the target audience: A community-based design workshop approach**

### **6.1 Introduction**

This chapter describes a community-based workshop carried out with participants within the target audience (of the lung screening information designs being developed in this thesis) which was used to further inform the design suggestions for the picture narrative lung cancer screening (LCS) information being developed (Study 3). The chapter first reports the community-based design workshop procedure and findings and then reports interviews that were carried out to evaluate this novel approach.

#### **6.1.1 Background**

Involving the intended target audience in the creation and development of a product is an important design principle that ensures acceptability, accessibility and cultural appropriateness (Bartholomew Eldredge, 2016). Involving the target population in the development of the design will help to ensure the language and imagery (both iconographic and metaphoric) used is more likely to be understood, recognisable, familiar and relevant. Additionally, the designs will be informed by the preferences of members of the target population, which will increase the likelihood of the target audience evaluating the designs positively (e.g., visually appealing, and interesting) leading to increased engagement and recall.

Question 1. What design preferences do people within the target audience have for print information about lung cancer screening?

It is also important to investigate the perceptions of the target audience surrounding LCS, as these perceptions will have an impact on how the message is received and, therefore, need to be considered when developing the LCS information. Additionally, investigating such perceptions will identify information preferences (i.e., what information do the target audience wish to be provided) and needs (i.e., what misconceptions do the target audience have about LCS).

Question 2. What perceptions do people within the target audience have about lung cancer screening?

### 6.1.2 Design workshop

Design workshops are workshops, carried out for a particular objective, within which stakeholders engage in activities together. Design workshops can be exploratory, generative, or evaluative in nature (Martin & Hanington, 2012). What activities are carried out during the workshop depend on the purpose of the workshop and the people or groups of people involved, but all activities are intended to be engaging and requiring reflection. Focus groups and interviews are methods most often used for qualitative health research into people's perception or experiences of a phenomenon (Gill & Baillie, 2018). However, a design workshop was considered a better approach to take in the current study for the following reasons.

Firstly, while interacting with the community groups prior to the workshop, I found out that people at the community centres were discouraged from taking part in research due to feeling that their contributions were not taken on-board or implemented after taking part in previous research. Therefore, it was believed an event that produced perceptible and 'real-time' outcomes (as is the case for design workshops) would be appreciated. Additionally, it was believed the method of data collection needed to be intrinsically rewarding for participants, to encourage their engagement (as is the case with group-based and creative activities).

Secondly, the target population have experienced marginalisation due to the levels of economic deprivation in their neighbourhood and community group members were disinclined to engage in research that they felt might be using them or taking advantage of them<sup>21</sup>. A design workshop is a research method that can empower the participant, with the focus being on collaboration, rather than 'conducting research on people'. It was hoped that this orientation towards empowerment would facilitate engagement in the research, as well as being a better experience for the invitees and more respectful of the community.

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<sup>21</sup> Members of the community groups, as well as workers at the community centre, expressed a concern for being taken advantage of by researchers with their own agendas, either by suggesting that this had happened in the past or indicating this was something they wanted to avoid. Several people described researchers coming in, taking what they want, then leaving.

Thirdly, questioning people directly about their design preferences is an ineffective way of accessing this kind of knowledge. Removed from the experience of interacting with design elements, participants will be forced to either remember or imagine the experience and any reports they provide about these will be a rationalisation of the experience (Nisbett & Wilson, 1977). Involving people in the process of ‘creative play’ is able to elicit thoughts and ideas that give a closer reflection of their experience of interacting with design elements as they interact with them (Ylirisku et al., 2007).

Finally, lung cancer can be a threatening and uncomfortable topic to engage with due to association with the upsetting experiences of illness and death. Directing participants’ attention towards creative and solutions-orientated activities can encourage deeper engagement with the topic, in a less threatening manner.

Due to these reasons, it was believed that an activity-based workshop with a solution focus would be better for engaging the participants in the research and answering the research questions, than either focus groups or interviews.

The social group format of a design workshop grants this method similar benefits to focus groups. Kitzinger (1994) reflects on several strengths of focus group discussions for qualitative research. People who are hesitant to take part in research, or wary of the researcher and their agenda, may be more inclined to take part in a group setting because of the security that comes with this, particularly if group members are already known to one another or have similar shared experiences. Recording and analysing group discussions gives priority to the participants’ language, concepts and worldviews, over the researcher’s pre-emptive interpretations. Group interactions can allow for more “everyday forms of communication” which can provide greater insight than responses in one-to-one interviews which are more likely to be moderated or censored (Kitzinger, 1994, p. 109). Consensus and agreement across the group can indicate group norms. This is useful for the current study, as identifying group norms around the issues of cancer screening and lung cancer will help in developing tailored information. The fact that design workshops are about working towards a common goal, while also focusing on idea generation rather than creating final products, should support group cohesion and openness.

Unlike with focus groups, the researcher’s position on the ways that knowledge is acquired is made explicit within a design workshop – knowledge acquisition is framed as created

through joint exploration, where insights are generated through the participants and research team reacting to and building on each other's "experiences, interpretations, and evaluations" (Stevens, 1996, p. 172). This is usually the aim of focus groups, but the structure of question-response and group conversation often renders this orientation to knowledge indiscernible for the participants. In these cases, participants may take it in turn to answer questions and respond as though they were each being interviewed, rather than approach the interaction in a relational way, reducing the richness of the data for interpretation.

### **6.1.3 Community-based workshop**

A community-based design workshop, centred around developing a LCS information leaflet for the community, was used to elicit participants' preferences in terms of the content and design of LCS information, as well as their perceptions related to LCS that may impact their reception of such information.

Question 3. Was a community-based design workshop a suitable and useful method for achieving the research aims and engaging the target population with the research?

## **6.2 Community-based design workshop**

### **6.2.1 Method**

An exploratory design workshop called 'Be involved in developing a health leaflet relevant to you' was carried out at Possilpoint community centre in January 2020. Ethical approval was obtained from the University of Glasgow's MVLS ethics committee for both the design workshop and the interviews (ethics code: 200190022, 28/10/2019).

#### **6.2.1.1 Collaborative research planning**

The workshop was planned and organised in collaboration between myself (the researcher) and a community development graduate volunteering for Link up, an 'Inspiring Scotland programme investing in 9 urban communities' (see, Stevens, 1996). The community development volunteer (CDV) had experience running community groups in several community centres in Glasgow including Possilpoint and was employed (£10 an hour) to plan and facilitate a workshop in collaboration with the researcher. The CDV and the

researcher met four times prior to the workshop and discussed; the overall structure of the workshop (timings and breaks), what information to share with participants, how to get participants to contribute their ideas (i.e., what activities to include), the organisation leading up to the workshop (including location, date, catering, supplies, and recruitment). The CDV and I reviewed a design activities bank (created by the researcher<sup>22</sup>) to decide which activities we would use in the workshop. The CDV and the researcher also joined three meetings with different community groups to discuss the workshop with the members. After each meeting, the CDV and the researcher spent time discussing the responses from the community group members and considered the workshop plan further.

### **6.2.1.2 Recruitment**

The workshop facilitator and the researcher attended several community groups known to include older adults at Possilpoint community centre and Lambhill community centre. At these meetings, we told members that we were organising a workshop, asked for their thoughts on the plan we had so far and asked when a suitable time and place would be for them to take part. If anyone was interested in taking part, they were asked to let the facilitator know and, once the date and time of the workshop was decided, he informed them in-person or by telephone. Invitation fliers were handed out at subsequent meetings that the researcher and facilitator attended separately, inviting ‘anyone aged 50 to 70 who smokes or has smoked’.

Possilpoint and Lambhill Stables community centres were targeted because they were both located in neighbourhoods with high levels of socioeconomic deprivation as defined by the Scottish Index of Multiple Deprivation (SIMD), and it was believed that these centres would be the best way to make contact with people within the target population (over 50-year-olds experiencing high levels of socioeconomic deprivation living in Glasgow). Possilpoint community centre is in the neighbourhoods of Ruchill and Possilpark, while the Lambhill Stables community centre is on the border between these neighbourhoods and Lambhill. Based on the SIMD 2020 data, 23% of people in Ruchill and Possilpark were ‘income deprived’ and 26% of working-age people had no formal qualifications, compared

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<sup>22</sup> I put together a list of activities identified in the co-design literature and grouped these based on whether they would be best for (1) eliciting and generating ideas, (2) creating products, or (3) making choices and evaluating ideas. These qualities align with the second, third and fourth phases of design: Exploration; Generation; Evaluation (Martin & Hanington, 2012).

to 19% and 13% respectively for the whole of Glasgow and 12% and 9% across Scotland (SIMD; The Scottish Government, 2020).

### **6.2.1.3 Procedure**

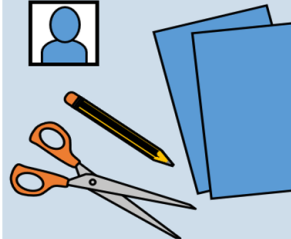
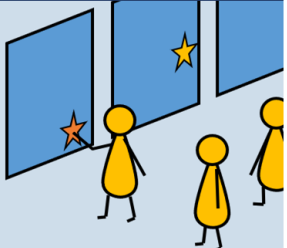
*Setting.* The CDV and I decided to run the workshop at Possilpoint community centre. This is where the CDV predominantly worked and could better support recruitment. There were two community groups that consistently met at the community centre once a week (a men's social group and an older women's social group) who included people from the target population. Members of these community groups said they would prefer the workshop to take place at the centre. The workshop took place in a room in the community centre with enough space for four separate tables for participants to work at, a projector screen and a table of refreshments.

*Workshop team.* The workshop was facilitated by the CDV. There were three volunteer helpers, one had been recruited through the University of Glasgow's community development graduate network and had experience facilitating community groups, while the other two were colleagues of the researcher and had experience carrying out qualitative research in group settings. The volunteer helpers and the researcher each supported a table during the workshop, providing direction and prompting ideas where needed. The artist hired to draw the picture narrative lung screening designs also attended the workshop. They had a degree in medical illustration and experience supporting community engagement events. They spent time at each table, asking participants for their thoughts and sketching ideas. The helpers and artist had been informed about the workshop plan and their roles during one-to-one meetings with the researcher prior to the workshop. Each member of the workshop team was given a schedule and instructions for the day, unique to their roles.

*Workshop schedule.* When entering the workshop, participants were given a folder (containing a schedule for the day – Appendix 6, the participant information sheet – Appendix 7, the consent form – Appendix 8 and a demographics questionnaire – Appendix 9) and introduced to the helper at the table where they were to be seated. Participants remained at the same table throughout the workshop. The main body of the workshop was in four parts (see, Figure 6-1). The first part, Orientation, was to allow for the workshop attendees (facilitators and researcher included) to establish shared goals and expectations for the aims and approach for the workshop. The second part, Exploration, was to allow

attendees to share and explore what they knew and thought about the topics inherent in the workshop aims. The third part, Ideation, was an opportunity for participants to formulate their ideas through creative practices. The final part, Consolidation, was an opportunity for participants to reflect on and evaluate the design ideas that had been generated. These four phases align with each phase of the British Design Council's double diamond approach to design (Figure 3.1).

Figure 6-1. Workshop sections and activities

| <b><u>Orientation</u></b>                                                                                                              | <b><u>Exploration</u></b>                                                                                                     | <b><u>Ideation</u></b>                                                                                     | <b><u>Consolidation</u></b>                                                                              |
|----------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|
| Establishing goals and expectations.                                                                                                   | Sharing knowledge and exploring thoughts.                                                                                     | Formulating ideas and creating designs.                                                                    | Reflecting and making decisions.                                                                         |
|                                                      |                                             |                         |                      |
| <ul style="list-style-type: none"> <li>• Introductions</li> <li>• Plan for day</li> <li>• Group rules</li> <li>• Consenting</li> </ul> | <ul style="list-style-type: none"> <li>• Presentation</li> <li>• Discussion</li> <li>• Break</li> <li>• Discussion</li> </ul> | <ul style="list-style-type: none"> <li>• Group poster making with design ideas</li> <li>• Break</li> </ul> | <ul style="list-style-type: none"> <li>• Presenting posters</li> <li>• Traffic-light stickers</li> </ul> |

*Part 1. Orientation.* The workshop began with the facilitator introducing the helpers, artist and researcher to the group, followed by the researcher explaining what was involved in taking part in the research, as well as the plan for the day. Participants were given the option to read a long version of the participant information sheet (Appendix 10). Participants then filled out the consent form and the demographics questionnaire (which covered age, gender, ethnicity, living situation, formal education, employment, car ownership, physical and mental health, and smoking status) with the assistance of the helpers at their table. At this point, participants were given an opportunity to ask questions of the workshop plan from the facilitator and the helpers. The facilitator then went through housekeeping.

*Part 2. Exploration.* The researcher then gave a presentation, providing the participants with a starting point for exploring design ideas informed by the work the researcher had

conducted so far. The presentation was an overview of the key considerations when designing print information (that the information needs to be engaging, accessible, acceptable and supportive) and a summary of the best design suggestions for achieving these. These design suggestions were identified through Chapters 4 to 5 and preliminarily prioritised by viability and strength of supporting evidence. The following design suggestions were covered in this presentation; using provocation (examples were ‘this could save your life’ and ‘I want to get cancer’), being personal (examples were ‘could save your life’ and an image of person holding up a sign and looking at the viewer, see Figure 6-2), being relatable (examples were including people with different appearances and including ‘everyday’ scenarios and objects), using stories (a patient narrative), using pictures (examples were decorative, photographic, line drawn and cartoonish) and using pictures to tell stories (example was a three-panel comic strip). Following the presentation, participants were asked to discuss, in their groups, ‘How to get people’s attention with print information and keep it’ (25 minutes). This was followed by a 20-minute break, after which, participants were asked to discuss ‘What information do people want about lung screening’ (16 minutes). For both discussions, helpers were provided with a list of questions to prompt discussion if needed (Appendix 11). The prompt questions were based around the target behaviours (engagement, decision-making and decision-enactment) and included the priority design suggestions identified through the previous studies.

*Figure 6-2. Image produce by Cancer Research UK for the Be Clear on Cancer campaign, 2016*



*Part 3. Ideation.* Participants were then asked to create posters about their ideas for a lung screening information leaflet (35 minutes). Participants were provided with example lung screening leaflets to prompt discussion and to use for putting and sticking on their posters (Appendix 12). This was followed by another 20-minute break.

*Part 4. Consolidation.* Participants were then asked to select two people to present their table's poster to the workshop attendees as a group and were given 10 minutes to prepare. This activity was included to provide participants an opportunity to elaborate on or confirm their interpretations of the elements included on the posters. The discussions between participants whilst preparing their presentations proved to be more useful as a source of information than the presentations themselves, as they used this time to clarify and vocalise why different items on the posters had been included. For the last activity of the day, participants were each given several red, yellow and green stickers and told to stick them on parts of the poster they thought would be good for a lung screening leaflet (green), not good (red), or they were uncertain about (yellow). Food and refreshments were available throughout the workshop.

#### **6.2.1.4 Data collection**

*Data sources.* The following data were collected during the workshop and used in the analysis: posters created by the participants (Appendix 13); notes written by the helpers during group discussions; and audio recordings captured during the workshop with devices at the centre of tables, once written consent had been attained. Additionally, I took notes after each visit to the community groups leading up to the workshop and immediately after the workshop took place. Having multiple data sources provides richer data and allows for a more considered interrogation.

*Reflexivity strategy.* The day after the workshop, I wrote several pages of reflection. While listening to audio-recordings, I kept reflective notes. Additionally, I interrogated the descriptions and comments I personally made during the workshop and the evaluation interviews.

#### **6.2.1.5 Data analysis**

Thematic analysis refers to the analytic approach of identifying common patterns (or themes) across cases (e.g., group recordings and participant contributions; Terry et al., 2017). This approach allows for description and interpretation of complex qualitative data. Braun and Clarke (2006) provide a method (via a list of phases to follow) to carry out thematic analysis, which was followed in this study.

*Familiarization:* I first listened through all the audio recordings, noting down the timings for when each workshop activity began and ended on each recording (including lunch and refreshment breaks). While doing so, I made initial notes about the data. Before and during transcribing each table's audio, I looked over the helper's notes and the table's poster for that table.

I transcribed each audio recording by hand across several A5 notebooks. This was to facilitate a speedier and more fluid evolving process<sup>23</sup>. For every new topic discussed, I included a time stamp and summary of what was discussed, in varying degrees of descriptiveness depending on the relevance to the research questions. For example, if the participants were talking about the food provided during the lunchbreak, I gave only that much information. Whereas, if someone mentioned cancer, I would quote this verbatim and include what was mentioned by other participants before and after. Speakers were indicated by their participant IDs. Within this notebook, I also recorded 'analytic memos', indicated by the reference "//note."<sup>24</sup>. When participants spoke about either (1) design preferences or suggestions, or (2) about cancer, screening or lungs, I transcribed this verbatim onto an A2 piece of paper. I produced a separate A2 page for each table and drew a simple sketch of the participants at the centre, for each, so that I could keep in my mind who was saying what and to be considerate of who they were and their relationship to the others in their groups, when interpreting the transcription (see Appendix 14, for the A2 page created for workshop table 4, as an example).

When writing quotes on the A2 posters, I placed items that were about similar concepts or topics (in respect to the research questions) closer to one another than items with different topics. With this approach, quotes began to form clusters. Connections across clusters were made visible with arrows and frames. From this, it was noticeable that information about participants' leaflet design preferences (research question 1) remained separate to information about participants' perceptions of LCS (research question 2). Therefore, for the remaining analysis, I used two higher order groupings: 'Design preferences' and 'Lung,

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<sup>23</sup> I am faster at writing by hand. Changes, and preceding thoughts, are recorded when writing in pen through crossing out, writing around the edges of text and using lines and arrows.

<sup>24</sup> I find recording notes as close to where the thought came to you is most helpful for the analysis. The notes can always be collected together later.

cancer and screening perceptions'. I separated the quotes and notes, copying them into an A4 notebook in one of two sections designated for the two higher order groupings<sup>25</sup>.

*Generating initial codes:* While copying the extracts into the notebook, I gave each entry a code that reflected its relevance or relationship to the higher order code. Coding was at the semantic level, capturing explicit or overt meanings, to produce a summary of participants' responses that stayed close to the participants' way of speaking.

*Searching for themes:* Once all extracts were moved and coded, I reconsidered and consolidated the codes and began to develop initial theme ideas. I then gathered the extracts into the potential themes they were relevant to, by digitally scanning the notebook pages and copy-and-pasting the extracts into theme sections in a Word document.

*Reviewing and defining themes:* To check whether these themes worked in relation to the workshop data, I created visual thematic maps for each of the higher order groupings (see Appendix 15 for the developing maps). Alongside establishing the final themes through the thematic maps, I also defined each theme in a report-like document, which was used to produce the following reported findings.

Through this report, participants' names have been replaced by an identifying code made of their group table number and participant number. Additionally, each table around which participants sat during the workshop (i.e., each group of participants) is referred to using the code T[table number]P[participant number].

## **6.2.2 Results from the community design workshop**

### **6.2.2.1 Participant characteristics**

There were more women who took part in the workshop than men (26.3%; see table to Table 6-1 for participant characteristics). All participants were unemployed or retired. Half of the participants had completed Highers, while the other had completed no formal education. Nearly all rented from the local authority or a housing association. All participants identified as white British or Scottish. This is relatively representative of

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<sup>25</sup> I originally set out by having my notes and quotes in Nvivo to code and keep track of them there, but I found that coding 'manually' was more suitable to my method of interpretation, which was to consider extracts by sentence and at a semantic level.

Ruchill and Possilpark, with only 10% of the community being ‘from a minority ethnic group’ based on 2011 Census data (The Glasgow Indicators Project, 2011). Participants were asked to rate their physical and mental health using two 5-point Likert scales ranging from ‘Excellent’ to ‘Poor’. An equal number of participants rated their physical health as ‘poor’, ‘ok/fair’ and ‘good’. Most participants reported ‘ok/fair’ and ‘good’ physical health (74%).

*Table 6-1. Summary of participant characteristics with anonymised participant identification numbers*

| <b>Table and Participant IDs</b> | <b>age</b> | <b>gender</b> | <b>smoking status</b> | <b>formal education</b> |
|----------------------------------|------------|---------------|-----------------------|-------------------------|
| T1P1                             | 67         | female        | former smoker         | Highers                 |
| T1P2                             | 63         | female        | current smoker        | Highers                 |
| T1P3                             | 60         | female        | current smoker        | no formal               |
| T1P4                             | 58         | female        | current smoker        | Other: SEC school       |
| T1P5 <sup>a</sup>                | 45         | female        | never smoker          | Highers                 |
| T2P1                             | 63         | male          | current smoker        | no formal               |
| T2P2                             | 57         | male          | current smoker        | no formal               |
| T2P3 <sup>a</sup>                | 75         | female        | never smoker          | no formal               |
| T2P4 <sup>a</sup>                | 73         | female        | never smoker          | Highers                 |
| T2P5                             | 77         | female        | current smoker        | Missing                 |
| T3P1                             | 62         | female        | current smoker        | no formal               |
| T3P2                             | 66         | female        | former smoker         | Highers                 |
| T3P3                             | 50         | female        | current smoker        | no formal               |
| T3P4                             | 74         | female        | former smoker         | Missing                 |
| T3P5                             | 63         | female        | former smoker         | no formal               |
| T4P1 <sup>a</sup>                | 47         | male          | current smoker        | Highers                 |
| T4P2 <sup>a</sup>                | 71         | male          | never smoker          | no formal               |
| T4P3                             | 54         | male          | former smoker         | no formal               |
| T4P4 <sup>a</sup>                | 79         | female        | never smoker          | Missing                 |

*Note.* <sup>a</sup> = participants who did not match the criteria for the target audience based on age or smoking status.

Participants were informed their names would not be used in any reports based on the workshop, to minimise concerns over their contributions being captured and read by others, as it was believed this could lead participants to only provide suggestions they deemed socially desirable or acceptable outside of the workshop context. As personal data

were collected during the study, anonymising the data also ensured the participants' information was protected.

Not all participants met the criteria of being between 50 and 75 years old, current or former smokers, living in or near Possilpark. Two participants (T1P5 & T4P1) were under 50 years old. The first person was there to accompany their friend (T1P4) to give them confidence to attend, while the second person was there to support their parent with dementia (T4P2). One participant (T4P4), who was over 75 and had never smoked, came to the centre expecting their usual community group meeting, rather than the workshop – they were encouraged to stay and take part. Three participants met the age criteria, but had never smoked (T2P3, T2P4, T4P2). Within group and conversational settings, responses are considered interactional and the meaning considered co-created. Therefore, all participants' contributions were included during the analysis, independent of their eligibility for lung screening. Participants' individual circumstances were considered throughout the analysis, with the researcher using a visual reminder of who sat where during the day to keep track of who was speaking<sup>26</sup>.

Kitzinger (1994) outlines the importance of considering the shared culture at play in group discussions and considering what might be censored due to the composition of the group. Two tables were composed of women only, one table had three men and two women and the other table had two men and four women – these numbers include the helpers. Due to gender power dynamics, women's voices can often be censored or marginalised in group settings with men. The men in the workshop were often more vocal than the women at their tables, but the fact there were proportionately more women across the group meant their voices were given equal space. I think the men would have been less forthcoming with their thoughts if the facilitator had been a woman rather than a man, but the fact that the two organisers were a man and a woman affirmed the validity of the voices of the genders within the workshop. While organising the workshop, there was concern from the facilitator and the community group members about having a mix-gender workshop, but several attendees (including the facilitator and the community development worker) commented on how well they thought people from the different community groups (i.e., the men's group and the women's group) worked together.

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<sup>26</sup> This was in the form of a simple drawing, with different colours indicating different participants (see extract map in Appendix 14 for example)

### 6.2.2.2 Design preferences

The following five themes describe aspects of design that participants considered important for print information about LCS as well as the meaning participants placed behind design characteristics, such as specific colours or visuals. The themes are ‘Information amount and relevance’, ‘Practical considerations’, ‘Desire for realism’, ‘The use of colours’ and ‘Accepted and recognised visuals’.

#### **Theme 1: Information amount and relevance: “a little information that’s relevant to you” - T4P4**

The amount of text and information was a point of contention for the participants. Participants argued strongly that the example leaflets both included too much information (for example, “too busy” T1P4 with “too much going on” T1P1) and not enough information (for example, “they look dreadful ‘cos you don’t get enough information” T4P1). Rather than being about whether there was or was not enough information, this issue was more about participants feeling the information was not relevant to them, with one participant saying it should be “a little information that’s relevant to you” (T4P4). What was clear was a need to ensure that invitees can immediately see the direct relevance of the information to themselves and that large amounts of text, and text in a different language, can make the information material seem irrelevant.

Often, when participants were saying there was too much information, they were referring to an example leaflet in its entirety. In these instances, there was a sense of feeling overwhelmed by having to read through a vast amount of disjointed information. For example, one participant said “when you are flipping back and forth it kind of puts you off” (T3P3). Some participants did indicate particular aspects or sections of the examples that they thought had too much information. Importantly, what I learnt from these instances was that what I was considering to be a short amount of text (for example, the text boxes in the NHS Lung Health Checks leaflet, Appendix 12) was described by participants as being too much. While referring to one of these text boxes, one participant said “going over the top a wee bit, they’ve given us a wee bit too much” (T4P3). Something that was particularly liked by table four were “the wee balloons” (T4P3), that each contained text and had a different coloured background (NHS Lung Health Checks leaflet, Appendix 12) because of their ability to break up the text into parts that were clearly different.

*Design suggestion box 6-1*

|                                                                           |
|---------------------------------------------------------------------------|
| Clearly indicate the relevance of the information at an individual level. |
| Have few pages and minimum amount of text.                                |
| Separate text with different colour backgrounds.                          |

**Theme 2: Practical considerations: “it’d be good to get an idea of what we’re gonna be getting into” - T2P2**

Participants were interested in knowing what was involved in screening, rather than why screening is done or whether to do screening. This focus on practical aspects of the screening process (how, rather than why) translated into participants saying the leaflet should include a picture of a scanner (T1, T2 & T4). Participants wanted to know practical information about where to go to get the screening (T3 & T4), what to expect during the screening (T1 & T2), and how they could get screened themselves (T3). Also, participants brought up concerns they had about lung screening that were all orientated to practical factors, including what the waiting time was for appointments or results (T2 & T3), and what a CT scanner was like (T2 & T3). Participants also thought it was important for a leaflet to include information and reminders about social support and other types of support. Participants at table 1 suggested photos of a family would be good “because the family would be there as well” (T1P3), “they’d be there for support” (T1P4), with participants at table 2 suggesting children should be included in the photos. It was also suggested that the leaflets should include information on “who to talk to” or contact “if you need help or any information” (T2T3).

*Design suggestion 6-2*

|                                                                                                            |
|------------------------------------------------------------------------------------------------------------|
| Gist information will likely be accepted and could focus on how to get screening over why to get screening |
| Include reference to additional support including family as support                                        |

**Theme 3: Desire for realism: “it’s better because its more realistic” - T1P4**

One theme that ran through the participants’ justifications for why certain content was considered acceptable or unacceptable was the importance of realism for a leaflet about LCS. There was consensus on table 3 that the abstract style image (Appendix 12, reference

E) was unsuitable, and they preferred the realistic images. Participants across different tables argued that stories<sup>27</sup> included should be about real people's experiences, with table 1 titling one of their poster sections 'TRUE STORIES'. Similarly, participants wanted the people in the photographs to be people "who've had the lung disease" (T2P2). Table 2 were in agreement that the leaflet should not be like "an advert" (T2P3), with the term 'advert' being used to imply the content of the leaflet was not true or not real.

One participant said he was not interested in other people's stories, and "reading this [pointing at a patient narrative in one of the leaflets] wouldn't help me". However, this participant also said "I'd rather listen to people who've got a problem [and hear] how they're getting out of it" and so he did feel it was helpful to hear other people's experiences. It is possible that the participant associated the term 'story' with something 'made-up' (i.e., not real) and it was this quality that the participant took issue with.

#### *Design suggestion 6-3*

|                                                                                                                                           |
|-------------------------------------------------------------------------------------------------------------------------------------------|
| Use visuals that closely resembles their referent (i.e., a realistic drawing style or photography)                                        |
| Make sure content conveys realism, in the visual style used and the types of stories included.                                            |
| Include information that establishes the authenticity of any people included in photos as well as any stories about people's experiences. |
| Be careful about using the term 'story'                                                                                                   |

#### **Theme 4: The use of colours: "Needs to be colourful" - T1P4**

Participants were quick to talk about the colours used in the example leaflets or the importance of the colours selected to make a leaflet more attention grabbing. Colour was an easy way into talking about design elements, with the helpers often offering choice of colour as an example design option.

Most reasons given for using colours in general, or using a particular colour, were to do with their natural ability to catch attention, either through being "a colour that'll hit you in the eye" (T2P2), or by being liked by a particular group (for example, "women like pink or

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<sup>27</sup> Most participants reflected on 'people's stories' because one of the cases contained section titles 'Michele's story' and 'Steve's story'

lilac” T3P2). However, participants did not explore which particular colours they liked themselves. When the helper on table 1 asked participants to choose which colours they wanted to be used for the leaflet, the participants focused again on colours that would be best because they were bright, rather than discussing colours that they each individually liked. This was perhaps a consequence of the poster creation format being about consensus rather than individual preferences.

More useful for the design purposes of this study were participants’ descriptions of local meanings associated with certain colours, which could be used to improve the communicative power of the leaflets. Participants at table 3 (3 men, 1 woman) suggested that tribe football colours would encourage football fans to read a leaflet, with football games being very popular and football club loyalty being significant in Glasgow. Participants at table 2 associated bright yellow with Marie Curie and the Beatson which are two organisations associated with cancer, saying “you see yellow and immediately know what it is” (T2P1). Additionally, the colours green, purple and blue were connected to hospitals generally. Participants also associated meanings with different colours in a way particular to the context of health and illness. Green was associated with healthiness “green for healthy, green for go” (T2P1), red with “danger” (T3P4), black with cancer, and pink was associated with healthy lungs “those [referring to lungs in one of the images] are nice and pink and healthy” (T3P4).

#### *Design suggestion 6-4*

|                                                                                                                                                        |
|--------------------------------------------------------------------------------------------------------------------------------------------------------|
| Use of green for ‘good’ and red for ‘alert’ will be recognised.                                                                                        |
| The colours yellow, green, purple and blue may be associated with health information.                                                                  |
| For illustrations, black will likely be perceived as indicating cancer while pink will likely be perceived as indicating healthy non-cancerous tissue. |

### **Theme 5: Accepted and recognised visuals**

In reflecting on participants’ responses to the different images, there were qualities and depictions that participants considered acceptable, or favourable, and those they considered unacceptable. There was a mixed reception to “cartoons”<sup>28</sup> in the example materials, with

<sup>28</sup> I refer to images as cartoons if any of the participants referred to them in this way (see Appendix 12, reference F)

several participants explicitly supporting their use and several others explicitly opposing their use. It was useful to investigate the reasons participants gave for their stance. What was important to participants was whether the comic style was “serious” enough (T1P1) and whether it “relates to the subject” (T4P4). Based on the images included on the produced posters, most participants liked photos with people in them. However, two participants on separate tables said they would rather there not be photos of a person because “all you are doing is looking at people” (T2P2). One participant said they would prefer images of parts of the body “because you’re actually looking at parts of your body [-] that is part of you”. Again, importance was placed on the relevance of the image to the reader. A reflection of this can be seen in one participant, whose identity as a grandparent was important to them<sup>29</sup>, believing the leaflet should have “a child somewhere in it”.

Across the groups, there was an acceptance for the use of images depicting ‘healthy’ compared to ‘unhealthy’ lungs, with table 2 including an image on their poster with one pair of lungs coloured in with black pen to represent “cancerous lungs” compared to a pair of “healthy lungs” (T2P2). Two participants on table 3 suggested using an image of ‘skull and crossbones’ to mean death.

Participants’ descriptions and reactions to the different images also presented an opportunity to discover what meaning participants took from, or associated with, particular icons and visual representations. Table 1 agreed that Ticks could be used to indicate benefits. There was indication that the commonly used visualization of a pair of lungs (see Appendix 12, materials from Quaife et al., 2020) was not expected by, or recognisable to, all participants. This is demonstrated in an exchange between two participants on table 1 while talking about a picture of an enlarged blood vessel (Appendix 12, reference B): “Are you sure there’s a pair of lungs on that?” (P1) “uh hu” (P3), then later when referring to the same picture “I thought that was it [the lungs] there” (P3). Similarly, a participant on a different table said “would most people know what they are? I think you would need to write lung”.

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<sup>29</sup> While speaking to this participant before the day of the workshop and at the end of an evaluation interview with them, they talked to me about their grandchildren.

*Design suggestion 6-5*

|                                                                                                                |
|----------------------------------------------------------------------------------------------------------------|
| Make sure the content of any pictures used are clearly relevant to the intended reader or the leaflet subject. |
| Use of ticks to indicate positive attributes will be recognised.                                               |
| When drawing lungs, assume they will not be recognisable to everyone, so add context and labels.               |

**6.2.2.3 Lung, cancer and screening perceptions**

Three main themes were developed to describe the ways in which participants spoke about topics surrounding LCS. These themes help to consider the ways in which different information about LCS may be engaged with by the target population.

**Theme 1: Diagnostic pathway over screening**

Participants' discussions were orientated around what things cause cancer and what are the signs if you have cancer (across all tables). This theme contained two subthemes; *'things that "can give you cancer"'* and *'the "early signs" of cancer'*.

***Sub theme: Things that "can give you cancer"***

Participants associated smoking with people getting lung cancer, with smoking being brought up as a topic of discussion across the groups when lung cancer was mentioned. On being asked by the helper "what information would be good to know about lung cancer", participants at table 2 spoke about smoking for several minutes. Upon seeing the example materials, one participant (a non-smoker) immediately said "if you're not interested in stopping smoking [-] you're not gonna read that at all" (T4P3), while another said to their friends in the group "so stop smoking you two" (T3P3), demonstrating a strong association between lung cancer and smoking. Several participants linked smoking directly to their brother (T2P2), pal (T2P1) and mother (T3P4) getting cancer. However, participants also disputed this focus on smoking, particularly when discussing the screening rather than cancer, giving examples of people getting lung cancer "who have never smoked in their lives" (T2T3), as well as examples of other things that "can give you cancer" (T2P5), like "some foods" (T2P5), "infection" (T3P3), or "drink"/alcohol (T2P2).

Participants, however, did not associate age with lung cancer, with only one participant connecting age with health during the workshop, saying "as you get older, wee things may

happen to you” (T3P3). Instead, participants took issue with the eligibility age included on the example leaflets and counter-argued that cancer “affects everyone, not just elderly or adults” (T2P5), with one participant saying, “I think that one’s [indicating to leaflet] stupid because people [younger than 60] can get lung cancer as well” (T1P2). Two tables included this sentiment on their posters and in priority positions, showing the importance participants placed on this issue; ‘cancer affects everyone’ (T2, section 1) and ‘can affect any age’ (T1, top right).

Through participants’ discussions, causes of cancer were framed as things that give you cancer rather than things that increase your risk of getting cancer. This in turn led to participants giving examples of when suggested causes (i.e., smoking and age) have not led to people getting cancer and of people getting cancer despite not meeting the eligibility criteria (i.e., non-smokers and children), with these examples being used as a counter-argument to the screening eligibility criteria identified on the example lung screening leaflets.

### ***Sub theme: The “early signs” of cancer***

Alongside focusing on the causes of cancer, participants also focused on the “early signs” (T2P3) of lung cancer. When participants shared stories about people they knew who had cancer, they included mention of the symptoms that those people experienced or that had gone ignored. Participants also wanted to know what the early signs of lung cancer were and wanted this information to be included on the posters. Table 2 included ‘signs + symptoms’ as a section on their poster, listing six examples. This orientation towards the signs of lung cancer led to participants reasoning that they did not need to engage in screening unless they experienced symptoms. For example, one participant reflected “if I feel ill, I’ll look at the relevant stuff” (T4P4).

### ***Design suggestion 6-6***

|                                                                                                                     |
|---------------------------------------------------------------------------------------------------------------------|
| include an explanation of the difference between screening and diagnosis                                            |
| include an explanation of the difference between a cause vs a risk factor                                           |
| Be clear that screening is for people without symptoms and justify why screening before symptoms arise is important |

## **Theme 2: Getting yourself checked out and knowing your body**

Across the groups, the topics of being able to know your own body and of using the screening test to know what is going on in the body were brought up and questioned. The dynamic between these two topics are described in the following subthemes; *‘You do vs “you don’t know what’s going on on the inside”’* and *‘Screening is an “opportunity” to “find out what’s happening”’*.

### ***Sub theme: You do vs “you don’t know what’s going on on the inside” - T3P2***

A theme of participants knowing or not knowing their own bodies permeated through their discussions. The orientation to being “aware of your own body” (T2P3) even came up when participants were discussing things to do to stay healthy and keep cancer away (table 2). The fact that screening is targeted at people without symptoms implies that people may have cancer without knowing about it, as well as implying that the screening test is better able to tell if a person has cancer than the person. For participants, this jeopardised their position as ‘knowers’ of their own bodies as well as jeopardising their perceived ability to know if they were healthy. Some participants reasserted that they do know what is going on in their bodies, with one participant saying “I think we’ve got to listen to our own body. We know when there’s something wrong” (T2P3). Other participants expressed not knowing what is going on in their bodies or whether they were healthy; “you don’t know what’s going on on the inside, even as we’re sitting here, we don’t know what’s going on” (T3P2) and “you don’t know if you are healthy” (T2P3). Here, the concept of screening asymptomatic people holds participants’ bodies as a site of contestation in terms of knowability.

### ***Sub theme: Screening is an “opportunity” to “find out what’s happening” - T3P2***

In light of participants being positioned as not able to know about their bodies, some participants framed screening as an “opportunity to go and see about yourself” (T1P2), so they could “find out what’s happening” (T3P2). Lung screening was described as an opportunity “to check your lungs to make sure your lungs are healthy or you’ve got a disease in your lungs” (T2P2).

Doing screening was taken as a given, likely due to the premise and objectives of the workshop being about designing a leaflet inviting people to lung screening. Due to this,

many of the phrases that participants suggested to be put on the leaflet were telling people to “go and get screened” (T1P1). Participants at table 1 particularly liked the phrase ‘the sooner you get screened, the better’ on one of the example leaflets. Some participants went on to say that, by doing screening, people were “actually looking after themselves” (T2P2) and “taking responsibility for your own health” (T3P3). There was also an expectation that people should be provided with the opportunity to do screening, with one participant saying “why don’t they send us for a CT scan once every six months” (T3P2).

#### *Design suggestion 6-7*

|                                                                                                                                                            |
|------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Frame screening as a tool for people to know their bodies, to place ownership of knowing on the invitees rather than the screening test or the clinicians. |
|------------------------------------------------------------------------------------------------------------------------------------------------------------|

|                                                                                                                       |
|-----------------------------------------------------------------------------------------------------------------------|
| Frame screening as an opportunity for people to look after their health, to provide invitees with a sense of control. |
|-----------------------------------------------------------------------------------------------------------------------|

### **Theme 3: Descriptions of lung cancer**

The term ‘lung disease’ was used synonymously with ‘lung cancer’ (T2 & T3) by participants, who referred to a lung with cancer as a diseased or unhealthy lung. Participants’ associations of lung cancer with a black diseased lung were reminiscent of the images used on smoking packets.

#### ***Sub theme: “spreads right through the body” - T1P3***

Cancer was described as something that spreads across, attacks and kills the person who has it. Participants both described cancer as something that spreads, as well as gave examples of people getting cancer all over their bodies, captured by the following quote: “spread right over his whole body” (T3P5). This idea of spreading was also combined with the characteristic of cancer as something that attacks the body; “if it’s gonna attack you all over your body [-] any part of your body” (T2P2). Here, participants’ interpretations of cancer held people’s bodies as a site of interaction between ‘person’ and ‘cancer’.

Only one participant referred to cancer as a “killer” (T3P4) directly, with participants more often using the euphemism “it’s too late” (T3P3) and “passed away” (T4P4) to indicate someone had “died with lung cancer” (T3P3). When discussing what should be written on a lung screening leaflet, participants at table 3 indicated the association between lung

cancer and death; “get a check-up, don’t take risks.” (P2) “Else your next appointment’s in a mortuary (P1)”. Accounts of cancer as something that causes death led some participants to challenge this description, arguing “it doesnae always end in death” (T3P3), while leading others to question whether the description was true, asking whether “it can be cured by [-] tablets or liquids” (T3P1). Participants’ declarations that cancer does not always lead to death was often tied to whether cancer was caught early enough.

***Sub theme: “They can save your life if they get you early” – T3P4***

Participants described cancer as something that could be “fixed”, but only if it was “caught early enough” (T1P1). With this, participants also described a point of being “too late” in finding cancer, synonymous to not “early enough”. For example, one participant said, “symptoms show it’s too late, it’s got a grip of you” (T3P3). This quote also ties back to the theme of cancer spreading across, and taking over, the body. Participants suggested that when cancer was found too late, people were “beyond help” and “there’s absolutely nothing you can do about it” (T3P3). Talk of early detection was present but minimal compared to talk of people’s experience of cancer and the signs of cancer.

***Design suggestion 6-8***

|                                                                                                                      |
|----------------------------------------------------------------------------------------------------------------------|
| Use the idea of cancer spreading to demonstrate cancer damage can be contained in regions and stopped in its tracks. |
|----------------------------------------------------------------------------------------------------------------------|

|                                                                                                                                                                                                                                                                                                |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Disrupt the binary view of cancer being found soon enough versus too late by providing examples of cancer being detected and treated at different stages, to promote the idea that there are more potential good outcomes than bad and to counter the sense of resignation tied to ‘too late’. |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

## **6.3 Evaluation interviews of the design workshop approach**

The workshop was followed by interviews with a selection of the people who attended the workshop (including the organising team) to evaluate whether the workshop design, and the activities used, were suitable/successful by considering whether the attendees found the approach to be acceptable and engaging.

### **6.3.1 Method**

#### **6.3.1.1 Procedure**

Interviews were conducted with a selection of attendees to the workshop to evaluate how well the workshop was received, what aspects attendees believed worked well and what they believed did not. Participants were invited to an interview as they were leaving the workshop. Some participants left their name and phone number with the researcher while others said they would be willing to be interviewed during their next community group meeting. The questions used in the interviews can be found in Appendix 16 and 17. The questions started by asking for participants' general reflections on the workshop, followed by asking about each main element (e.g., each activity). All but one interview was audio recorded and transcribed verbatim (not including non-verbal information beyond long pauses and laughter). An interview with one participant (P18) was not audio recorded because it took place in a noisy room at the community centre, so written notes were taken instead.

#### **6.3.1.2 Analysis**

A framework approach was taken to the analysis (Gale et al., 2013). The interview transcripts were coded section-by-section based on semantic meaning. The extracts were then gathered into pre-determined categories based on the main procedural sections and elements of the workshop. Within these categories, the coded extracts were collected into themes that could summarise participants' feedback in relation to each workshop element<sup>30</sup>. See Appendix 18 for a table outlining the final coding framework, with example extracts.

### **6.3.2 Results from the evaluation interviews**

#### **6.3.2.1 Sample**

Seven workshop participants were interviewed (Table 6-2) as well as the facilitator, the artist and one of the helpers. Interviews with the participants and the facilitator took place within a week of the workshop and lasted between 10 and 26 minutes, while interviews with the helper and the artist took place more than two weeks later and were much longer (57 minutes and 70 minutes, respectively). Most interviews took place at the community

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<sup>30</sup> Codes and themes were generated that did not fit into these categories but, for the aims of the evaluation, these were not considered further – providing a concise but shallow evaluation of the workshop as experienced by the attendees.

centre. Participants P6 and P9 were the only participants interviewed together and in their home. They were a married couple and P6 had early-stage dementia, so benefited from her partner being present. They had been at different tables during the workshop and P6 contributed independently to the interview, giving reflections unique to the table that she was on. The helper was interviewed in a university meeting room and the artist was interviewed via video call, which likely accounts for the differences in interview lengths.

### 6.3.2.2 Findings

Participants' general feedback for the workshop was positive, with participants saying it was enjoyable and good. Participants appreciated having the same small groups of people working together through the workshop and having a helper within each group. It was considered important to be in small groups to allow everyone to be heard. The helpers were seen to provide support, encouragement and keep the participants on task. The helper and artist who were interviewed felt the workshop benefited from having a facilitator who was already known by the participants, as this helped to establish trust. Participants reported feeling informed enough about the study before agreeing to take part, and reported being used to completing forms similar to the consent and demographic questions. The artist felt being involved in the workshop was a benefit to their design process, being able to gain greater insight about the participants and their ideas. The artist felt the poster creation activity was particularly helpful for this.

*Table 6-2. Interview participant characteristics*

| <b>Table and Participant IDs</b> | <b>age</b> | <b>gender</b> | <b>smoking status</b> | <b>formal education</b> |
|----------------------------------|------------|---------------|-----------------------|-------------------------|
| P17 (T1P1)                       | 67         | female        | former smoker         | Highers                 |
| P9 (T2P1)                        | 63         | male          | current smoker        | no formal               |
| P11 (T3P4)                       | 74         | female        | former smoker         | Missing                 |
| P6 (T3P5)                        | 63         | female        | former smoker         | no formal               |
| P13 (T4P1)                       | 47         | male          | current smoker        | Highers                 |
| P16 (T4P3)                       | 54         | male          | former smoker         | no formal               |
| P18 (T4P4)                       | 79         | female        | never smoker          | Missing                 |
| Artist                           | 31         | female        | never smoker          | Masters                 |
| Facilitator                      | 38         | male          | current smoker        | Bachelors               |
| Helper                           | 31         | female        | current smoker        | Bachelors               |

Interviewees felt the presentation given by the researcher was good for setting the scene for the day and that it was not too long. Interviewees felt the discussions after the presentation allowed participants and helpers time to settle in and get comfortable within their groups, as well as being an opportunity for the groups to establish shared expectations for the workshop and interactions. The poster creation activity received the most positive feedback, with participants saying they enjoyed this activity and the artist and helper corroborated this. The poster presentation activity pushed the comfort zones of the participants who presented and was something some participants had not ever done before or would not usually do. Even so, participants enjoyed the opportunity to see other people's posters. Participants disliked the sticker activity due to the implication that the red sticker represented a negative evaluation of other people's work. This activity also gleaned little insight in terms of the research aims, because it did not record the meaning attached to participants' sticker placement. However, participants appreciated the chance to move around and take a closer look at other people's posters, so an activity similar to this should be used, but without the simplistic measure of evaluating participants' work directly.

## **6.4 Discussion**

### **6.4.1 Main findings**

The primary aim of this study was to determine key design preferences that members of the target audience had for information about lung screening, with the assumption that taking these preferences into account when designing the picture narrative LCS information material will produce designs that are more accessible, acceptable and engaging to the target audience. The study was also used to investigate the information preferences and needs of the target audience. These findings identify information that may need to be provided to people living in more deprived areas of Glasgow when invited to LCS, to increase engagement with the materials and support informed decision-making.

#### **6.4.1.1 What design preferences do people within the target audience have for print information about LCS?**

Five themes were developed during the analysis that captured the main design preferences people had for the LCS information materials. The first finding was that participants insisted the information must be relevant to the reader, this echoes print health information design guidelines which stipulate that the information must be presented in a way that

makes the relevance of the information clear to the reader. Participants' appraisals of the length of the materials was often connected to considerations over the relevance of the information. This analysis suggests an important connection between the amount of information invitees wish to receive and the perceived relevance of the information. It might be that perceived relevance and personal importance of the information has a greater impact on engagement with the materials than concerns over the length.

Participants indicated being primarily interested in the practical aspects of taking part in screening. These findings suggest that people in the target audience are more likely not to question guidance from health care professionals or the NHS. This finding has implications for supporting informed decision-making. It will likely be important to inform people about the potential results and associated risks of LCS when they attend their screening appointment, as it is likely attendees from the target audience will not have considered this information. Sharma et al.'s (2019) qualitative study, with a lung screening-eligible population (based on the USPSTF guidelines) in the US, also found participants wanted information about the test procedure and wanted to see images of the CT scanner.

This study found it was important to the participants that LCS information materials convey realism, which can be achieved by including information about real peoples' experiences and using a realistic visual style. This focus on realism is likely due to associations with perceived credibility of the information, which is an important attribute for health information to achieve (Eagly & Chaiken, 1993).

An important finding from this study, and one that was related to participants' desire for realism, was that using a cartoonish style in information about LCS was not deemed appropriate. The style of cartoons was seen as not appropriate for the seriousness of cancer and potentially demeaning to an adult audience. Alam et al. (2016) also found comics to be considered inappropriate and trivialising when testing the use of comics for breast cancer treatment information provision with women from low socioeconomic backgrounds. This is an important consideration to take forward when designing the picture narrative LCS information. Witek (2012) identifies two main modes used in comics: 1) the cartoon and, 2) naturalistic, with the first using the style that participants were referring to within the workshop. Therefore, it would be pertinent to consider the second comics mode when designing health information for an adult audience for topics that are perceived as serious.

The study also provided insight into the ways certain visuals and design choices may be understood or interpreted by people within the communities of the target audience. For example, that the colour yellow may be associated with the work of cancer organisations. These associations can be used to create designs that can quickly indicate to the target audience the type of content of the information included and can be used to indicate relevance or stimulate interest (as with the case of using football tribe colours). Knowing the meanings that the target audience may associate with these different design elements is also important for developing LCS information materials that will be recognised as intended. For example, that black or dark colours indicate unhealthy lungs, but that this is more often associated with damage from smoking than with cancer. The images of cancer found in the comics (analysed in Study 2) similarly found these colours being used to indicate cancer.

#### **6.4.1.2 What perceptions do people within the target audience have about LCS?**

Participants' discussions about lung cancer most often orientated around the causes of cancer and what the signs and symptoms of lung cancer are. Participants were primarily interested in ways they could reduce their chances of, or avoid, getting cancer. This finding again reflects participants' engagement in a solution-focused coping strategy (Leventhal et al., 2016). However, in this instance, it detracted away from thoughts about doing screening. The finding that participants are interested in taking action when faced with LCS information supports framing screening as a way of taking control or as a way to reduce your chances of poorer cancer outcomes. Participants' preoccupation with the signs of cancer indicates that the nature of screening as being for asymptomatic people is not being recognised by the target audience. Hudson et al.'s (2017) focus-group study with US citizens who had a high risk of getting lung cancer similarly found participants focused on the signs of cancer as indicators for needing to do screening. It will therefore be important to establish ways of ensuring invitees are aware that screening is for people who are asymptomatic.

The second theme identified through participants' discussions about LCS describes a divide found in participant perceptions between: 1) feeling like they know their own body, therefore do not need to do screening, and 2) feeling like they would not know if they had cancer, therefore it would be good to do screening. This first perspective reiterates the

belief that screening is for people with symptoms, but also identifies that participants are unaware of, or do not believe that, lung cancer does not cause symptoms until the later stages. This finding is consistent with other studies conducted in the UK (Patel et al., 2012; Quaife et al., 2017) and the US (Draucker et al., 2019). With the second perspective, participants constructed screening as something that they could use to know more about their bodies. This finding suggests encouraging invitees to see screening as a way to know more about their health could support future engagement with LCS and is already being used within the ‘M.o.T for your lungs’ approach in the UK screening trial (Quaife et al., 2020). This approach may provide invitees with a sense of personal control which has been shown to be a factor associated with higher engagement in protective health behaviours (Ruiter et al., 2014).

The final theme describes participants’ perceptions about lung cancer, which was not only perceived as a “killer” but also as something that could be “fixed” if caught early. Both attitudes have similarly been found in a UK-based survey and focus groups with people eligible for LCS and from socioeconomically deprived communities (Quaife et al., 2017). This identifies that the target audience will likely be responsive to messages about the effectiveness of cancer treatment when detected early. The connection between early detection and screening was minimal across participants’ discussion, suggesting that cancer screening messages around early detection may not be well known within the target audience and ought to be promoted in the LCS information materials.

#### **6.4.2 Strengths and Limitations**

The workshop was able to elicit design qualities for lung screening information that were important to participants. The fact that the workshop was oriented towards design provided a non-threatening way to collect data on the target audience’s perceptions towards LCS and preferences for LCS information provision. For example, the participants and helpers started discussions by focusing on simple design elements such as colour or layout, which then led to participants making remarks about lung cancer and screening.

A limitation of this study was that people took part in the workshop who did not fit the target population of the designs being created. The workshop included people who had never smoked, who are not the intended population that the lung screening information is being designed for. Smoking status is likely to have played a role in participants’ interactions and contributions during the workshop, as the association between smoking

stigma and lung cancer has been found in other UK populations (Marlow et al., 2015). Therefore, the participants who smoke may have been reticent about contributing certain opinions. However, non-smokers were a minority in the group ( $n = 5/19$ ).

On reflection, I wish I had used the examples of picture narratives used in UK cancer screening leaflets found during Study 1 (the content analysis of cancer screening leaflets) as discussion starters and reference materials during the workshop. Instead, I selected materials that could demonstrate the different styles of pictures identified in Study 1.

### **6.4.3 Evaluation of the community-based design workshop approach**

#### **6.4.3.1 Workshop evaluation and reflections**

In adopting a community-based approach, alongside recruiting participants through the community groups, the workshop was a success in terms of recruitment, engagement and developing design suggestions. There are several qualities that made the workshop used in this study ‘community-based’; it was 1) attended by members of a community, 2) intended to benefit members of the community, 3) taking place at a central gathering place in the community (a community centre), 4) planned in collaboration with members of the community, and 5) facilitated by someone known by or part of that community. Nineteen people attended the workshop, which can be considered an achievement as people in low-resource areas are usually considered ‘hard-to-reach’ for similar qualitative research (such as focus groups). Participants showed high levels of engagement through the workshop and reported enjoying the activities. Rich data were collected from the workshop that could help answer the research questions, through the table audio-recordings, the posters created by the attendees and the reflections of the workshop team.

#### **6.4.3.2 Additional reflections**

There were multiple points of familiarity within the workshop setting and plan for the participants: 1) the facilitator was already known to the participants and the researcher, 2) the community centre, the room and the ground rules for a community group meeting were already well known to the participants, and 3) the researcher had met many of the participants several times before the workshop. This building up of familiarity likely fostered mutual feelings of trust and safety between the attendees (including the researcher and facilitator).

The discussion activity, following the researcher's presentation, was used by groups as an opportunity to further align their intentions and expectations for the aims of the workshop, establish group dynamics and establish a shared position on the acquisition of knowledge to be taken through the workshop (e.g., that knowledge was to be generated in a collaborative manner). Therefore, the discussion activity played a role in both the orientation and exploration stages of design.

#### **6.4.4 Conclusions**

The current study provided a useful way of establishing design suggestions for print LCS information that were based on the preferences and perceptions of people aged between 50 and 75 who had a smoking history and were living in low-resource neighbourhoods in Glasgow. This study also connects perceptions surrounding lung cancer screening found in the study sample to wider findings across the UK.

## **Chapter 7. Creating the picture narrative lung cancer screening test designs**

The current chapter describes the process followed to create the final picture narrative lung screening information developed and tested for this thesis project. Rather than design a LCS information leaflet in its entirety, this project was interested in developing example picture narrative lung screening information that could be tested in an experimental study – the aim of which was to determine if providing the target audience information about lung screening in a picture narrative format would be considered acceptable and could support decision-making. From this point on, these examples will be referring to as the ‘test designs’. The process followed to create the test designs is described in two parts; 1) the development of the prototype test designs, followed by 2) the usability testing and resulting modification to create the final test designs (Study 4).

### **7.1 Prototype development**

The following steps were followed for developing the prototype test designs: 1) Synthesis of design suggestions to determine design priorities to guide idea generation and ensure the designs were theory- and evidence-based; 2) Selection of the LCS information that the picture narratives would be created for; 3) Identification of best practice guidelines for print health information materials; 4) Review of the information by a medical expert to improve the accuracy and suitability; 5) Creations of initial test designs through idea generation and reflection; and 6) Designs produced with support of professional artist. These steps align with those in the double-diamond approach to design.

#### **7.1.1 Design priorities**

The design suggestions identified through the previous chapters were collected into a single document which was then used to guide and support the development of the test designs. The different design suggestions were synthesised, with similar suggestions being combined, and contradictory suggestions being appraised. To come to a decision about suggestions that contradicted one another, I considered the quality of the evidence behind them and the practicality of applying the suggestion to a picture narrative. Using this design brief ensured the designs were based on the research findings on ways to support

engagement, comprehension and decision-making specific to the target audience and for lung screening information.

### **7.1.2 LCS information selection**

The information to be included in the test designs was selected from the UK national screening committee's (2018) guidelines for screening information provision. Table 7-1 lists the different types of information that should be provided to invitees of a screening test and outlines which information was targeted in the test designs. I produced a document of text with the selected information written as gist-based messages. Gist-based information provides the base-level message (Blalock & Reyna, 2016) and has been found to be a successful method for increasing screening comprehension (S. G. Smith et al., 2015). I based the content of this on LCS information described in Chapter 1, while also referring to information materials already produced about lung cancer and lung screening (Macmillan Cancer Support, 2017; Quaife et al., 2020, provided in their supplementary materials). The following sections were included; what lung screening is, the benefits, eligibility criteria, potential results, harms and risks (see Appendix 19). I also referred to Hoffman et al's (2018) study which suggested alternative, more accessible, terminology and phrasing for elements of LCS information that are often found difficult to understand (such as 'risk' and 'overdiagnosis'). In particular, Hoffman et al's (2018) study suggested referring to overdiagnosis as "cancers that would never become life threatening" and being "treated for cancer that would never harm you", referring to false positives as "false alarms", and comparing radiation exposure during the test to other situations of exposure.

### **7.1.3 Development of an integrated list of recommendations for print**

#### **health information that support decision making and behaviour change**

To identify techniques based on best practice that could support the target audience with reading the information materials and engaging in decision making, I looked to print health information evaluation tools<sup>31</sup>. I focused on evaluation tools, because these are based on research findings and tested during development, while this is not required of guidelines.

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<sup>31</sup> To identify development and assessment papers for relevant guidelines and toolkits, I conducted database searches (EBSCOhost, Ovid, PubMed) using the following terms (Evaluation, Analysis, Guidelines, Strategy, Tool, Measure & Leaflet, Booklet, Pamphlet & Successful, Effective, Suitable, Good, Quality, Supportive).

*Table 7-1. Information to provide to people before participating in lung cancer screening based on the UK National Screening Committee guidelines (2018)*

| <b>Cancer screening information Category</b> | <b>Information to provide to people before screening</b>                                                                                                                                                                                                                                | <b>Was this included in test design <sup>a</sup></b> |
|----------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------|
| Condition information                        |                                                                                                                                                                                                                                                                                         |                                                      |
| Condition                                    | A description of the health condition                                                                                                                                                                                                                                                   | Yes                                                  |
| Incidence and prevalence                     | Incidence and prevalence of the condition being screened for                                                                                                                                                                                                                            | No                                                   |
| Test information                             |                                                                                                                                                                                                                                                                                         |                                                      |
| Procedure                                    | A description of the testing process                                                                                                                                                                                                                                                    | Yes                                                  |
| Eligibility                                  | Who is the screening being offered to                                                                                                                                                                                                                                                   | Yes                                                  |
| Performance values                           | Test performance (sensitivity, specificity and positive/negative predictive value)<br>i.e., An explanation of the chances of each screening outcome compared to outcomes based on no screening                                                                                          | No                                                   |
| Benefits and harms                           | Potential benefits, risks, limitations and uncertainties of taking the test                                                                                                                                                                                                             | Yes                                                  |
| Result possibilities                         | Possible outcomes and decisions that may ensue                                                                                                                                                                                                                                          | Yes                                                  |
| Choice information                           |                                                                                                                                                                                                                                                                                         |                                                      |
| Choice options                               | Clarification that it is a personal choice to accept or decline screening                                                                                                                                                                                                               | No                                                   |
| Emphasize personal rights                    | Clarification that both choices will be fully supported<br>i.e., Confirm continued quality of care regardless of decision                                                                                                                                                               | No                                                   |
| Decision support                             |                                                                                                                                                                                                                                                                                         |                                                      |
| Values clarification                         | <sup>b</sup> Encourages reader to consider their values with regards to the outcomes of the decision options, providing imaginable information on the physical, social or psychological effects<br>i.e., whether they would be able or willing to undergo diagnostic tests or treatment | No                                                   |

*Note.* <sup>a</sup> The information not included in the test designs was deemed something that could be omitted without impacting the coherence of the message. <sup>b</sup> this is an additional category from the National Quality Forum screening criteria (2016).

A systematic review by Finnie et al. (2010) and literature review by Kaphingst et al. (2012), evaluating the most extensive consideration of print health material success, helpfully collected studies and assessment tools. Finnie et al. (2010) used the categories of suitability from the Suitability Assessment of Materials (SAM; Doak et al., 1996) while Kaphingst et al. (2012) used their own categories of health literacy demand. My personal search found four additional health information materials assessment tools (indicated in Table 7-2). Eleven health information material assessment tools were identified (see Table 7-2). The SAM+CAM, created by Helitzer et al. (2009), applied many of the recommendations compiled in a review by T. Hoffmann and Warrall (2004) and used similar organising categories (Content -> Content; Language -> Literacy demand; Organisation & Layout and Typography -> Layout/Typography; Illustrations -> Graphic Material; Learning and motivation -> Learning simulation/Motivation; with the addition of numeracy).

The identified tools did not use consistent terminology and varied greatly by what items they included. Therefore, I used a framework approach to synthesize the tools, gathering similar items under the same entries and expanding the framework with each original item. The toolkit produced by Centers for Disease Control and Prevention (2019) was found to have the most extensive guidance on using pictures in print health information materials out of the tools identified. Appendix 20 shows what guidance for the use of picture was included for each of these tools.

This synthesis identified that print information evaluation tools lacked measures of education and behaviour theory constructs that have been shown to support information engagement and comprehension. The only tool that did measure such constructs was the latest version of SAM. However, this was limited to a single question that asked ‘please list any theories of behaviour that have been used’, which does not outline design choices that should be used and makes it difficult for designers to apply behavioural theory to their leaflets. I used the list of behaviour change techniques developed by Michie et al. (2013) to identify techniques that could support the target audience with participating in lung screening. I coded each technique for whether it was suitable to use in print information material about lung screening. Forty-seven potentially suitable techniques were identified (see Appendix 21).

The behaviour change techniques identified as suitable were integrated with the list of recommendations created from synthesising the print information assessment tools. This produced a comprehensive list of items to include when designing print health information (see Appendix 22). The final categories of effective print health information design were as follows: Engaging (attention, interaction, and tone), Accessible (literacy demand, numeracy demand, graphical 'technical diagram' demand, graphic demand, and population suitability), Acceptable (credibility, and cultural sensitivity), and Supportive (clarity of purpose, confidence, comfort, investment, practical guidance, and technical guidance). These categories are based on communication outcome rather than aspects of a print material, to provide an overarching explanation as to why each recommendation is expected to be effective.

#### **7.1.4 Expert review**

Dr Kevin Blyth, Professor of Respiratory Medicine and Honorary Consultant in Respiratory Medicine based in Glasgow, was interviewed for feedback on the LCS information (in text format). This was important to ensure that the information to be used in the test designs was medically accurate. Dr Blyth has clinical experience working with the target audience and provided useful insights into what terms and aspects of the information people often find confusing and provided alternatives that they find to be helpful in practice.

#### **7.1.5 Creation of initial test designs**

##### **7.1.5.1 Generating picture narrative design ideas**

With all the design suggestions collected and the textual information determined, I then developed preliminary versions of the test designs. The approach I followed for this was to alternate between sketching design ideas and reflecting on what I had drawn. For both activities, I used and referred to the design brief. I entered the reflective exercise each time I had completed an A2 page with drawings, but I also wrote reflections as they came to me while drawing. The following picture narrative ideas are examples of more substantially developed ideas created and reflected upon through the process.

Table 7-2. *Print health information evaluation tools*

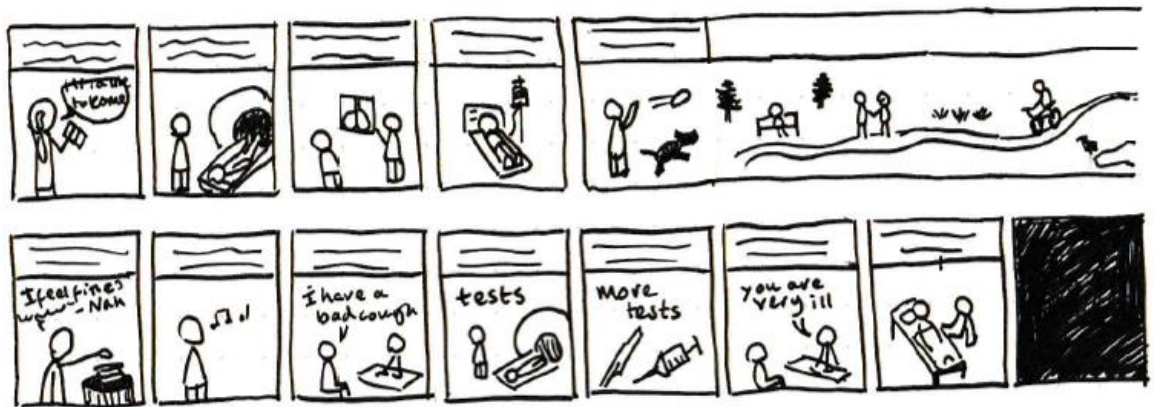
| <b>Citation</b>                  | <b>Full title</b>                                                   |
|----------------------------------|---------------------------------------------------------------------|
| <b>Guideline</b>                 |                                                                     |
| NCI, 1994                        | Clear & Simple                                                      |
| <b>Toolkits</b>                  |                                                                     |
| NHS, 2003                        | Toolkit for producing patient information                           |
| CDC, 2009                        | Simply Put V3                                                       |
| NWT Literacy Council, 2015       | A plain language audit toolkit                                      |
| <b>Assessment tools</b>          |                                                                     |
| BALD, Baker, 1997                | Baker Able Leaflet Design                                           |
| BIDS, Bernier, 1996              | Bernier Instructional Design Scale                                  |
| *Baur & Prue, 2014               | CDC Clear Communication Index                                       |
| Moody & Rose, 2004               | ClearDOC index                                                      |
| CSAT, Guidry et al., 1998        | Cultural sensitivity assessment tool                                |
| *EQIP, Moulton et al., 2004      | Ensuring Quality for Patients tool                                  |
| Kaphingst et al., 2012           | Health Literacy INDEX                                               |
| HLE2, Rudd et al., 2019          | Health Literacy Environment Assessment tool V2                      |
| *PEMAT-P, Shoemaker et al., 2014 | Patient Education Materials Assessment Tool for Printable materials |
| SAM+CAM, Helitzer et al., 2009   | Suitability and Comprehensibility Assessment of Materials           |
| *TEMPtED, Clayton, 2009          | Tool to Evaluate Materials Used in Patient Education                |

*Note.* NCI = National Cancer Institute, NHS = National Health Service, CDC = Centers for Disease Control and Prevention, NWT - Northwest Territories. \* Assessment tools identified through search additional to those reviewed by Finnie et al. (2010) and Kaphingst et al. (2012)

One illustration I developed was of two parallel comic strips (Figure 7-1), one depicting an ‘early detection and survival through screening’ scenario while the other depicts a ‘late detection and early death through not screening’ scenario. The sequential aspect of comics can be used to depict events happening at the same time and in parallel. This was similarly done by Brotherstone et al. (2006), depicting the growth of a tumour with and without flexible sigmoidoscopy intervention. It was a conscious decision to depict two characters going through the stages, rather than visualising the events at the level of the tumour, as was done by Brotherstone et al. (2006), for two reasons; firstly, to take advantage of the personalising capability of including people in the narrative and secondly, because guidelines on the use of pictures in health materials advise depicting things within context (and that anatomical things in particular should be presented in relation to the entire body).

The first panel of the first strip is of someone on the phone saying “hi, I’d like to come in for lung screening” and the last panel is the length of four and is missing the righthand border, intimating extension of life and opening of opportunity. The first strip of the second strip is of someone thinking “I feel fine” and throwing the leaflet in the bin. This strip ends with an entirely black panel. Originally, I had thought to put an icon of an empty hospital bed but, to avoid heightening negative emotions while still insinuating the character was dead, this panel could be entirely black.

Figure 7-1. Picture narrative example 1



I worked on this idea further, developing an alternative design for the same message as in the picture narrative above (Figure 7-2). Instead of using parallel comic strips, this design uses visualised narrators holding each ‘story’. This way of presenting the information could overcome negative perceptions people have of comic strips, while still capitalising on useful comic conventions. An important difference from the previous design is the omission of a visual portrayal of the ‘late detection and early death through not screening’ scenario, which is instead alluded to by the narrator saying, “Susan’s story [who went for screening] has a happy ending”.

I decided against including these illustrations in the final material, because I believed text statements about ‘early detection saves lives’ would be convincing enough for a population for whom there have been multiple media campaigns promoting this message (such as the Detect Cancer Early campaign and the Be Clear on Cancer Campaign, Cancer Research UK, 2022b). Additionally, surveys of UK populations have shown that most people already endorse beliefs about the benefits of cancer screening (Quaife et al., 2018; Waller et al., 2016). However, I believe these illustrations could have an impact on reducing

feelings of uncertainty and fear, as they show the process in neat steps and show that lung cancer does not always lead to death. This would be something worth studying further.

Figure 7-2. Picture narrative example 2



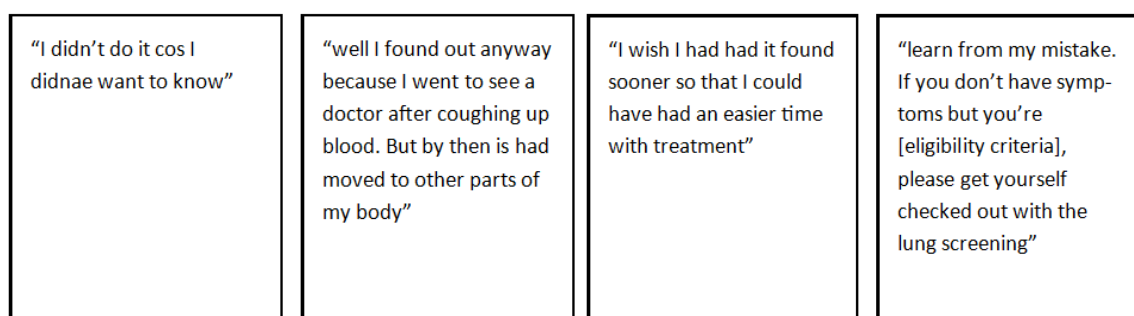
The aim of the following picture narrative was to clarify the difference between screening and diagnosis and to make it clear that screening is for people who have not got symptoms (Figure 7-3). Images of a magnifying glass and a needle were used to indicate the different approaches. When reflecting on the illustration, I felt the symbols would not clearly represent the different approaches for people in the target audience. In the end, it was decided that this was more suitably captured in two sentences, and that the visual narrative elements added little to the explanation.

Figure 7-3. Picture narrative example 3



The following script for a comic strip (Figure 7-4) was developed which could counter barrier perceptions, but I felt it was not informative enough for the lung screening information materials. It also did not take advantage of the integrated aspect of visuals and narrative to explain.

Figure 7-4. Picture narrative example 4



To communicate the message ‘finding cancer early can improve treatment outcomes’, I first produced the illustration below (Figure 7-5). However, I felt this image lacked narrative. I was also concerned that several visual elements that were included could be challenging; the divide representing two time points indicated by the dotted line, and the speaking characters being smaller than the ‘figure’ character. I, therefore, created an alternative version of this illustration that kept the figures of the man with cancer separate (Figure 7-6). Originally, I had included specific ages above each of the three men’s heads to indicate that they increase in age from left to right. However, using specific ages would be problematic for people who make very literal interpretations. At this point, I realised the benefit of being able to visually portray aging, and difference in age, while avoiding the need for writing specific ages.

Figure 7-5. Picture narrative example 5

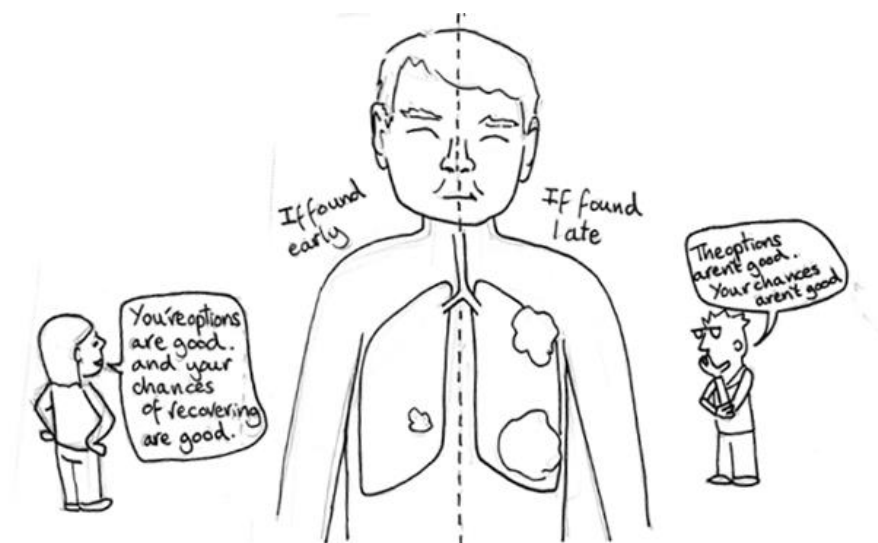
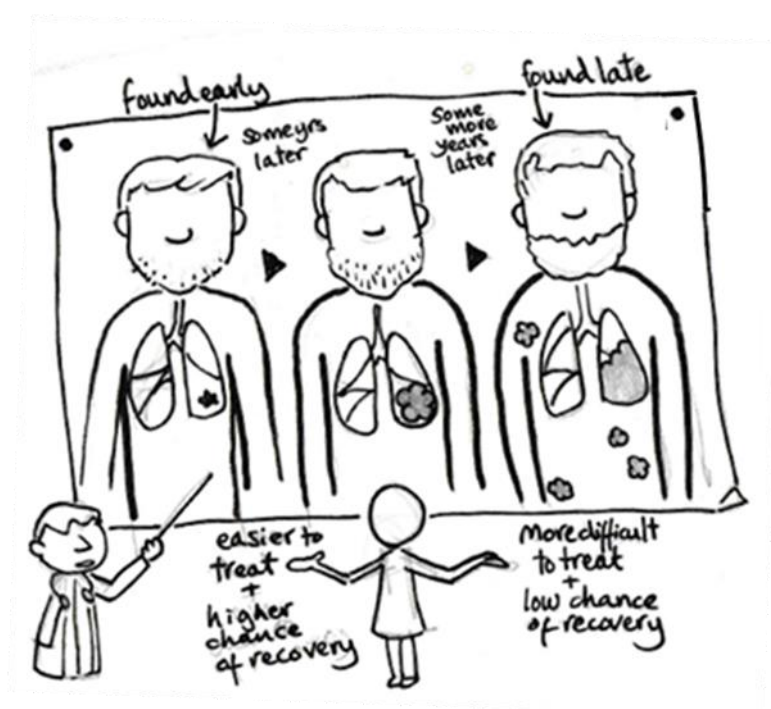
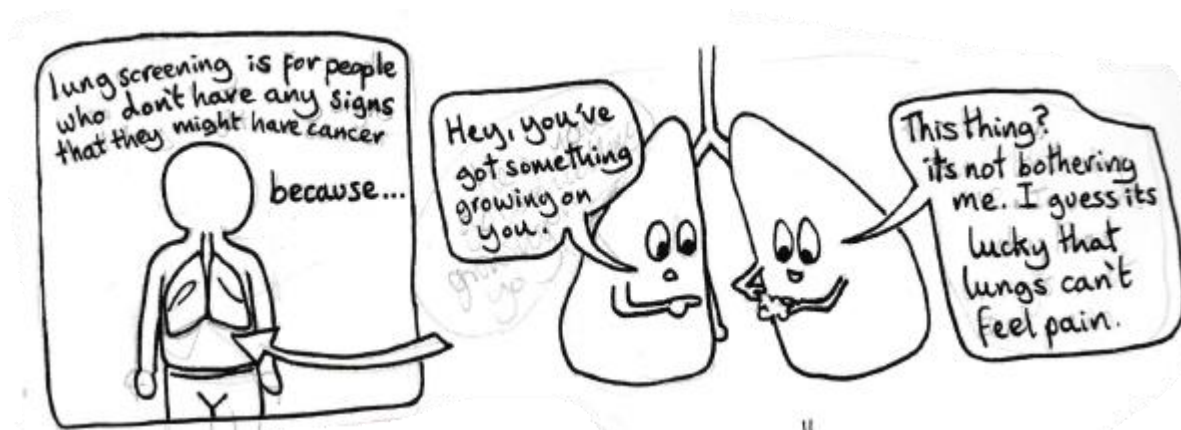


Figure 7-6. Picture narrative example 6



The following picture narrative was created in an attempt to counter the perception ‘I would feel if I had lung cancer’ found in the literature review, and repeated in the design workshop findings (Figure 7-7). The intention was to place the lungs in relation to the human body and include humour to diffuse negative emotions associated with thinking about cancer. I have also used the term ‘something growing’, which avoids mention of cancer, while keeping the main message of the illustration clear.

Figure 7-7. Picture narrative example 7



This illustration is very similar to what was used in the final version of the test designs. The main difference was the cartoon style of lungs was replaced with a more naturalistic look, as one of the findings from the design workshop was a preference for realism when communicating lung screening information.

#### 7.1.5.2 First version of test designs

I brought the ideas together in four pages of designs, each covering one of the following four topics: ‘what’s the point of lung screening?’, which included a description of the benefit of screening and the health condition, and an explanation of why screening is for asymptomatic people; ‘So... What is lung screening?’, which included a description of the procedure and the possible results; ‘Who is lung screening for and why?’, which included a reminder of the benefits and a description of the eligibility criteria; and ‘What risks come with doing lung screening?’, which described the risks and harms. These initial test designs can be found in Appendix 23.

#### 7.1.6 Working with artist

A professional artist (CM) was employed to draw the test designs. The artist was a medical illustration graduate with experience of working with the public, through public engagement events and community work. I sent the first version of the test designs to the artist, along with a ‘design brief’ which outlined goals of the lung screening information being designed and a ‘design board’ which included example comics and notes on different

stylistic choices<sup>32</sup>. The artist had participated in the design workshop (Chapter 6) and taken their own notes during this, which they also used to inform their illustrations.

After being sent the first version of the test designs, the artist sent me example illustrations which I made comments on. They then sent me a version of all the illustrations which I also gave comments on. They then sent me a complete version of the design pages (four pages containing all the LCS information and illustrations). Unfortunately, due to limited funding, I was unable to continue to work with the artist after this stage. I assessed the designs produced by the artist against the design priorities and made changes where appropriate (see Appendix 24 for the final designs). These designs were used as the prototypes assessed through the usability study described below.

It was very beneficial that the artist had participated in the design workshop (Chapter 6) as they thought of ways of visualising things (such as the CT scanner and the lungs) based on their time working with the participants. Having the opportunity to hear the artists' reflection by interviewing them after the workshop also helped my creative process (see Chapter 6 for a description of these interviews).

### **7.1.7 Final design elements**

Table 7-3 outlines the informational content included in the prototype designs and where each is located. Following this, Table 7-4 outlines all the decisions made regarding the design elements that were included in the design prototypes and identified how they were informed by the research reported in Chapters 4 to 6.

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<sup>32</sup> Included on the design board were illustrations of cancer produced by different cancer organisation (Cancer Research UK, 2020; Macmillan Cancer Support, 2017)

Table 7-3. Gist-based messages covered in the test designs and their placement

| Gist-based message                                                                                                                                                                                                                                                                                                                                                   | Placement on prototype design <sup>a</sup> |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------|
| <b>Early diagnosis.</b><br>Finding cancer early, when the cells have only recently become cancerous and have only recently started growing bigger, can increase chances of successful treatment and survival.                                                                                                                                                        | A                                          |
| <b>Cancer.</b><br>Cancer can grow bigger, spread to other parts of body and, so, becomes more difficult to treat.                                                                                                                                                                                                                                                    | B                                          |
| <b>Benefits of screening.</b><br>Cancer screening increase chances of having cancer found early, which can improve treatment outcomes.                                                                                                                                                                                                                               | C                                          |
| <b>For asymptomatic people.</b><br>Be clear that screening is for people without symptoms and explain why                                                                                                                                                                                                                                                            | D                                          |
| Countering belief that ‘people would know if they have lung cancer’ by explaining it doesn’t cause any obvious symptoms                                                                                                                                                                                                                                              | E                                          |
| Countering belief that ‘people would know if they have lung cancer’ by explaining the lungs do not feel any pain                                                                                                                                                                                                                                                     | F                                          |
| <b>Procedure.</b><br>Provide practical information including, what the scanner looks like and what happens during the screening. a CT scanner is hoop-shaped machine that a person lies in and it captures images of the inside of the body from multiple angles.                                                                                                    | G                                          |
| <b>Result possibilities.</b><br>Include explanation of the following results: no signs of cancer found, abnormal result (i.e., signs of something that might become cancer), cancer found and incidental findings. Also describe ‘watch and wait’ and show treatment is possible.                                                                                    | H                                          |
| <b>Screening vs Diagnosis.</b><br>include a clear distinction between screening and diagnosis – from workshop findings                                                                                                                                                                                                                                               | I                                          |
| <b>Eligibility criteria.</b><br>Describe who will be invited and explain why.<br>People over 50 and smoke heavily within past 15 years and are under 75 years old will be invited to lung screening because the first criteria means you have a high chance of getting lung cancer and the second criteria mean you have a high chance of benefiting from treatment. | J                                          |
| <b>Risks of screening.</b><br>Describe the negative features of doing lung screening as they effect the invitee.                                                                                                                                                                                                                                                     | K                                          |
| False-positive results and unneeded additional testing: There is a chance of being found to have signs suggestive of cancer that are found to not be cancer after diagnostic testing                                                                                                                                                                                 | L                                          |
| False-negative results and missed treatment opportunities: There is a chance that cancer will be missed by the test                                                                                                                                                                                                                                                  | M                                          |
| Overdiagnosis: There is a chances of being treated for a cancer that does not need treatment as it never would have harmed you                                                                                                                                                                                                                                       | N                                          |
| Tests, radiation exposure and biopsies.                                                                                                                                                                                                                                                                                                                              | O                                          |
| Psychological effects of participation: Aspects of screening process can cause people stress and worry                                                                                                                                                                                                                                                               | P                                          |

Note. <sup>a</sup> These Letters are labelled on the prototype designs in Appendix 24.

Table 7-4. Design decisions and justifications

| Design component                    | Application (i.e., what has been included)                                                                                       | Justification (i.e., why was this included)                                                                                                                                                                                                                                                                                                                                                        |
|-------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Introductory title for each section | A male and a female talking head<br>Speech in personal tone, with active and direct phrasing.<br>Characters ‘looking at’ reader. | [review] personal tone and ‘looking at’ reader, draws, and maintain, attention.<br>[other] Man and women to indicate information is relevant for both.                                                                                                                                                                                                                                             |
| Characters                          | Sherlock Holmes dog as character who ‘interacts’ with the cancer and as silent model of doctor                                   | [WS] Liking dogs.<br>[WS] Disliking of doctors as authority figures but also appreciating recommendations to come from medical professionals<br>[review] animal characters are imbued with traits associated with that animal within a culture<br>[other] Sherlock Holmes is a popular character in the UK and is associated with well-established symbols (deer stalker hat and magnifying glass) |
|                                     | Single character going through different screening related processes                                                             | [review] Important to have person interacting with objects and demonstrating actions<br>[other] helps reader perceive continuity through the screening process and the information<br>[other] better to not overload reader with more characters/depictions than necessary                                                                                                                         |
| Illustration style                  | Realistic                                                                                                                        | [WS] Tendency to literalness<br>[WS] Dislike for cartoonish style<br>[review] Realism requires less interpretation, good for older cognition                                                                                                                                                                                                                                                       |
| Structuring                         | Colour in background showing different sections                                                                                  | [WS] Participants indicated they appreciated different sections having different coloured backgrounds                                                                                                                                                                                                                                                                                              |
| Colours                             | Background colours light yellow, blue, green and pink                                                                            | [WS] Multiple colours were associated with medical information<br>[review] Pastel colours gentle, good for making information less ‘threatening’<br>[other] colours chosen so that colours of objects in the illustrations would stand out in comparison                                                                                                                                           |
|                                     | Cancerous cells more purple than normal cells                                                                                    | [WS] Cancer thought of as black or darker than the ‘healthy’ cells                                                                                                                                                                                                                                                                                                                                 |
| Depictions                          | Lungs visualised as being on the man’s chest                                                                                     | [review] anatomical images to be depicted within context of entire body                                                                                                                                                                                                                                                                                                                            |
|                                     | Cancer drawn as an innocuous and funny looking character                                                                         | [review] to overcome fear and avoidance when thinking about cancer, include humour and show cancer as unthreatening.                                                                                                                                                                                                                                                                               |

Note. WS = finding from carrying out the design workshop with members of the target audience (Chapter 6). Review = identified during literature review.

## 7.2 Usability testing

### 7.2.1 Introduction and study aims

Usability testing was conducted to identify potential accessibility issues with the prototype designs and guide improvements, and to ensure the suitability of the concepts, terms and images used. Eastmond and Pettersson (1988) demonstrated that even simple icons and pictures can be interpreted very differently from their intended meaning and result in a range of interpretations. V. Hoffmann (2002) reports several illuminating examples of visual symbols being unrecognisable to an audience who do not know the conventions being used (see pages 136 to 149). Therefore, to ensure the message is interpreted as intended, it is essential to assess the interpretations and associations made by the target audience. Usability testing is also an opportunity to identify if aspects<sup>33</sup> of the designs are deemed unacceptable or inappropriate to the target population, which will impact the success of the picture narrative LCS information.

Question 1. Were the picture narrative elements used in the prototype designs recognised as intended by members of the target audience?

Question 2. Were aspects of the designs acceptable to members of the target audience?

Usually, usability testing and revisions would be conducted iteratively. The processes outlined by the double diamond approach is iterative and cyclical and carried out until the product is deemed ready for release. However, the current project was interested in conducting a scientifically rigorous assessment of the ways in which the designs were interpreted and how they might be improved. To allow for this, a single round of interviews based on the same prototypes were carried out. Doing so meant that I could conduct an in-depth analysis of the data, with participants responding to the same design content.

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<sup>33</sup> I differentiate between design elements and design aspects here, with ‘element’ referring to specific instances within the design pages, while ‘aspect’ refers to a characteristic of the designs. For example, the image of a doctor speaking to the reader would be an element while the use of a doctor character as the provider of a message would be an aspect.

### **7.2.1.1 Thinking aloud approach**

In think-aloud tests, participants are required to verbalise their thoughts while interacting with a tool (e.g., the print information material). These verbalisations are then analysed to make interpretations about the participants thinking (whether that be about their inference, mental models, decision processes or reasoning; Ericsson & Simon, 1998). The assumption behind using a think-aloud approach is that the responses that participants give as they are interacting with an object are more reflective of cognitive processes that are occurring than responses participants give when asked to describe or explain their thoughts (i.e., question-answer interview format). The latter approach results in respondents reflecting on and rationalising their thought process, which Ericsson and Simon (1998) contend is invalid data for usability testing. Therefore, a think-aloud test was used in the current study to elicit verbalisation that were more likely to reflect participants initial interpretations of the designs.

## **7.2.2 Method**

### **7.2.2.1 Recruitment strategy**

Purposive and snowballing recruitment was used. Inclusion criteria were anyone aged between 50 and 75, smoke, and live in a neighbourhood in Glasgow ranked in the most deprived SIMD quintile<sup>34</sup>. Community workers<sup>35</sup> and community group organisers known to work with people within this group were asked to share details about the study within their community groups and people they worked with who met the inclusion criteria<sup>36</sup>. I provided them with recruitment fliers they could share (Appendix 25). Invitees were given the researcher's contact details to enquire about taking part in the study. Often, people interested in taking part wished for their name and phone number to be shared with the researcher through the community worker, and to then be contacted by the researcher about the study. I also contacted the administrator of several Facebook groups associated with the target neighbourhoods to share the recruitment flier (Appendix 26). Invitees were offered £10 for participating, with the option of receiving this as cash, shopping voucher or charity donation. The money was posted to participants on completion of the interview with a

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<sup>34</sup> The following areas were targeted: Priesthill and Househillwood, Govanhill, Gorbals, Govan, Drumchapel, Easterhouse, Springboig and Barlanark, Parkhead, Dalmarnock and Camlachie.

<sup>35</sup> Community Connectors employed through the Thriving Places programme, link workers working as part of the Scottish Deep End project, and community development workers based within community centres.

<sup>36</sup> Over 70 people were contacted and 18 responded

letter thanking them for their time and with study fliers to share with people they knew. People who were interested in taking part in the study were posted a pack containing a letter with the agreed interview time (Appendix 27), a participant's information sheet and privacy notice (Appendix 8), and the prototype picture narratives. Verbal consent was recorded at the start of the interviews. Ethical approval was obtained from the University of Glasgow's MVLS ethics committee (ethics code: 200200021, 22/01/2021).

### **7.2.2.2 Interview procedure**

The interview process was piloted with two people. During piloting, I found participants paused to ask me questions during the think-aloud activity which disrupts the process and participants were hesitant and unsure about doing the activity. Consequently, I updated the activity guidance to make clear that I would not be answering questions, but would take note of them and answer them at the end of the interview. I also acknowledged the potential awkwardness they might feel and the strangeness of the task (see Appendix 29 for the interview schedule including the final think-aloud activity script used).

As this research was conducted during COVID-19 social distancing restrictions, participants were offered the choice of a video interview via Zoom or a telephone interview. At the beginning of the interviews, participants were further informed about the study and given the opportunity to ask for more information, before being asked to give consent to being audio recorded. The interview then followed in two parts, the first was a think-aloud activity to invoke responses that could indicate recognition and acceptability of the designs, followed by semi-structured open-ended questions to supplement the data from the think-aloud activity as well as identify aspects of the designs that participants liked or disliked (see, Appendix 29 for the interview topic guide). The main instruction in the thinking-aloud activity was for participants to say out loud whatever they may be thinking or feeling while reading through the design pages. The only verbal prompt used during the think-aloud activity was 'what are you looking at now'. The semi-structured interview section asked participants to describe each illustration, if they had not done so already, and then asked participants whether there were parts of the designs (with prompting to think about sections, words and then pictures) that they either particularly liked, did not like, felt were overcomplicated or difficult to understand. Participants were then asked demographic questions regarding age, gender, ethnicity, smoking status and history, car ownership, home ownership, formal qualification, and employment status. These questions were based on those piloted and used in the design workshop study

(Chapter 6). Participants were also asked whether they usually find medical leaflets easy or difficult to understand (reading confidence) and, how much they previously knew about cancer screening (cancer screening awareness) and lung cancer (lung cancer awareness). The researcher then answered any of the questions that participants asked during the think-aloud activity, followed by a debriefing.

### 7.2.2.3 Analytic method

The interviews were transcribed verbatim and directly next to the area of the designs that were being spoken about (on a different copy of the prototype for each participant, see Appendix 30 for an example). To maintain a distinction between responses to the think-aloud questions and responses to the follow-up questions, '2nd' was written at the start of each response that was given during follow-up questions.

First, a coding framework was used to answer question 1 (were the picture narrative elements recognised by participants). This framework had a row dedicated to each design element of the prototype designs (which included both a picture of the section and a description of the intended message) and a column for each participant (who were referred to by participant number, gender, age and postcode-level SIMD<sup>37</sup>; see Appendix 31 for an example). A content analysis was then conducted, moving all utterances made about each design element into the framework. Each cell was then coded for recognition (recognised; not recognised; undetermined) on the following two levels:

- 1) Depiction recognition: Does the drawing (i.e., how the image is rendered) meet (i.e., resemble) the intended depiction for the participants. For example, did the drawing of the plaster look like a plaster to the participants.
- 2) Message recognition: Does the depiction (i.e., what is being depicted) meet (i.e., convey) the intended message for the participants. For example, did the depiction of 'a plaster on lungs on chest of a man' represent 'the man has received treatment for lung cancer' to the participants.

Additionally, indications of potential readability issues, such as misreading or stammering, were coded. Table 7-5 shows the full coding frame. To support the analysis, analytic notes

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<sup>37</sup> To support interpretation, I also included information about the participants that I felt had a strong impact on their interpretation of the lung screening information, within the table under their participant numbers. For example, P1 and P5 both mentioned having been in a CT scanner before.

were also written within cells to keep a record of the reasoning behind coding choices. The next step of the analysis was to make summations about the degree to which each design element was recognisable for the participants. I wrote these in a column at the end of the table in which the extracts were coded, allowing for continuous reflection on the data. For each summation, I also wrote ideas for how the designs might be improved.

*Table 7-5. Usability testing coding frame*

| <b>Code</b>                        | <b>Description</b>                                                            |
|------------------------------------|-------------------------------------------------------------------------------|
| Depiction recognised               | Indication that the depiction has been interpreted as intended                |
| Depiction not recognised           | Indication that the depiction has not been interpreted as intended            |
| Depiction recognition undetermined | It is unclear whether the depiction has been recognised as intended           |
| Message recognised                 | Indication that the message has been interpreted as intended                  |
| Message not recognised             | Indication that the message has not been interpreted as intended              |
| Message recognition undetermined   | It is unclear whether the message has been recognised as intended             |
| Potential readability issues       | Instances where participants misread or stumbled on a word or section of text |

*Note.* Indications of recognition were based on, 1) the correct or alternate interpretations being made, and 2) participants reporting that they did not understand, or were confused by, some aspect.

A separate content analysis was conducted to answer question 2 (were the design aspects considered acceptable to, and appreciated by, the participants). All utterances that indicated that the designs were acceptable (or not) to the participants or indicated the designs were appreciated (or not) by the participants were collected. I then coded the extracts inductively at a semantic level, specifically coding for what aspect of the designs the extract was in reference to (for example, characters introducing each page). Then, similarly coded extracts were grouped together and assessed for whether the aspect was acceptable or appreciated by participants.

#### **7.2.2.4 Reflexivity**

To support interpretation of participants' comments during analysis, I kept two note documents. The first document was for recording information about the participants and interview context. For example, did they have a TV on in the background, were there interruptions, what did the participants say about themselves, and did they talk about other things during the interview. I also included reflections on participants' responses to the

questions asking whether they usually find health information materials difficult or easy to read, how much they were aware of cancer screening and of lung cancer. The second document was for reflections on how I conducted the interview, anything that might have impacted our interaction and the responses that interviewees gave. I included the direct quote or a description of the situation and then my reflection.

### **7.2.3 Results**

Interviews were conducted with eleven people within the target audience. Three of these interviews were excluded from the analysis as they lived in affluent neighbourhoods and, therefore, did not reflect the target audience. Two participants were recruited via Facebook, two through a community connector and four through a link worker. An additional two people agreed to take part in an interview, but then could not be contacted.

#### **7.2.3.1 Participant characteristics**

All participants, apart from one, were female and all said they were white British or Scottish ( $n = 8$ ). Participants took between 8.5 minutes to 14.5 minutes to read through the test designs during the read aloud task. All but one participant had a smoking history equivalent to 10 or more cigarettes a day for 20 or more years ending no more than 15 years ago if no longer smoking. The participant who did not meet this criteria had stopped smoking 20 years ago. Two interviews took place via video call, while the others were conducted over the phone<sup>38</sup>. Additional demographic information are reported in Table 7-6.

### **7.2.4 Results**

#### **7.2.4.1 Were the depictions recognised?**

The following pictorial representations were found to be well recognised by all participants; the lungs, speech balloons, the dog as a doctor, the CT scanner, and computer screen. Nearly all participants recognised the dog as a detective (Sherlock Holmes).

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<sup>38</sup> I found the interviews over the phone were more conducive to the thinking aloud method as it felt more normal that participants would necessarily need to describe to me what they were looking at, whereas the participant on the video calls would look to me for confirmation or reassurance that what they were saying was 'correct' which is problematic for think-aloud tests.

Table 7-6. Participant characteristics

| Characteristic                                          | <i>n</i>        |
|---------------------------------------------------------|-----------------|
| Age <i>M</i> (range)                                    | 62.3 (53 to 70) |
| Gender                                                  |                 |
| Male                                                    | 1               |
| Female                                                  | 7               |
| Smoking history <sup>a</sup>                            |                 |
| Within eligibility criteria                             | 7               |
| Not within eligibility criteria                         | 1               |
| Postal SIMD quintile                                    |                 |
| 1 <sup>b</sup>                                          | 3               |
| 2                                                       | 3               |
| 3                                                       | 2               |
| Home ownership                                          |                 |
| Rent from housing association, local authority, council | 6               |
| Own outright                                            | 2               |
| Vehicle ownership                                       |                 |
| None                                                    | 7               |
| One                                                     | 1               |
| Education                                               |                 |
| No formal education                                     | 2               |
| College, SVQ                                            | 6               |
| Employment                                              |                 |
| Retired                                                 | 4               |
| Part time                                               | 2               |
| Full time                                               | 2               |
| Reading confidence <sup>c</sup>                         |                 |
| Low                                                     | 2               |
| Medium                                                  | 4               |
| High                                                    | 2               |
| Cancer screening awareness                              |                 |
| Low                                                     | 3               |
| Medium                                                  | 5               |
| High                                                    | 0               |
| Lung cancer awareness                                   |                 |
| Low                                                     | 1               |
| Medium                                                  | 5               |
| High                                                    | 2               |

Note. <sup>a</sup> Broadest eligibility criteria for lung screening based on currently available programmes,  $\geq 10$  a day for  $\geq 20$  years within last 15 years, <sup>b</sup> 1 = Most deprived, <sup>c</sup> Participants were specifically asked about reading medical and health information.

However, one participant did not recognise the magnifying glass, and another did not recognise the footprints. The image of the dog in a chair and being surprised out of a chair by something was recognised as such. However, the depictions of the cancerous growth were not easily recognisable, with three participants referring to them as “symbols” (P4), “pink clouds” (P5) and “pink image” (P10). Nearly all participants recognised the depictions of the man with a question mark and a plaster in front of his lungs, with only one participant not recognising the image of the plaster. The image of a cigarette pack was not mentioned by any participants.

#### **7.2.4.2 Were the messages recognised?**

Participants did not readily associate the image of the detective dog character looking at footprints with the message of ‘searching for signs of cancer’. Two participants identified the intended message behind the image of the dog being surprised and no participants construed an inappropriate message from this image. The depiction of the man talking to a doctor, on page 1, was recognised by all. However, the image was not associated with the intended message and, for most participants, distracted from the message by making it look as though a consultation with the doctor is the first step to screening which also led participants to ask about symptoms of lung cancer. The illustration explaining the lungs do not feel any pain was recognised on both levels. However, some participants questioned the relevance of the information while others did not believe it.

Participants connected the image of the CT scanner with the proceeding image of the dog looking at a screen and associated both images with the intended meaning. One participant indicated that having the image of the scan presented before the image of a doctor helps to differentiate screening from diagnostic testing; “it’s a routine, lung screening because - you know - the patient going to the doctor comes later on in the leaflet, you know - it doesn’t show you straight away that the patient is going to the doctor” (P2).

The illustration explaining the follow-up procedure to finding signs that might become cancer was relatively well understood, even with the binoculars and cancer cells not being recognised. Including a specific timeframe (‘3 months or 1 year’) in this section caused participants to worry about the length of this timeframe. This is not necessary information needed to make an informed decision about attending lung screening. It was unclear whether participants drew the intended meaning from the illustration explaining the difference between screening and diagnostic tests or whether they made meaning entirely

from the text information. Information about the specific diagnostic tests caused some participants to stop and wonder at this, with some participants saying there was not enough information about the tests. The inclusion of information about the diagnostic tests distracted from the main message of this section.

Only two participants mentioned the tick icons. Participant 2 said “tick tick tick you know that’s self explanatory that’s actually quite good”. However, participant 5 interpreted that the listed information were options they had to tick, which is not the intended meaning of this section. Some, but not all, participants interpreted the message associated with the two images of the man with the a question mark and plaster in front of his lungs as intended.

For the last illustration on page three, participants recognised that the picture was of the dog weighing up/balancing balls, but they expressed that they did not know what this was meant to represent. In my pursuit to reduce the number of images to minimise visual and information complexity, I ended up excluding visuals that supported the interpretation of this image. The image of weighing up risks and benefits may be recognisable to cancer screening communicators but is not intuitive for people not in this group. The illustration explaining false-positive results was interpreted mostly in line with the intended meaning while the illustration explaining false-negatives was only minimally described, suggesting the meaning was not clear to participants. Participants did not associate the intended meaning to the illustration of two identical looking cancers used to explain the slow growing cancers being indistinguishable from other cancers. The images used to explain radiation exposure were recognised on both levels, with participants appreciating the use of a “small ball” (P13) to indicate quantity ‘units’. The final illustration of the aspects of screening that can cause people stress were recognised by all participants, both in terms of intended depiction and intended message. Participants appreciated that it was the same person as it showed “the journey” (P4).

#### **7.2.4.3 Readability issues**

The following terms and phrases were found to be an issue for some participants: ‘easier to treat’, ‘this will mean less suffering’, ‘plastic bed’, ‘benefits of screening are from improving your chances’, and ‘simpler treatment options’, as well as the entire phrasing of section 3 on page 3 regarding slow growing cancers. One participant interpreted ‘Signs of cancer’ to mean ‘evidence of cancer’, with other participants also believing that being told

they have signs of cancer was the same as being told they have cancer. The phrase ‘slow growing’ is not intuitive and puts emphasis on growth rather than the speed.

One participant was unable to read the text in the speech balloon on page 2, likely because of the different font and smaller size. The text on the radiation illustration was also too small for one participant to read. One participant found the text on the green background difficult to read.

By listening to the order in which participants read the materials, the following layout issues that impacted readability were also identified. The label ‘left alone, the cancer has kept growing’ was read before ‘here, the cancer is still small’ by one participant. I believe this is because the first statement was positioned higher than the second and was not clearly a part of the second section. This also happened with another participant for the illustrations on page three, where the higher label (‘not actually cancer’) was read first although it was to the right of the other label (‘signs of cancer’). Some participants skipped over the second sentence in the white space on the first page and two participants read the ‘but’ in the middle of the sentence above. On the second page, it was more natural for participants to read the sections in columns, from 1 to 3 to 2 to ‘extra’. No other layout issues were found.

#### **7.2.4.4 Were the design aspects acceptable and appreciated?**

All participants gave positive feedback about the designs in general terms. However, very few extracts were found that indicated whether the participants found aspects of the designs acceptable or appreciated them. The design aspects that participants reflected on were the colours used, the story-like nature of the information, the dog character, the characters introducing each page, and the drawing of cancer. All but one of the comments in these extracts were positive towards the designs. Participant 12 felt the picture of the women should instead be of a man as to not suggest that the information was only for women. Participants 1 and 5 both laughed when seeing the dog character, with participant 1 saying “Aye (laughs) wee doggy woggy, I know, I love dogs and animals [-] people can relate to that instead of a person cos people love dogs (laughs)”. Participant 13 said the picture of the “wee cells” were “self-explanatory” and Participant 1 said “the wee way cancer grows naw you- that’s fine that’s fine and how you identify that”.

### 7.2.5 Discussion

This study was able to identify aspects of the picture narratives in the prototype designs that were recognised (i.e., the participant's interpretation matched the intended meaning) and those that were not. It was useful to consider recognition both at the level of the depictions (i.e., did my drawing of a picture of a dog look like a dog to the participants) and at the level of the message (i.e., was the picture of a dog holding magnifying glass regarded as a detective). The images that were more symbolic in nature, such as the depiction of the cancerous cells and the footsteps, were most often not recognised by the participants. This is to be expected, as the meaning behind symbols develops through conventional use and requires shared understanding to be interpreted (Barry, 1997; V. Hoffmann, 2002).

An important finding was that the comics conventions of speech balloons and narrative progression across panels were understood by all participants. Additionally, none of the participants reported finding the designs unacceptable, supporting the use of the style of the picture narrative in the prototypes.

This study was also able to identify potential readability issues from instances where participants either had difficulty reading a word or read a word incorrectly. This not only indicated terms and phrases that participants did not recognise, but also indicated layout issues that had an impact on readability of the designs.

From the data collected, it is unclear to what degree the designs were appreciated by the participants (i.e., whether they found the designs to be interesting or enjoyable). It is possible that participants non-verbal responses (i.e., facial expressions and changes in posture) could be used to assess their levels of appreciation towards the design. However, it was not possible to conduct these interviews in person, as has been originally planned, due to covid-related restrictions.

The interviews highlighted to me that I became so immersed in the imagery and signs I was using while creating the information designs that I did not notice that the image of the 'dog balancing balls' did not make sense when taken out of context. This demonstrates why piloting and usability testing is important, independent of how easy-to-read or clear you think the designs are.

### 7.2.5.1 Strengths and limitations

This study used data from a relatively small sample size ( $n = 8$ ). However, as the findings are not being used to derive generalisations about the target audience or build theory, this sample size was suitable. Additionally, it has been argued that as few as five participants are needed for thinking-aloud testing to identify most usability issues (Nielsen, 1994). Only one of the participants identified as male, which means there may have been aspects of the designs that were less recognisable to men that may have been missed. Recruitment was, otherwise, successful in terms of recruiting people with minimal or low formal education, medium to low cancer screening experience, smokers and people living in areas with high SIMD.

Participant characteristics data on reading confidence, cancer screening awareness and lung cancer awareness was collected via self-report on single item questions. This data was suitable for the intended use within the study, which was to supplement the analysis.

Using a think-aloud approach, in combination with a qualitative analysis, was found to be a suitable way to study participants' recognition of images. Ericsson and Simon's (1998) guidance to use a neutral prompt in the think-aloud task was followed (which was 'what are you looking at now') and interaction between the participants and myself was kept to a minimum. However, they also suggest using a training task, which was not done in the current study. The training task was intentionally circumvented to reduce participant burden and to avoid participants feeling they were being asked to do something irrelevant. The think-aloud protocol used in the study was developed through pilot testing which I believe contributed to the efficacy of the think-aloud activity in producing useful data. The data was also strengthened by the combined use of the think-aloud activity with follow-up semi-structured interview questions.

This study generated limited data for answering question 2, this is likely a consequence of people being unlikely to comment on design aspects that they find acceptable. However, the fact that no participant reported any design elements as unacceptable suggested that they were found to be acceptable.

### **7.2.5.2 Conclusion**

The approach taken in the usability study was found to be an informative method for analysing peoples' perceptions of picture narrative information to use to improve the accessibility of the designs, while also maintaining scientific rigour. The approach taken was found not to be suitable for accessing the extent to which participants might have appreciated the design elements and aspects.

## **7.3 Design modification**

To apply the findings from the usability interviews to the test designs, I moved the summations and re-design ideas (that I had written for each design element during the analysis) onto the design pages and next to the corresponding section of the page. I then sketched ideas of ways to improve the designs based on the summations directly onto the design pages, using a digital drawing tablet (see Appendix 32 for example pages). Once the sketches were complete, I produced the final design pages (Appendix 33). These final design pages were then evaluated for acceptability and effectiveness in the study described in the next chapter.

## **Chapter 8. Outcome testing of the picture narrative LCS information designs: A randomised controlled trial**

### **8.1 Introduction**

This chapter describes a questionnaire study of Randomised Controlled Trial (RCT) design undertaken to evaluate the acceptability and effectiveness of the final picture narrative designs created through the previously described phases of the project (Study 5). The primary aim of the study was to determine if using picture narrative format to inform people about lung screening can increase LCS knowledge, improve self-identification of LCS eligibility and reduce barrier attitudes towards LCS. Another aim of the study was to determine whether picture narrative format impacted the equitability of the LCS information provision. A third aim was to explore whether participants' perceptions differ between the different formats of LCS information and whether these perceptions drive an association between information format and knowledge acquisition. In addition to these aims, the study assessed whether the picture narrative format would be deemed acceptable to the target population.

#### **8.1.1 Background and study aims**

As determined in Chapter 1, uptake of screening should be informed (i.e., participants have been involved in the decision to take part and their decision aligns with their values and circumstances) and equitable (i.e., screening benefits all eligible members of the population and does not contribute further to health disparities). To assess whether the picture narrative lung screening information could help towards the first goal of informed uptake, the main outcomes measured in this RCT were LCS knowledge acquisition, LCS eligibility self-assessment accuracy and LCS attitudes. These three outcomes are considered important elements of an informed decision (Ghanouni et al., 2016).

Question 1. Do the picture narrative LCS information designs produce improvement in LCS knowledge, correct self-identification of LCS eligibility and LCS attitudes compared to text with pictures format or text-only format?

To assess whether the picture narrative format could help towards equitable uptake, sociodemographic information about the participants was collected and used to investigate whether information format (the three trial conditions) had a different impact on the outcomes for different populations. This is important to assess because there are inequalities in cancer screening participation across socioeconomic groups (Douglas et al., 2016), including the UK Lung Screening trials (Ali et al., 2015). Additionally, a high proportion of people invited to lung screening will be living in areas of greater socioeconomic deprivation, because smoking and associated health conditions are more common (Hovanec et al., 2018). This puts an even greater importance on the intervention being effective for people living in these areas. Therefore, I was interested in whether the alternative picture narrative format was more supportive for people experiencing greater socioeconomic deprivation.

Question 2. Does the impact of the information format on knowledge acquisition differ across socioeconomic deprivation?

This study was also interested in determining if the picture narrative formats would be considered acceptable to people invited to LCS. It is important that health messages are well received in order to increase the audiences' engagement with, learning from, and making use of, the information (Greenwald, 1968). This will also allow for us to consider whether the picture narrative format is worth taking forward and potentially implementing in the future (Sekhon et al., 2017).

Question 3. Are the picture narrative LCS information designs considered acceptable within the target population?

If message format (i.e., pictorial and narrative) does have an impact on knowledge, it would be pertinent to investigate why – by looking into potential mechanisms involved. Recipients' perceptions of the following qualities of a message can impact communication outcomes; perceived attractiveness, enjoyment, interest, ease of use, personal relevance, trustworthiness, and appropriateness (Bull et al., 2001; McGuire, 1989). To be able to contribute to the theory of using picture narrative format in health communication, it will be worth investigating to what degree these factors are involved in any association between information format and knowledge acquisition in the current study.

Question 4. Can the impact of information format on knowledge acquisition be explained by perceptions towards the design?

## **8.2 Methods**

### **8.2.1 Trial design**

This was a parallel three-arm randomised control trial with allocation ratio 1:1:1, comparing the following conditions: LCS in picture narrative format (intervention condition), text with pictures format (control condition 1), and text without pictures format (control condition 2). The trial protocol was registered on ClinicalTrials.gov (NCT05016570) prior to the start date.

### **8.2.2 Recruitment**

For a flow diagram of the progression through the phases of the randomised trial across the two recruitment strategies, see Figure 8-1. Ethical approval was obtained from the University of Glasgow's MVLS ethics committee (ethics code: 200200021, 22/01/2021).

#### **8.2.2.1 Address data**

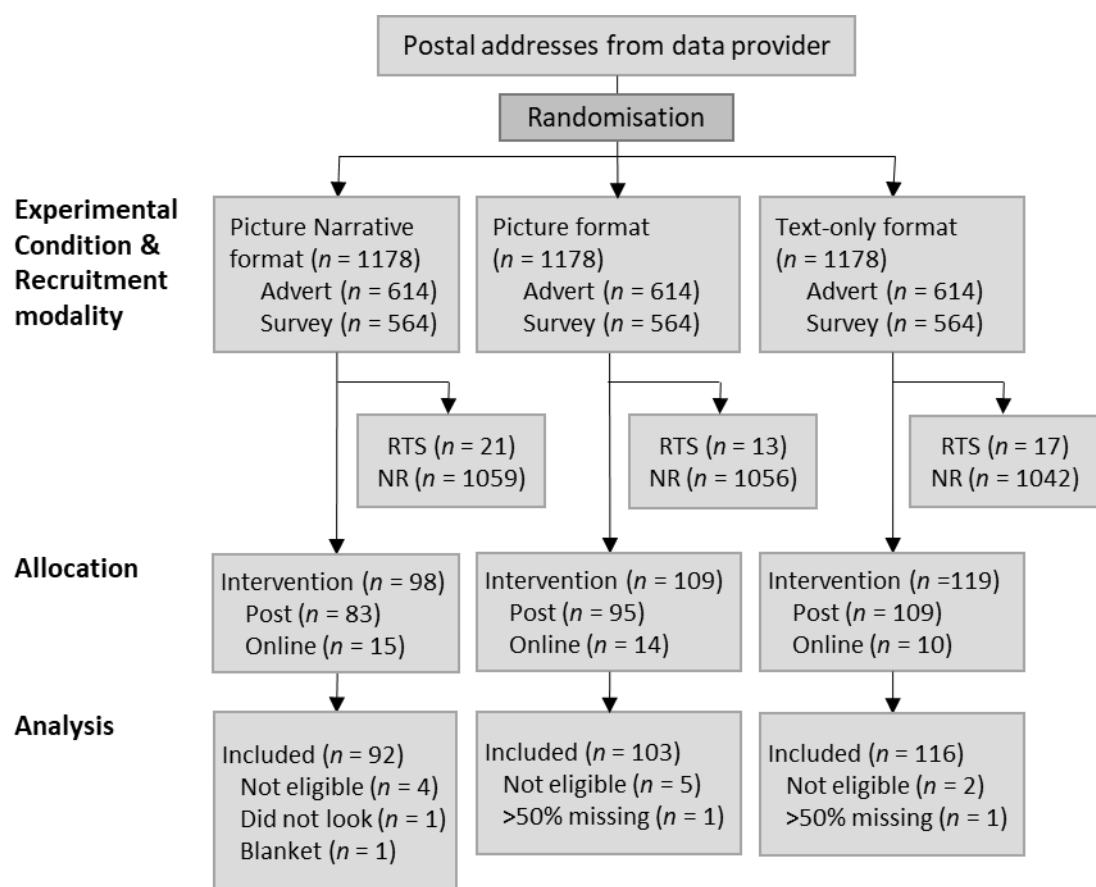
The postal addresses of 5,000 potentially eligible individuals were obtained from a GDPR-compliant data broker, Experian. The data request was for the names and postal addresses of anyone aged between 49 and 75 living in three postcode areas in Glasgow (G32, G3 and G11). These postcode areas were selected because, together, they met the desired weighting across postcode-based SIMD level: Quintile 1 = 37.5% (highest deprivation), Q2 = 24.5%, Q3 = 18.5%, Q4 = 11%, and Q5 = 8.5%. Areas with higher deprivation were over-sampled because response rates are often lower from people experiencing greater deprivation (Bonevski et al., 2014; McCaffery et al., 2002).

#### **8.2.2.2 Recruitment modality**

Potential participants, as identified by the data provider, were recruited to the study in one of two ways, they were either posted a recruitment flier ( $n = 1,692$ ; see Appendix 36) or posted an envelope containing a study invitation letter and the questionnaire pack ( $n = 1,842$ ; see Appendix 37 and 38). Individuals who received the recruitment flier had the option to either complete the questionnaire online by typing a website address (provided on the flier) into their browser or contact the primary researcher (by phone or email), to be

sent a print version of the questionnaire. Individuals who received the invitation letter and questionnaire pack also had the option to complete the questionnaire online (website address provided in the letter) or use a pre-printed free-post envelope provided to return the questionnaire by post. The website address each invitee received was for a copy of the online survey corresponding to the condition they had been randomised to and the SIMD quintile of their postcode (there were 15 versions in total, demonstrated in Table 8-1). The approach of using fliers was taken to supplement the direct recruitment method, as a resource saving alternative.

*Figure 8-1. Flow diagram of the progress through randomised trial phases*



**Reasons for exclusion**

**Advert** = sent invitation flier

**Survey** = sent invitation letter with full questionnaire pack

**RTS** = Returned to sender

**NR** = No response (i.e., the remaining invitees not accounted for)

**Not eligible** = did not meet participant eligibility criteria

**Post** = Completed by post

**Online** = Completed online

**Blanket** = Indiscriminate; all answers given were 1<sup>st</sup> response options

As an incentive to participate, all invitees were offered inclusion into a prize draw, if they returned a completed questionnaire, with the chance to win £250, two chances to win £100, and three chances to win £50.

*Table 8-1. Versions of the online questionnaire for identifying study condition and postcode level SIMD of the participants*

| Study condition   | Postcode-level SIMD quintiles |     |     |     |     |
|-------------------|-------------------------------|-----|-----|-----|-----|
|                   | 1st                           | 2nd | 3rd | 4th | 5th |
| Picture narrative | v1                            | v2  | v3  | v4  | v5  |
| Text and pictures | v6                            | v7  | v8  | v9  | v10 |
| Text-only         | v11                           | v12 | v13 | v14 | v15 |

### 8.2.2.3 Questionnaire development

The print version of the questionnaire was pilot tested with five members of the priority target population (between 50 and 75 years old and living in Glasgow in areas with SIMD in the 1<sup>st</sup> quintile) and one community development worker with experience of working with this population. Four people gave their feedback by post (due to Covid restrictions), one person completed the questionnaire with the researcher, and the community development worker gave feedback by email. Overall, the feedback was positive. A few modifications were made based on the feedback, including writing ‘would not’ as ‘wouldn’t’ and including ‘business owner’ in the employment options. The online version of the questionnaire was created based on the final version of the print questionnaire. The online version was then pilot tested by three individuals over 50 years old and an information technology professional. The feedback was positive. Several formatting issues were highlighted, which were then amended.

### 8.2.2.4 Questionnaire design

The questionnaire contained 35 questions regarding the participants’ perceptions of the LCS information designs, LCS knowledge, perceived LCS eligibility, LCS attitudes, time spent viewing the design, previous LCS awareness, health information literacy, demographic characteristics (including age, gender, ethnicity, smoking history, education, employment, vehicle ownership and home ownership), and feedback regarding the study procedure.

Participants who received the print questionnaire were sent an envelope containing a letter introducing the study, followed by a Participant Information Sheet and a Privacy Notice, a four-page A4 booklet (A3 folded) with the LCS information designs (in one of the three formats, described in Table 8-2) and the questionnaire in an 8-page booklet (see Appendices 37 and 38). The questionnaire begins with a set of statements outlining what the participants are consenting to by completing and returning the questionnaire. The questionnaire ends with information on how to take part in the prize draw, information on where to get advice and support regarding cancer, and further information on how to return the questionnaire. Each questionnaire had a version number printed on the bottom of the first page that indicated which study condition and which SIMD quintile the participant was in.

*Table 8-2. Intervention materials*

|              |                                                                                                                                                                                                                                                                                                                                                                              |
|--------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Intervention | Picture narrative format (Appendix 33)<br>Contained information on the following screening decision topics; what is screening, eligibility criteria, benefits and risks. Contained text and visuals integrated through narrative sequences. Designed and prototype tested with people aged between 50 and 75 living in areas of Glasgow with high socioeconomic deprivation. |
| Comparator 1 | Active control: Text with pictures format (Appendix 34)<br>Contained the same written information, in the same order, as is in the intervention. Contained pictures copied from the intervention materials that have been stripped of their narrative elements (for example, no speech bubbles and no longer in a narrative sequence).                                       |
| Comparator 2 | Active control: Text-only format (Appendix 35)<br>Contained the same written information, in the same order, as is in the intervention.                                                                                                                                                                                                                                      |

The first page of the online survey had a narrated video<sup>39</sup> covering the information in the Participant Information Sheet, a link to the Participant Information Sheet and Privacy Notice, and instructions on how to get more information, including contact details of the researchers and two screening questions. The first screener question asked how they found out about the questionnaire (sent a flier; sent a letter and the questionnaire). The second asked for the size of the screen they were viewing the questionnaire on (large, e.g.,

<sup>39</sup> This video can be accessed using this link: [https://youtu.be/7\\_Up9M-Bs6k](https://youtu.be/7_Up9M-Bs6k)

computer or laptop; medium, e.g., netbook or larger tablet; and small, e.g., phone or tablet). If they responded ‘medium’, an additional question box opened explaining that the questionnaire was best viewed on a large screen and to type ‘yes’ if they wished to continue. If they responded ‘small’, they were taken to a new page where it was explained that the questionnaire was not suitable to complete on a small screen and to type in their home address, if they wished to be sent a print copy. On the second main page of the questionnaire a list of the consent statements was provided, and participants were asked if they agreed or disagreed with these. Those who indicated they agreed were taken to the next page which contained the LCS information designs, one below the other. Those who indicated they did not agree were taken to a page thanking them for their interest. At the bottom of the page with the LCS information designs was a ‘next’ button which took participants to the questionnaire questions. At the end of the questionnaire, participants were given the option to be taken to a separate survey where they could leave their contact details, if they wished to be included in the prize draw.

#### **8.2.2.5 Participant Eligibility Criteria**

Individuals meeting the following criteria were included in the study. Individuals not meeting these criteria were excluded.

- Willing and able to give informed consent for participation in the trial.
- Aged between 50 and 75.
- Resident in Glasgow.

#### **8.2.2.6 Recruitment dates**

Data collection began in August 2021 and ended 6 weeks after the invitations had been sent. This was considered sufficient time for people to respond and, most questionnaires were received within the first two weeks of the invitation letters being sent.

### **8.2.3 Measures**

#### **8.2.3.1 Participant characteristics**

*Age, gender and ethnicity.* In the print version, the questions for these three characteristics used free-text response options (indicated by a line after the question). The gender and ethnicity questions included a few example responses written under the line. For example:

‘What is your ethnicity? \_\_\_\_\_

(for example, Scottish, British, Pakistani, African, Chinese)’<sup>40</sup>

Participants had the option to leave these questions unanswered. In the online version, the response option for these three questions was a scroll selection. There was a ‘My X is not listed’ option for each which opened a free-text response option. There was also a ‘prefer not to say’ option for each.

*Smoking status and history.* Participants were asked the following about smoking cigarettes: ‘Do you smoke or have you ever smoked cigarettes?’; ‘If yes,’ ‘At what age did you become a regular smoker?’; ‘How many cigarettes would you usually smoke a day?’; ‘Do you currently smoke or have you stopped smoking?’; ‘If you no longer smoke, how many years ago did you stop smoking?’. When participants gave a range in response to the questions ‘What age did you start smoking and how many cigarettes smoked a day’ (e.g., “31 to 34 years”) the highest amount was used, to overcome any tendency to understate or underestimate amount smoked.

*Formal education.* Participants were asked to indicate which qualifications they had completed (within five groups of qualifications grouped by similarity in formal education level) or indicate ‘Have not completed any formal education’. For the study analysis, participants’ highest formal educational attainment was grouped into three levels: None or low, Medium, and High. None or low included no formal education, apprenticeship, Highers, Ordinary Grade (O-Grade), General Certificate of Secondary Education (GCSE). Medium included vocational qualifications, Diploma, National Vocational Qualification (NVQ)1, NVQ2, Advanced Higher, Advanced Subsidiary level (AS level), Advance level (A level), and Certificate of Sixth Year Studies and NVQ3. High included Bachelor's degree, NVQ4, Masters and PhD.

*Employment status.* Participants were asked to indicate their current employment out of the following: ‘Retired’, ‘Unemployed’, ‘Part-time employed’, ‘Full-time employed’, ‘Self-employed’, ‘Business owner’, ‘On paid sick leave’, and ‘On un-paid sick leave’. They could also select ‘Something else’, with the option to write their response.

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<sup>40</sup> This format was used to save space and reduce participant burden. The examples given were based on the largest populations living in Glasgow

*Vehicle ownership.* Participants were asked if they owned none, one or more than one car or van.

*Home ownership.* Participants were asked to indicate their accommodation out of the following: ‘Own outright’, ‘Buying on mortgage’, ‘Rent from local authority’, ‘Rent from housing association’, ‘Rent from private landlord’, and ‘Do not own or rent’. They could also select ‘Something else’, with the option to write their response.

*Socioeconomic deprivation.* Formal education, employment status, vehicle ownership and home ownership were used to create a category for high socioeconomic deprivation. These indices have been used as a measure of socioeconomic position in previous research (Robb et al., 2009), with the addition of employment status. A score of 1 was given for each of the following indicators; not owning a home (‘Rent from local authority’, ‘Rent from housing association’ or ‘Do not own or rent’), not owning a vehicle (no car or van), no formal education (‘Apprenticeship’ without any other formal education indicated or ‘Have not completed one of these’), and unemployment (‘Unemployed’ or ‘unpaid sick leave’). Participants scoring 2 or more (i.e., having 2 or more indicators of socioeconomic deprivation) were coded as likely to be experiencing socioeconomic deprivation.

Participant’s neighbourhood-level socioeconomic deprivation was also collected based on Scottish Index of Multiple Deprivation (SIMD) quintile for the postcode they lived in (The Scottish Government, 2020). This SIMD quintile was indicated by the version number on the print questionnaire or by the version of the online questionnaire used. Within the sample, the score created for individual socioeconomic deprivation was highly correlated (Pearson’s  $r = -0.481$ ,  $p \leq .001$ ,  $N = 302$ ), with higher scores correlated with lower SIMD quintiles (more deprivation neighbourhoods), showing the score to be a valid measure.

*Health information proficiency.* Participants were asked ‘Do you ever find it difficult to read or understand health and medical information?’ with the response options ‘Yes, often’, ‘Yes, sometimes’ and ‘No, never’. This item was used to measure an aspect of health literacy, with the intention to determine whether the picture narrative information was more supportive than other formats, specifically for people with low health literacy, who would usually struggle with these forms of health information. People who said they often found health information difficult were more likely to spend more than ten minutes reading the designs ( $n = 14/26$ ), while those who said they only sometimes or never found

health information difficult were more likely to read the designs for between 2 and 10 minutes ( $n = 106/164$  &  $73/118$ ;  $\chi^2 = 14.81$ ,  $df = 4$ ,  $p = .005$ ,  $n = 308$ ), suggesting validity in the measure.

### 8.2.3.2 Covariates

*Previous LCS awareness.* Participants were asked ‘How much did you know about cancer screening tests before doing this questionnaire?’ and ‘How much did you know about lung cancer before doing this questionnaire?’ with the response options ‘Nothing’, ‘A little’, and ‘A lot’. Responses were scored from zero (‘Nothing’) to two (‘a lot’) and combined as a sum to create a single previous awareness score.

*Fidelity.* The following item was used to record whether participants viewed the information designs: ‘How much time did you spend looking at the design?’ with the response options ‘Did not look at the pages’, ‘Less than 2 minutes’, ‘Between 2 to 10 mins’ and ‘More than 10 mins’.

### 8.2.3.3 Primary outcomes

*Knowledge.* LCS knowledge was measured using a true/false type measure with six questions (see Table 8-3), with one question related to each of the following topics: Procedure, Eligibility – who, Eligibility – why, Benefits, Adverse effects, and Potential results. The design of this measure was based on previously tested screening knowledge measures (Kregting et al., 2020 – breast cancer; Michie et al., 2002 – prenatal; S. K. Smith et al., 2012 – colorectal cancer). Participants were asked to indicate whether they believed each item to be true (with a tick) or false (with a cross). The correct answer items ( $n = 19$ ) all mapped onto information contained in the designs. The incorrect answer items were either reversals of the correct information or misconceptions about LCS identified in previous research ( $n = 10$ ). A ‘do not know’ option was not included due to concern that an additional option box overcomplicated the questionnaire design. For assessment of overall knowledge, a knowledge score was calculated based on the number of true items marked as true (scale 0 to 19). The alpha coefficient of reliability was 0.74, indicating acceptable internal reliability.

Table 8-3. Knowledge measure items

| LCS topic            | Questions                                                                                  | Answers                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|----------------------|--------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Procedure            | What happens during a lung screening CT scan?                                              | <ul style="list-style-type: none"> <li>- you remain standing</li> <li>- you lie down during*</li> <li>- you have to undress your upper body</li> <li>- you go into a scanner that is shaped like a hoop*</li> </ul>                                                                                                                                                                                                                                                    |
| Eligibility<br>- who | Who would most likely benefit from lung screening?                                         | <ul style="list-style-type: none"> <li>- People of all ages</li> <li>- Younger people (under 50 years old)</li> <li>- Older people (over 50 years old)*</li> <li>- People who smoke any amount</li> <li>- People who smoke heavily*</li> </ul>                                                                                                                                                                                                                         |
| Eligibility<br>– why | What are the reasons for inviting one group of people to lung screening and not everybody? | <ul style="list-style-type: none"> <li>- If people have more chance of being harmed by the process than benefiting, they are not invited*</li> <li>- If people are unable to have treatment due to other health conditions, they are not invited*</li> <li>- It would be too expensive to screen everyone</li> <li>- People are only invited if they are more likely to have lung cancer*</li> <li>- Not everyone is likely to benefit from lung screening*</li> </ul> |
| Benefits             | What reasons are there for doing lung screening?                                           | <ul style="list-style-type: none"> <li>- It's the best way of finding lung cancer early*</li> <li>- It can reduce people's chance of dying from lung cancer*</li> <li>- It can reduce people's chance of dying from causes other than lung cancer*</li> <li>- It can stop people from getting cancer</li> <li>- It can tell you how much you'll benefit from stopping smoking</li> </ul>                                                                               |
| Adverse effects      | What are the harms and potential harms that come with lung screening?                      | <ul style="list-style-type: none"> <li>- A lot of radiation</li> <li>- A small amount of radiation*</li> <li>- Stress or worry*</li> <li>- Being sent for diagnostic tests but not actually having cancer*</li> <li>- Being treated for a cancer that would have not caused any harm in your lifetime*</li> </ul>                                                                                                                                                      |
| Potential results    | What are the different results you might get back if you went for lung screening?          | <ul style="list-style-type: none"> <li>- You do not have cancer</li> <li>- Scan found no problems*</li> <li>- Scan found signs that might be lung cancer*</li> <li>- Scan found signs of something that might become lung cancer in the future*</li> <li>- Scan found signs of a condition that is not lung cancer*</li> </ul>                                                                                                                                         |

Note. \* indicates the true answer items.

*Eligibility self-assessment accuracy.*<sup>41</sup> This measure was used to determine whether participants could accurately identify their own eligibility for LCS in relation to the eligibility criteria described in the designs. Participants were asked ‘If lung screening became available in your neighbourhood, would you be one of the people invited?’ with the response options ‘yes’, ‘no’ or ‘not sure’.

The age and smoking history data also collected by the questionnaire were used to determine each participant’s ‘actual’ eligibility for screening (between 50 and 75 years old, smoked average of 10 or more cigarettes over 20 years, and quit no longer than 15 years ago). Self-reported eligibility and actual eligibility were then compared to create two groups: 1) correct interpretation (where calculated eligibility and self-reported eligibility match), or 2) incorrect interpretation (where calculated eligibility and self-reported eligibility do not match) and ‘not sure’.

*Attitudes.* Participants’ attitudes towards LCS was assessed using the following four items previously used by Smits et al. (2018): ‘I wouldn’t want to know if I had lung cancer’ (Fear), ‘I don’t think there is any point going for LCS because it won’t affect the outcome’ (Fatalism), ‘If lung cancer is found early, there’s a better chance of successful treatment and survival’ (Benefits), and ‘I would be so worried about what might be found by the screening that I would prefer not to go’ (Worry). The wording of the item for LCS benefits had been adapted from ‘If lung cancer is diagnosed early, it is more likely to be treatable’ based on stakeholder feedback. Response options for these items were ‘Strongly agree’, ‘Agree’, ‘Disagree’, ‘Strongly disagree’ and ‘Not sure’. During analysis, all items were grouped as either negative (strongly agree and agree) or positive (strongly disagree and disagree), with the Benefits item reverse scored. Responses were grouped in this way because the study was interested in whether design format has an impact on the direction of lung screening-relevant attitudes rather than strength of these attitudes and a four-point Likert scale is too granular to make an assessment about scale differences, with the relation between the categories being unknown. ‘Not sure’ responses were treated as missing values during analysis.

#### **8.2.3.4 Secondary outcomes**

*Design appeal.* ‘Appeal’ was used as a measure of how acceptable and engaging the designs were for participants. An item for each of the following nine characteristics was

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<sup>41</sup> To my knowledge, this is a novel approach to assessing a key aspect of informed LCS participation.

used to assess appeal: looked good, enjoyable to read, interesting, easy to understand, relevant to the participant, trustworthy, appropriate for the topic, helpful for someone deciding about having lung screening, and good at explaining LCS. These characteristics were chosen due to their known impact on message reception (Greenwald, 1968). Response options for each item were a four-point Likert scale uniquely worded to the characteristic being assessed; 'Really [characteristic]', 'Somewhat [characteristic]', 'Not [characteristic]', and 'Really not [characteristic]/Not at all [characteristic]'. A midpoint was not used based on guidance from Chyung et al. (2017). There was also a 'Not sure' option. 'Not sure' responses were treated as missing values. The ratings for each of the 9 items were scored from 0 ('Really not [characteristic]') to 3 (Really [characteristic]) and summed to create an overall appeal score (scale from 27). Internally, consistency/reliability for the scale was acceptable (Cronbach's  $\alpha = .753$ ).

*Amount of information.* One item measured whether participants felt the information designs provided enough information with response options being 'Yes', 'No, not enough', 'No, too much' and 'Not sure'. 'Not sure' responses were treated as missing.

#### **8.2.4 Sample Size**

A priori power calculations were conducted using the statistical package G\*power (Faul et al., 2009) to determine sample size. The Cohen's  $d$  effect size of 0.1266 was found by Smith et al (2015) for bowel cancer screening knowledge scores between two conditions similar to those in the present study; 1) received a colorectal cancer screening information brochure, and 2) received the same information brochure plus gist information. To detect an effect size of 0.1266 (small) as significant at a level of 1.6% (selected based on Bonferroni correction;  $0.05/3 = 0.016$ ), for an analysis of variance test with 3 groups of equal size, a sample size of 795 is needed to confer 80% power.

Based on empirical simulations, Fritz and MacKinnon (2007) calculated that a mediation analysis using Baron and Kenny's Causal-Stepped approach would need a sample size of 562 to provide 80% power to detect a large partial mediation ( $\tau' = 0.14$ ) when the effect sizes for the paths between the condition (X) and the mediator (M; path  $\alpha$ ), and between the mediator (M) and the outcome (Y; path  $\beta$ ), are both small (Cohen's  $f$  of 0.14, equivalent to 2% variance).

Based on these calculations, the target sample size to recruit was 795 (265 per group).

## 8.2.5 Randomisation

### 8.2.5.1 Sequence generation

In the first round of recruitment, 3,384 of the postal addresses were randomised into recruitment modality and study condition (2 x 3 groups), and stratified for postcode-based SIMD. Excel's Rand() function was used to generate a random number in a new column next to every postal address. The table sort function was then used to sort the newly created column, followed by the column containing SIMD quintile ranks for each address, into ascending order. The addresses were then batched into the six groups for each SIMD quintile, with batch sizes differing for each quintile in accordance with the previously used weighting: Q1  $n = 424$ , Q2  $n = 276$ , Q3  $n = 208$ , Q4  $n = 124$ , and Q5  $n = 96$ .

Many less people requested a print questionnaire than prepared for, resulting in 150 printed unused questionnaire packs. Therefore, a second round of recruitment was done three weeks after the start of data collect using these questionnaire packs. The randomisation method used was the same, this time only randomising into study condition (3 groups), with the following weighting across SIMD quintile for each condition: Q1  $n = 19$ , Q2  $n = 12$ , Q3  $n = 9$ , Q4  $n = 6$ , and Q5  $n = 4$ .

### 8.2.5.2 Blinding

The trial was unblinded, as participant were intended to view the intervention (the LCS designs). However, the participants were unaware of the different trial conditions or what the intervention was. Also, the intervention and data collection were self-administered. Therefore, the researcher's knowledge of the participants' allocation could not bias the results.

## 8.2.6 Statistical methods

### 8.2.6.1 Missing data

Data were complete for age, and gender. The following cases were missing by characteristic; ethnicity ( $n = 2$ ), formal education ( $n = 5$ ), home ownership ( $n = 3$ ), vehicle ownership ( $n = 2$ ), employment ( $n = 1$ ), LCS eligibility ( $n = 6$ ), and socioeconomic deprivation ( $n = 3$ ). Only two participants were missing health information proficiency data and four were missing prior awareness scores.

*LCS Knowledge.* A large portion of knowledge scores were missing, 33.8% (105/311). Many participants completed the knowledge questions incorrectly (24.8%), only ticking answers they thought were correct and not crossing any they thought were false. The number of missing knowledge scores did not differ across condition ( $p = .212$ ), age ( $p = .568$ ), gender ( $p = .976$ ), screening eligibility ( $p = .086$ ) or previous awareness ( $p = .468$ ). Missing knowledge scores did differ across highest formal education ( $\chi^2 = 12.53$ ,  $df = 2$ ,  $p = .002$ ,  $N = 306$ ), with more participants in the no or low education group missing the most data (40.9%), and participants in the high education group missing the least data (17.2 %). Missing knowledge scores differed across socioeconomic deprivation ( $\chi^2 = 18.97$ ,  $df = 1$ ,  $p < .001$ ,  $N = 308$ ), with missing data being more likely in the group with 2 or more indicators of deprivation (51.6% vs 26.0%). Therefore, assessment of knowledge across formal education and socioeconomic deprivation should be made with caution.

A second LCS knowledge score was created that only included the knowledge items that were ‘true’, and all missing responses were coded as ‘incorrect or unknown’, unless 1 or more whole questions were missing data, in which case the score was coded ‘missing’. This resulted in 30 missing cases (9.6%). However, the data had a double-peaked (bimodal) distribution that was not present previously, suggesting that much of the newly included data was collecting around a lower score. This is likely due to participants often only ticking 1 response per question as well as not marking the false responses, which would produce a lower total score.

To reduce potential bias due to excluding missing ‘false’ responses, a score based on only the true items in the measure was used (scale from 0 to 19) instead. This still left 31.5% (98/311) missing data.

*LCS Eligibility self-assessment accuracy.* Missing 15.4% (48/311). Chi test found the missing data for eligibility self-assessment accuracy not to significantly differ across condition ( $p = .235$ ), gender ( $p = .655$ ), SIMD ( $p = .998$ ), socioeconomic deprivation ( $p = .097$ ), health information proficiency ( $p = .394$ ) or prior awareness (high vs not;  $p = .816$ ). Therefore, the data could be assumed to be missing at random.

*LCS Attitudes.* The following amounts of data were missing across the four attitude items: ‘Wouldn’t want to know’ had 9.6% missing. This did not significantly differ across condition, gender, SIMD, socioeconomic status, or prior awareness. ‘Won’t affect the

outcome' had 8.0% missing. This did not significantly differ across condition, gender or prior awareness, but was significantly different for socioeconomic status ( $\chi^2 = 11.47$ ,  $df = 1$ ,  $p = .001$ ,  $N = 308$ ) with more missing data in the high socioeconomic deprivation group (16.1% vs 4.7%). 'Better chance of successful treatment' had 6.4% missing. This did not significantly differ across condition, gender, prior awareness, but was different for socioeconomic status ( $\chi^2 = 6.24$ ,  $df = 1$ ,  $p = .012$ ,  $N = 308$ ) with more missing data in the high socioeconomic deprivation group (11.8% vs 4.2%). 'Would prefer not to go' had 6.4% missing. This did not significantly differ across condition, gender, SIMD or prior awareness, but was significantly different for socioeconomic status ( $\chi^2 = 8.91$ ,  $df=1$ ,  $p = .003$ ,  $N = 308$ ). There were too few cases across groups for SIMD, eligibility accuracy and health information proficiency to be evaluated.

*Design Appeal.* The item with the most missing data was for 'relevance' at 5.5%, followed by 'trustworthiness' and 'good at explaining', both at 4.8%. The design appeal score had 17.7% (55/311) missing data. Chi-square tests found the missing data for eligibility self-assessment accuracy not to significantly differ across condition ( $p = .236$ ), gender ( $p = .525$ ), SIMD ( $p = .510$ ), socioeconomic deprivation ( $p = .277$ ), LCS eligibility ( $p = .164$ ) or health information proficiency ( $p = .343$ ). The missing data did differ across prior awareness, with people with high prior awareness having fewer missing data (7.8%) than people without (18.1%;  $\chi^2 = 4.0$ ,  $df = 1$ ,  $p = .045$ ,  $N = 307$ ). The data was assumed to be missing at random for all analyses not involving previous awareness.

### 8.2.6.2 Parametric assumption testing

*Previous awareness score.* The scores for previous awareness were not normally distributed ( $W(307) = 0.87$ ,  $p < .001$ ) due to being leptokurtic (0.13), with the majority of participants scoring 2 (166/307 = 54.1%). Therefore, previous awareness was separated into those scoring highly (scores of 3 and 4) and those not scoring highly (scores 0 to 2).

*Health information proficiency.* Only 26 (8.4%) participants reported 'often' finding health information difficult to read. Therefore, health information proficiency was dropped from all subsequent analyses.

*LCS Knowledge.* The Shapiro-Wilk normality tests found the knowledge score not to be normally distributed ( $W(210) = 0.96$ ,  $p < .001$ ), with skewness of -0.29 (minimally skewed towards higher scores) and kurtosis of -0.64 (flatter than the normal distribution). Levene's

test of equality of variance found there was homogeneity of variance based on the Means ( $F(2, 207) = 1.27, p = .283$ ). The picture condition had two outliers more than 2 standard deviations from the mean (scores of 5 and 7) and the text-only condition had one (score of 8). These were entered as missing during analysis.

*Design appeal.* The original study protocol outlined that a score for positive appeal would be created from a sum of the number of positive ratings (combining ‘somewhat x’ and ‘really/very x’) given by a participant (score 0 to 9). The Shapiro-Wilk test of normality found this positive appeal score to not be normally distributed ( $W(262) = 0.42, p < .001$ ). Skewness was -5.05 which is very skewed towards the higher scores. Kurtosis was 40.80 which is very leptokurtic. Therefore, an alternative method of calculating an overall knowledge score was used where very negative = 0, negative = 1, positive = 2, and very positive = 3. One outlier was removed (score = 9) due to being almost two standard deviations ( $2.66 \times 2$ ) away from the next score (14). The scores were still not normally distributed, but were much less skewed (-0.80) and kurtosis was closer to normal (0.14), making the data suitable for Kruskal-Wallis test. Levene’s test found variance to be homogenous ( $F(2, 258) = 0.54, p = .582$ ).

### **8.2.6.3 Primary outcomes**

One-way analysis of variance (ANOVA) is robust against violations in the assumption of normativity, so was used to test the impact of condition on LCS knowledge score and design appeal. These were followed up with Kruskal-Wallis tests (non-parametric equivalent to ANOVA) to avoid type II error. Multiple comparisons were performed with Bonferroni’s adjustment. The impact of condition on LCS eligibility self-assessment accuracy and LCS attitudes were assessed with chi-square test of independence. Near significant tests were followed up with comparisons across the conditions by assessment of the Pearson’s adjusted residuals and their p-values (Bonferroni method).

Exploratory analyses were conducted on individual knowledge items and individual appeal items using the chi-square test of independence. To control for family-wise error rate, the p-values considered significant for each statistical test was based on Bonferroni correction ( $0.05/\text{number of outcome variables}$ ). Pairwise deletion of cases was used during the analyses where values were missing.

#### **8.2.6.4 Mediation analyses**

A mediation analyses following Baron and Kenny's (1986) stepped approach with linear regressions was planned, using the PROCESS macro, to test mediation of knowledge through appeal, with previous awareness as a covariate and gender as moderator on the b path, with 5000 bootstrap samples. However, the sample size of 562 necessary for the test to be appropriately powered was not met, and so the test was not carried out.

#### **8.2.6.5 Moderation analyses**

Moderation analyses was conducted using Hayes' (2013) PROCESS macro version 4.0 to test whether study conditions moderated the effect of gender or socioeconomic deprivation on knowledge while controlling for previous awareness.

#### **8.2.6.6 Sub-group analyses**

Subgroup analysis was used to test if several factors of interest (age; gender; ethnicity; smoking status; formal education; and socioeconomic deprivation) moderated the effect of treatment on the outcome measures, to examine heterogeneity of treatment effect (i.e., equitability of the intervention) across these groups, by running the primary analyses with data split for each moderator.

### **8.3 Results**

#### **8.3.1 Final sample**

A total of 311 questionnaires were returned completed and eligible for inclusion in the study. There were 51 questionnaires and fliers returned undelivered (labelled as Return To Sender: RTS). Of the questionnaires returned, 15 (4.0%) were excluded from the study sample due to either not meeting the eligibility criteria (incorrect age,  $n = 5$ ; not living in Glasgow,  $n = 6$ ; did not read the materials,  $n = 1$ ) or not being completed correctly (missing more than 50%,  $n = 2$ ; first response given for all items,  $n = 1$ ). No invitees responded saying they did not want to take part.

The advertisement flier achieved a response of 2.9% (49/1692) and the invitation letter with questionnaire pack achieved a response of 15.0% (277/1842). Table 8-4 presents the responses across the study conditions. Completion rate (i.e., eligible responses out of those delivered and excluding RTS) was 8.8% (311/3157), with 2.7% (46/1686) for invitation by

flier and 14.7% (265/1797) for invitation by letter. Response rates did not differ significantly across study condition ( $p = .233$ ), but did differ across SIMD quintile ( $p < .001$ ) and gender ( $p = .020$ ). These differences are investigated further in the following section.

#### **8.3.1.1 Factors influencing response (for invitation by letter)**

I have considered the response rates out of those assumed to have been successfully delivered, as I was interested in whether seeing the different design formats (three study conditions) influenced willingness to take part (response) as a proxy of engagement with the designs. Therefore, RTS and ineligible responses (e.g., incorrect age, and not living in Glasgow) were excluded. Study condition did not impact on response rate for posted questionnaires ( $p = .069$ ). Invitees in the 1<sup>st</sup> SIMD quintile (most deprived) were significantly less likely to respond (10.8%, Standardized Pearson Residual  $z = -3.81$ ,  $p < .001$ ), while invitees in the 3<sup>rd</sup> SIMD quintile (middle group) were significantly more likely to respond (20.7%, Standardized Pearson Residual  $z = -3.23$ ,  $p = .001$ ) than the other groups (see Table 8-5). Gender was also associated with response rate, with women being more likely to respond than men (17.1% vs 12.3%;  $\chi^2(1, 1776) = 8.18$ ,  $p = .004$ ).

#### **8.3.1.2 Response modality**

More people completed the questionnaire by post ( $n = 274$ ) than online ( $n = 37$ ). More people sent fliers responded online (31/1692 = 1.8%) than people sent the invitation letter and questionnaire pack (6/1842 = 0.3%). People with less than 2 socioeconomic deprivation indicators were significantly more likely to complete the questionnaire online (15.8% vs 3.2%;  $\chi^2 = 9.73$ ,  $df = 2$ ,  $p = .002$ ,  $N = 308$ ) and people with a high level of formal education were significantly more likely to complete the questionnaire online (29.3%) compared to people with medium (10.4%) or none to low formal education (7.0%;  $\chi^2 = 20.53$ ,  $df = 2$ ,  $p < .001$ ,  $N = 306$ ).

#### **8.3.1.3 Partial completion rate**

There were three main ways the included questionnaires were partially completed; whole pages missed out (likely accidentally missed by participants;  $n = 12$ ), eligibility self-assessment question missed out ( $n = 27$ ) and 'Falses' not marked on knowledge questions ( $n = 74$ ). A total of 125 of the included questionnaires had one or more of these. These types of partial responses did not significantly differ across gender or screening eligibility.

People with no or minimal formal education and people with more than 2 indicators of socioeconomic deprivation were significantly more likely to complete the knowledge questions on the print questionnaire incorrectly, with 32.2% in the no and low education group ( $\chi^2 = 14.90$ ,  $df = 2$ ,  $p = .001$ ,  $N = 269$ ) and 40.0% in 2 or more indicators group ( $\chi^2 = 11.68$ ,  $df = 1$ ,  $p = .001$ ,  $N = 271$ ).

#### **8.3.1.4 Prize draw participation**

Of the people who returned a print questionnaire, 94 requested to be included in the prize draw (8 by call, 16 by email, 64 by text, and 6 written on the questionnaire<sup>42</sup>). The prize draw code provided by six of these respondents did not correspond to a returned questionnaire and were therefore excluded. Of the people who completed the postal questionnaire, 82 (29.9%) were included in the prize draw. Of the people who completed the online questionnaire, 25 (64.1%) were included in the prize draw. People in the low socioeconomic group were less likely to request to be included in the prize draw (24.7%) than people in the high socioeconomic group (36.3%;  $\chi^2 = 3.23$ ,  $df = 1$ ,  $p = .047$ ,  $N = 308$ ).

*Cost analysis.* In total, 311 participants were recruited and £7,401.61 was spent (not including worked hours). This is equivalent to £23.80 per eligible participant recruited. Considering only the recruitment strategy of sending invitation letter accompanied by questionnaire pack (with prize draw still at £600); the cost was £21.89 per each eligible participant recruited.

#### **8.3.1.5 Participant characteristics**

Table 8-6 shows the demographic characteristics of the participants across the study conditions and Table 8-7 shows participants smoking status and LCS eligibility across the conditions. No characteristic was found to be associated with study condition, demonstrating that recruitment was suitably randomised. Most participants indicated that they were British (99.5%, including Scottish,  $n = 249$ ; English,  $n = 2$ ; Welsh,  $n = 1$ ). The other ethnicities given were African ( $n = 2$ ), Chinese ( $n = 2$ ), Italian ( $n = 2$ ), Irish ( $n = 1$ ) and Sri Lankan ( $n = 1$ ).

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<sup>42</sup> Even though the questionnaire instructions said to text, call or email, for data protections reasons.

### 8.3.1.6 Confounding variables

Table 8-8 reports the confounding variables across study conditions, which includes questionnaire modality, time spent reading, health information proficiency, and previous awareness of lung cancer and of cancer screening.

## 8.3.2 Outcomes

### 8.3.2.1 LCS Knowledge

*Overall score (scale from 0 to 19).* Nearly all participants answered more than 50% of the items correctly (50% being no better than random), with only five scoring below 50%. Table 8-9 reports knowledge scores across the study conditions. One-way ANOVA found the knowledge scores differed across condition ( $F = 3.24$ ,  $df = 2$ ,  $p = .041$ ,  $N = 209$ ). Post hoc tests showed people were more likely to have a lower knowledge score in the picture narrative condition ( $M = 14.7$ ,  $sd = 2.11$ ) than the picture condition ( $M = 15.62$ ,  $sd = 1.92$ ), after adjusting for multiple tests with the Bonferroni correction ( $p = .041$ ). The nonparametric equivalent follow-up Kruskal-Wallis test affirmed this finding ( $H(2, 210) = 6.87$ ,  $p = .032$ ), with post hoc tests showing people were more likely to have a lower knowledge score in the picture narrative condition (median = 14.5) than the picture condition (median = 16.0), after adjusting for multiple tests with the Bonferroni correction ( $p = .012$ ).

Picture narrative condition was also worse than text-only condition, but this only just met significance ( $p = .057$ ).

*Individual items.* The item ‘It’s the best way of finding lung cancer early’ had a very small number of missing data ( $n = 9$ ) compared to the other items (ranging from 31 to 76). Only two items differed significantly in whether they were answered correctly across the study conditions. People in the text-only condition were more likely to incorrectly mark ‘You have to undress your upper body’ as true (33.7%,  $z = 3.24$ ,  $p = .001$ ), while people in the picture condition were more likely to answer this item correctly (87.5%,  $z = 2.55$ ,  $p = .011$ ;  $\chi^2 = 11.56$ ,  $df = 2$ ,  $p = .003$ ,  $N = 247$ ). People in the picture narrative condition were more likely to incorrectly mark ‘Scan found signs of a condition that is not lung cancer’ as false (23.5%,  $z = 4.51$ ,  $p < .001$ ), while people in the picture condition were more likely to answer this item correctly (96.6%,  $z = 2.65$ ,  $p = .008$ ;  $\chi^2 = 20.73$ ,  $df = 2$ ,  $p < .001$ ,  $N = 264$ ).

### 8.3.2.2 LCS Eligibility self-assessment accuracy

Only 32.8% of participants gave a correct assessment of their LCS eligibility (as described in the intervention), with 79.7% of eligible respondents correctly identifying themselves as so and 18.4% of ineligible respondents correctly identifying themselves as so. Eligibility assessment accuracy did not significantly differ across the study conditions ( $\chi^2(2, 264) = 4.82, p = .090$ ; see Table 8-10), although post hoc testing suggested more people in the picture narrative condition were more likely to give an incorrect assessment of their eligibility (76.9%,  $z = 2.13, p = .033$ ).

### 8.3.2.3 LCS Attitudes

Over 50% of participants responded strongly positive to each of the LCS attitude items. Less than 10% of participants responded negative or strongly negative to the unbeneficial, beneficial and worry items, while 26.3% of participants responded negatively to the fear item.

Participants did not differ in their responses to ‘I wouldn’t want to know if I had cancer’ ( $\chi^2 = 1.53, df = 2, p = .466, N = 277$ ) or ‘I would be so worried about what might be found by the screening that I would prefer not to go’ ( $\chi^2 = 0.04, df = 2, p = .980, N = 275$ ) across the study conditions. Responses to the other two attitude items were underpowered due to receiving too few negative responses.

### 8.3.2.4 Design appeal

*Overall score (scale from 0 to 27).* The majority of participants (73.6%) had a score of 23 or above, suggesting high levels of perceived appeal. Table 8-9 reports the appeal scores across the study conditions. Study condition did not have a significant association with appeal ( $W(2, 261) = 0.94, p = .626$ ).

*Individual items.* Most participants in the picture narrative condition reported the pages looked really good (64.0%), somewhat enjoyable (59.1%), really interesting (63.7%), very easy to understand (57.3%), somewhat relevant (56.5%), very trustworthy (74.2%), very appropriate (64.8%), very helpful (81.2%), and very good at explaining (79.3%)

Participants in the picture narrative condition were more likely to give a positive rating for ‘relevant to you’ (94.1%,  $z = 3.01, p = .003$ ) compared to the other conditions ( $\chi^2 = 9.41, df$

= 2,  $N = 298$ ,  $p = .009$ ). The other ratings did not significantly differ from the other conditions. It is important to note that all of the appeal items, except ‘enjoyed reading’ and ‘relevant to you’, were underpowered due to the predominantly positive responses.

#### **8.3.2.5 Amount of information**

Most participants in the picture narrative condition reported the pages provided enough information (93.2%).

#### **8.3.2.6 Mediation analyses**

There was no significant effect of appeal on knowledge and the sample size was too small to have adequate power. Therefore, mediation analyses were not run.

#### **8.3.2.7 Moderation analyses**

A model of the effect of gender on knowledge, with condition as moderator and controlling for previous awareness, was not significant ( $p = .069$ ). A model of the effect of socioeconomic deprivation on knowledge with condition as moderator and controlling for previous awareness was significant ( $p < .001$ ) and explained 12.27% of the variance in knowledge scores. The interaction effect between socioeconomic deprivation and condition was significant ( $F(2, 197) = 3.80$ ,  $p = .027$ ). Receiving the lung screening information in a format with text accompanied by pictures (picture condition) produced the smallest disparity in knowledge score across the two socioeconomic deprivation groups (fewer than 2 indicators; 2 or more indicators), while receiving a format that included only text (text-only condition) produced the greatest disparity (see Figure 8-2). The conditional effect of socioeconomic deprivation on knowledge was not significant for picture condition ( $t = -0.79$ ,  $p = .433$ ) or picture narrative condition ( $t = -1.92$ ,  $p = .057$ ), but was significantly different for the text-only condition ( $t = -4.82$ ,  $p < .001$ ).

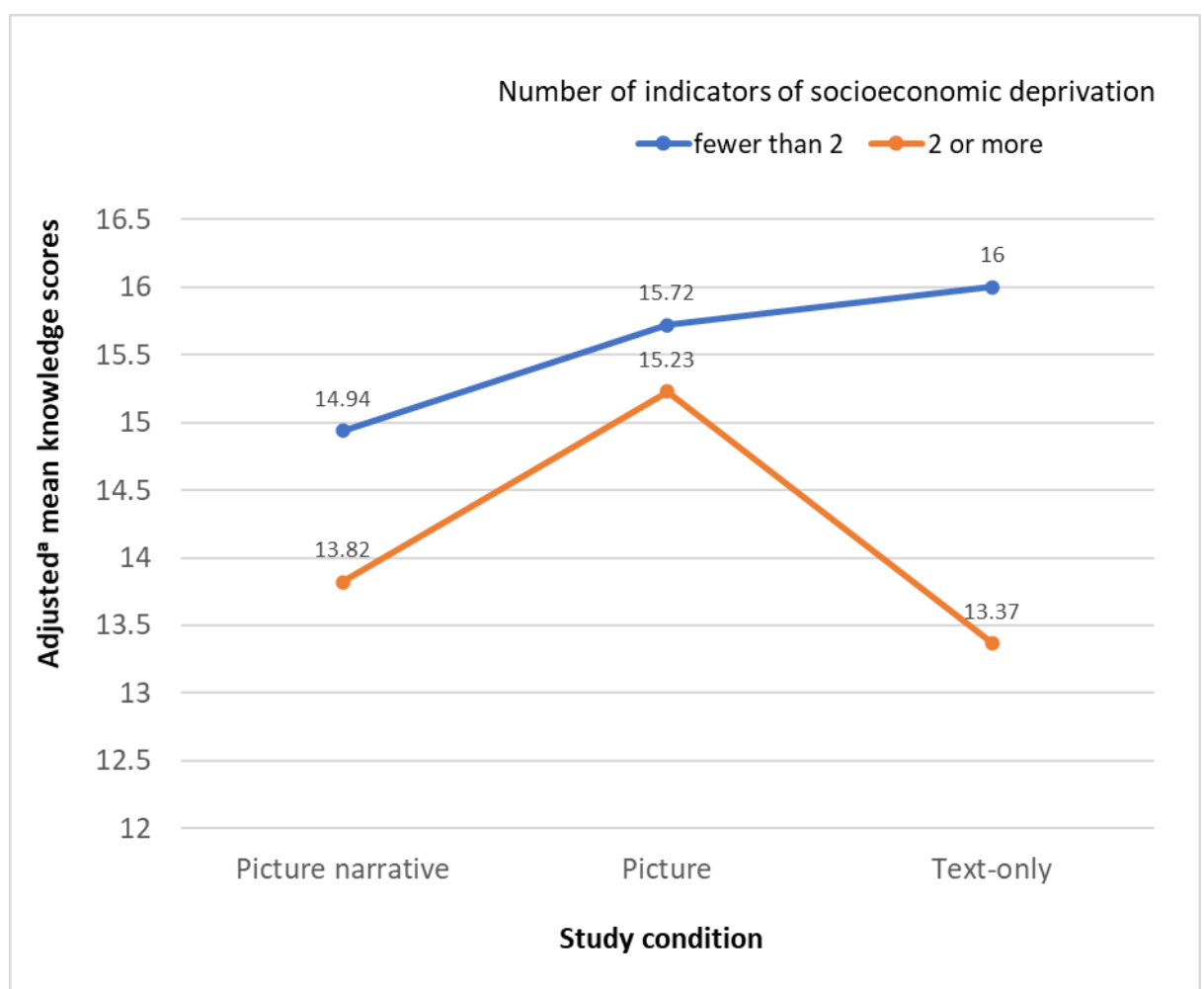
#### **8.3.2.8 Subgroup analyses**

During subgroup analyses, the directions of the results for condition on knowledge score were found to remain the same (i.e., not significant) for ages 58 to 62, ages 63 to 68 (test remained significant,  $p = .031$ ), men, women (remained significant,  $p = .052$ ), people with fewer than 2 indicators of deprivation (remained significant,  $p = .019$ ), people with 2 or more indicators of deprivation, never smokers, eligible for LCS (remained significant,  $p$

= .006), and no or low formal education (remained significant,  $p = .017$ ), medium formal education.

Direction of findings for knowledge scores changed for ages 51 to 57 (picture condition worse), ages 69 to 75 (text condition similar to picture narrative), not eligible for LCS (text condition similar to picture narrative) and high formal education (text condition better), although none of these comparisons were statistically significant.

Figure 8-2. Interaction between socioeconomic deprivation and condition on knowledge score



Note. <sup>a</sup> Adjusted based on inclusion in moderation model with previous awareness as covariate

Findings for eligibility self-assessment accuracy and design appeal score remained non-significant when split by age quintile (1<sup>st</sup> and 4<sup>th</sup> quintile underpowered), gender, socioeconomic deprivation, having ever smoked and eligibility for LCS (eligible group underpowered). Participants with no or low formal education were significantly less likely to correctly identify their LCS eligibility if they were in the picture narrative condition (17.9%,  $z = -2.61$ ,  $p = .009$ ), while people in the picture condition were more likely to be correct (46.7%,  $z = 2.01$ ,  $p = .041$ ;  $\chi^2 = 7.80$ ,  $df = 2$ ,  $p = .020$ ,  $N = 138$ ). The medium and high formal education groups remained insignificant. Formal education did not impact on the result for design appeal. The LCS Attitude data was too polar for subgroup analyses.

## 8.4 Discussion

### 8.4.1 Findings

#### 8.4.1.1 Was LCS information in a picture narrative format more supportive and equitable, compared to a text-only and a text-with-pictures format?

The primary aim of this study was to test whether using a picture narrative format for lung cancer screening (LCS) information was more supportive than using text with pictures or text alone. This was measured in terms of supporting knowledge acquisition about LCS, supporting accurate LCS eligibility identification, and encouraging positive attitudes surrounding LCS. The results of this study suggest the picture narrative format was not more supportive than using text accompanied by pictures, with participants in the group who received the picture narrative format being more likely to have a lower LCS knowledge score and more likely to give an incorrect assessment of their LCS eligibility. Most participants had positive attitudes related to LCS (covering fear, benefit of early detection, treatment efficacy and worry), independent of which intervention condition they received.

Participants were much more likely to say incorrectly they would be invited to screening than say incorrectly they would not be invited, suggesting there could be a problem with inappropriate participation in a future programme. This finding could be tied to the popular belief that ‘screening should be for everyone’, a response identified in Study 3 (Chapter 6).

A secondary aim of this study was to test whether a picture narrative format can minimise inequity in the support provided by health information materials, specifically looking at

differences across level of socioeconomic deprivation experienced and gender. There was no association between gender and knowledge scores. However, a moderation analysis found information format (study condition) did impact on the association between socioeconomic deprivation and LCS knowledge scores. The text-with-pictures format was superior to the text-only format in terms of equitable support for improving LCS knowledge. This is in line with previous findings (Houts et al., 2006; Schubbe et al., 2020). The picture narrative format was better than the text format, but worse than the text-with-pictures format. Although, these differences were not statistically significant.

Most participants reported having positive attitudes related to LCS. The fear item for attitudes to LCS was rated more negatively than the other three items. This is in line with previous findings (Quaife et al., 2017).

#### **8.4.1.2 Was the picture narrative LCS information considered acceptable within the target population?**

The picture narrative format was rated as highly positive as the two other formats, with most people giving the designs a positive or very positive rating. This suggests the picture narrative format was generally perceived as acceptable by the target population. However, as there was a clear ceiling effect in the appeal measure, it is likely that the measure used was not sensitive enough to identify differences in appeal across the conditions. This also meant I were unable to test design appeal as mediator on LCS knowledge acquisition.

Participants who viewed the picture narrative information format were more likely to rate the information as relevant, compared to the other formats. This is likely because the white male character was the primary figure in the text with picture version (due to oversight), whereas the man, woman and dog characters were equally dominant in the picture narrative version. This supports the idea that images are the more immediate or relied upon indicator of relevance (Geise & Baden, 2015).

#### **8.4.1.3 Was the impact of design format on LCS knowledge acquisition explained by perceptions towards the designs?**

Question 4 of the study was not tested because there was no effect found from the design format on knowledge acquisition and the test would have been underpowered due to sample size.

#### **8.4.1.4 Impact of recruitment method on uptake and inclusion in prize draw**

Recruitment was more successful when sending the invitation letter with questionnaire pack directly, compared to sending an invitation flier (15.0% vs 2.9% completed questionnaires). Two people who contacted me requesting to be sent a print version of the questionnaire said the link on the flier was not working. Further investigation found one was typing the link into the search engine while the other had not typed the address correctly. The weblinks on all the versions of the fliers were checked after this and found to be correct and working. Therefore, it was likely that needing to type out the website address was a key barrier to participating when receiving the invitation flier.

The response rate for the invitation letter was lower than anticipated based on other survey studies. Robb et al. (2017) achieved a response rate of 40.7% to postal questionnaires about bowel cancer screening information materials using a £250 prize draw incentive similar to the current study. S. G. Smith et al. (2015) achieved a response rate of 22% to a survey also about bowel screening. However, recruitment in the current study was successful in respect to receiving a high response from people living in areas of high socioeconomic deprivation. This was in fact more successful than was anticipated, resulting in a slight over-recruitment of people from the 1<sup>st</sup> SIMD quintile and under recruiting people from the 4<sup>th</sup> and 5<sup>th</sup> SIMD quintiles. Men were less likely to respond than women, but only by a difference of 5%. However, recruitment of people with ethnicities that were not white British was low. This is likely due to targeting three postcode areas, when people with different ethnicities are somewhat segregated across Glasgow (Kelly & Ashe, 2014).

People completing the online survey were more likely to apply to be included in the prize draw (likely due to greater ease in requesting inclusion) and more people from affluent areas were likely to complete the online survey. The fact that people from neighbourhoods with high socioeconomic deprivation were less likely to request to be included in the prize draw should be paid attention to, with this incentive strategy potentially maintaining inequality.

### 8.4.2 Strengths

As predicted, previous awareness related to lung cancer and cancer screening (as a measure of prior knowledge) attenuated the strength of the findings. This is an important covariate to measure when testing knowledge at a single time-point.

Although the final sample size was lower than the target, the invitation letter with questionnaire pack was a relatively successful strategy for recruiting people experiencing higher levels of socioeconomic deprivation.

### 8.4.3 Limitations

The main limitation of this study is the large risk of self-selection bias. People who would benefit from a picture narrative format may have been less likely to take part due to the invitation letter, participant information sheet and questionnaire all being in a text-only format. Whereas people who find textual information easy to understand may have been more likely to take part due to finding the information pack less burdensome. In a similar vein, people who find textual information easy to understand would also find the knowledge questions easier to complete, potentially biasing the results so that the text condition produced better knowledge scores. I was able to partially control for this by investigating the impact for people with no or low formal educational attainment. Self-selection bias will have been less of an issue for the online version of the questionnaire, as the flier was designed to have a balance between visual and textual elements, the participant information was provided in a video and participants could not see the format of the intervention or the questionnaire questions in advance.

#### 8.4.3.1 Limited power

Due to the final sample size, several of the planned analyses were unable to be carried out. The sample size was powered at 80% to find a medium effect size ( $f = 0.25$ ) for LCS knowledge score ( $N = 209$ ) and powered at 90% to find a medium to small effect size ( $w = 0.25$ ) for eligibility assessment accuracy ( $N = 264$ ) and LCS attitude rating ( $N = 281$ ), with significance level set at of 1.6% (based on Bonferroni correction for three primary outcomes;  $0.05/3 = 0.016$ ). Also, the sample was powered to 80% to find a medium to small effect ( $f^2 = 0.06$ ) with significance at 5% ( $N = 204$ ) for a simple mediation analysis with 3 predictors (2 condition dummy variables and 1 covariate). Therefore, if study condition produced a small effect size for any of the primary outcomes, the statistical tests

would not have been sensitive enough to detect these differences. However, it could be argued that such small effect sizes would not be clinically useful if this were to be the case.

Health information proficiency could not be investigated in the analyses due to too few participants reporting often finding health information difficult to read or understand.

#### **8.4.3.2 Unsuitable measures**

The measures used for the primary outcomes had several limitations, which were as follow:

*Informed decision-making.* The study was interested in whether LCS information format impacted on informed decision-making. However, intention to screen was not measured (due to lung screening not yet being available) and so a final decision could not be compared to the informed decision elements (sufficient knowledge, positive attitudes, consideration of personal values; Marteau et al., 2001). Therefore, the study only partially tested informed decision-making.

*LCS Knowledge.* The measure of LCS knowledge returned many missing cases. The measure asked participants to tick all items they believed were correct and cross all that they believed to be false. Many people did not indicate whether they thought any of the items were false and many only ticked one response per question. Unticked boxes could not be used in the analyses as indicating ‘false’, because individuals who only ticked one item per question would have received an inaccurate knowledge score. For the online version of the questionnaire, this was not an issue because of the survey function that highlighted incomplete items to the participant and only allowed continuation to the next page once they were completed. This measurement limitation disproportionately impacted people with no or low formal education and people with more than two indicators of socioeconomic deprivation, indicating this question type (multi-response true/false) was exclusionary. The exclusion of these participants from the analyses of condition on knowledge score (due to missing data) may have biased the findings, concealing true impact of condition on knowledge.

Unfortunately, the true/false question type was an alteration made after pilot testing (to align with other knowledge measures used). The issue of participants not indicating false items could have been highlighted during pilot testing. Still, many more participants only

gave one response per question, which was not an issue identified during piloting. A ‘do not know’ option, which has been used in previous screening knowledge measures (Kregting et al., 2020; Michie et al., 2002; S. K. Smith et al., 2012), was not included in the current study, in order to reduce burden. However, this may have reduced the sensitivity of the measure as missing responses were analysed as missing. Whereas, if they had been indicated as ‘don’t know’, they could have been analysed as incorrect. An option to overcome both the issue of participant burden and missing responses could have been to include a ‘do not know’ answer item per question rather than per item.

As anticipated from S. G. Smith et al. (2015), who found effect size of 0.1266, the effect size for knowledge scores in the current study was small (0.174). There is justification for not using knowledge measures like this in the future. Such a small effect is difficult to detect without spending lots of money and resources on printing and posting questionnaires and does not necessarily produce a clinically meaningful finding. Interviews potentially provide a more suitable method for measuring cancer screening knowledge and have been used by other researchers (Brotherstone et al., 2006; Wang et al., 2017). Interviews can also be resource-intensive but are able to capture more meaningful data.

*LCS Eligibility self-assessment accuracy.* Many participants did not complete the self-reported LCS eligibility item. I believe this was due to the placement in the questionnaire (at the bottom of the second page), which made it more likely to be skimmed over. On further considering this measure, I believe some people would have selected ‘Not sure’ due to not wanting to get the answer wrong (desirability bias), rather than not believing one way or the other. To accommodate this issue, ‘Not sure’ could be replaced with a ‘More information needed’ response option.

*Design Appeal.* The instrument used to measure appeal was not sensitive enough to detect differences in perceived appeal of the designs, due to the ceiling effect. This is a common issue with satisfaction measures. Using an ‘Overall experience rating’ (Pekarik et al., 2018), which includes a ‘beyond very good’ response option using wording such as superior or outstanding, can reduce this ceiling effect. Alternatively, Wang et al. (2017) used a passive measure of likelihood of engaging with comic strips about colorectal cancer screening by measuring willingness to engage with a research study after seeing the comic strips that were to be viewed. They also recorded how many of the comic strips the participants continued to give feedback on, after the first one (having been given the option

to look at only one). Although, the current study did look at response by study condition and found response did not differ significantly across the three information formats. But, again, this could have been a consequence of the text-heavy information pack and questionnaire used.

*Other measures.* Ethnicity was poorly defined and poorly measured, leading to its removal from the analysis. This meant losing information about the study population and not being able to investigate whether the different information formats were equitable for different ethnicity populations. The ethnicity data that was collected suggested a mostly homogenous demographic.

#### **8.4.4 Conclusion**

The picture narrative format was rated as appealing, suggesting the use of this format would be engaging and acceptable to the target population. Participants who received the picture narrative format of LCS information were more likely to have lower knowledge scores and incorrectly identify personal LCS eligibility. However, this finding should be taken/applied with caution, due to self-selection bias and the text-based method of data collection. The data was limited on whether attitudes towards LCS were impacted by information format. The text with picture format was most equitable in supporting LCS knowledge, while the text-only format was the least equitable.

*Table 8-4. Response characteristics (i.e., returned questionnaires) by study condition and invitation modality*

|                        | Total            |       | Condition                             |       |                             |       |                               |       |
|------------------------|------------------|-------|---------------------------------------|-------|-----------------------------|-------|-------------------------------|-------|
|                        | <i>n</i> = 3,534 |       | Picture narrative<br><i>n</i> = 1,178 |       | Picture<br><i>n</i> = 1,178 |       | Text-only<br><i>n</i> = 1,178 |       |
|                        | <i>n</i>         | %     | <i>n</i>                              | %     | <i>n</i>                    | %     | <i>n</i>                      | %     |
| Returned undelivered   |                  |       |                                       |       |                             |       |                               |       |
| (RTS)                  | 51               | 1.4   | 21                                    | 1.8   | 13                          | 1.1   | 17                            | 1.4   |
| Ineligible             | 11               | 0.3   | 4                                     | 0.3   | 5                           | 0.4   | 2                             | 0.2   |
| Excluded               | 4                | 0.1   | 2                                     | 0.2   | 1                           | 0.1   | 1                             | 0.1   |
| Non-response           | 3,157            | 89.3  | 1,059                                 | 89.9  | 1,056                       | 89.6  | 1,042                         | 88.5  |
| Final response         | 311              | 8.8   | 92                                    | 7.8   | 103                         | 8.7   | 116                           | 9.8   |
| Invitation modality    |                  |       |                                       |       |                             |       |                               |       |
| Advert invitation      |                  |       |                                       |       |                             |       |                               |       |
| Sent                   | 1,692            | 100.0 | 564                                   | 100.0 | 564                         | 100.0 | 564                           | 100.0 |
| Completed <sup>a</sup> | 49               | 2.9   | 17                                    | 3.0   | 17                          | 3.0   | 12                            | 2.1   |
| Letter invitation      |                  |       |                                       |       |                             |       |                               |       |
| Sent                   | 1,842            | 100.0 | 614                                   | 100.0 | 614                         | 100.0 | 614                           | 100.0 |
| Completed <sup>a</sup> | 277              | 15.0  | 75                                    | 12.2  | 86                          | 14.0  | 104                           | 16.9  |

*Note.* <sup>a</sup> Excluded cases removed

Table 8-5. Response rate by study condition, SIMD and gender for participants recruited through posted invitation letter with questionnaire pack.

|                         | Sent     | Included <sup>a</sup> |      | Response   |      |                    |      | Pearson's Chi-squared tests        |
|-------------------------|----------|-----------------------|------|------------|------|--------------------|------|------------------------------------|
|                         |          |                       |      | Unreturned |      | Returned completed |      |                                    |
|                         | <i>N</i> | <i>n</i>              | %    | <i>n</i>   | %    | <i>n</i>           | %    |                                    |
| Invitation letters sent | 1,842    | 1,779                 | 96.6 | 1,514      | 85.1 | 265                | 14.9 |                                    |
| Condition               |          |                       |      |            |      |                    |      |                                    |
| Picture narrative       | 614      | 589                   | 95.9 | 514        | 87.3 | 75                 | 12.7 | $\chi^2(2, 1779) = 5.40, p = .067$ |
| Pictures with text      | 614      | 595                   | 96.9 | 509        | 85.5 | 86                 | 14.5 |                                    |
| Text-only               | 614      | 595                   | 96.9 | 491        | 82.5 | 104                | 17.5 |                                    |
| SIMD quintile           |          |                       |      |            |      |                    |      |                                    |
| 1 (highest deprivation) | 693      | 670                   | 96.7 | 598        | 89.3 | 72                 | 10.7 | $\chi^2(4, 1779) = 20.86, p <.001$ |
| 2                       | 450      | 440                   | 97.8 | 377        | 85.7 | 63                 | 14.3 |                                    |
| 3                       | 339      | 324                   | 95.6 | 257        | 79.3 | 67                 | 20.7 |                                    |
| 4                       | 204      | 195                   | 95.6 | 159        | 81.5 | 36                 | 18.5 |                                    |
| 5 (lowest deprivation)  | 156      | 150                   | 96.2 | 123        | 82.0 | 27                 | 18.0 |                                    |
| Gender                  |          |                       |      |            |      |                    |      |                                    |
| Male                    | 837      | 803                   | 95.9 | 705        | 87.8 | 98                 | 12.2 | $\chi^2(1, 1779) = 8.37, p = .004$ |
| Female                  | 1,005    | 976                   | 97.1 | 809        | 82.9 | 167                | 17.1 |                                    |

Note. <sup>a</sup> This is total sent, excluding Return to Sender and ineligible responses. SIMD = Scottish Index of Multiple Deprivation derived from postcode.

Table 8-6. Respondent sociodemographic characteristics by study condition

|                                        | Total          |        | Condition                       |        |                        |        |                          |        |                                           |
|----------------------------------------|----------------|--------|---------------------------------|--------|------------------------|--------|--------------------------|--------|-------------------------------------------|
|                                        | <i>n</i> = 311 |        | Picture narrative <i>n</i> = 92 |        | Picture <i>n</i> = 103 |        | Text-only <i>n</i> = 116 |        |                                           |
|                                        | <i>n</i>       | %      | <i>n</i>                        | %      | <i>n</i>               | %      | <i>n</i>                 | %      |                                           |
| Age <i>M</i> ( <i>SD</i> )             | 63.3           | (6.70) | 64.1                            | (6.68) | 63.1                   | (6.73) | 62.7                     | (6.27) | <i>F</i> (2, 310) = 1.17, <i>p</i> = .311 |
| Gender                                 |                |        |                                 |        |                        |        |                          |        |                                           |
| Male                                   | 127            | 40.8   | 37                              | 29.1   | 45                     | 35.4   | 45                       | 35.4   | $\chi^2$ (2, 311) = 0.56, <i>p</i> = .755 |
| Female                                 | 184            | 59.2   | 55                              | 29.9   | 58                     | 31.5   | 71                       | 38.6   |                                           |
| Highest formal education               |                |        |                                 |        |                        |        |                          |        |                                           |
| None or low <sup>a</sup>               | 171            | 55.9   | 50                              | 54.9   | 59                     | 58.4   | 62                       | 54.4   | $\chi^2$ (4, 306) = 1.85, <i>p</i> = .763 |
| Medium <sup>b</sup>                    | 77             | 25.2   | 22                              | 24.2   | 22                     | 21.8   | 33                       | 28.9   |                                           |
| High <sup>c</sup>                      | 58             | 19.0   | 19                              | 20.9   | 20                     | 19.8   | 19                       | 16.7   |                                           |
| Employed                               |                |        |                                 |        |                        |        |                          |        |                                           |
| Yes <sup>d</sup>                       | 276            | 89.0   | 82                              | 89.1   | 93                     | 91.2   | 101                      | 87.1   | $\chi^2$ (2, 310) = 0.94, <i>p</i> = .625 |
| No                                     | 34             | 11.0   | 10                              | 10.9   | 9                      | 8.8    | 15                       | 12.9   |                                           |
| Homeowner                              |                |        |                                 |        |                        |        |                          |        |                                           |
| Yes <sup>e</sup>                       | 227            | 73.7   | 66                              | 72.5   | 76                     | 74.5   | 85                       | 73.9   | $\chi^2$ (2, 308) = 0.10, <i>p</i> = .950 |
| No                                     | 81             | 26.3   | 25                              | 27.5   | 26                     | 25.5   | 30                       | 26.1   |                                           |
| Vehicle owner                          |                |        |                                 |        |                        |        |                          |        |                                           |
| None                                   | 108            | 35.0   | 30                              | 32.6   | 29                     | 28.4   | 49                       | 42.6   | $\chi^2$ (4, 309) = 6.17, <i>p</i> = .187 |
| One                                    | 164            | 53.1   | 48                              | 52.2   | 61                     | 59.8   | 55                       | 47.8   |                                           |
| More than one                          | 37             | 12.0   | 14                              | 15.2   | 12                     | 11.8   | 11                       | 9.6    |                                           |
| Socioeconomic deprivation <sup>f</sup> |                |        |                                 |        |                        |        |                          |        |                                           |
| Fewer than two indicators              | 215            | 69.8   | 64                              | 70.3   | 75                     | 73.5   | 76                       | 66.1   | $\chi^2$ (2, 308) = 1.44, <i>p</i> = .487 |
| Two or more indicators                 | 93             | 30.2   | 27                              | 29.7   | 27                     | 26.5   | 39                       | 33.9   |                                           |

*Note.* <sup>a</sup> From no formal qualifications to equivalents of Scottish Highers. <sup>b</sup> Equivalents to National Vocational Qualification from levels 1 to 3. <sup>c</sup> Equivalent to Bachelor's degree, NVQ4 and higher. <sup>d</sup> Full-time, Part-time and Self-employed. <sup>e</sup> Own or buying on mortgage. <sup>f</sup> combined indices of no or low formal education, no employment, no vehicle ownership and no home ownership

Table 8-7. Respondent smoking status and LCS eligibility by study condition

|                                         | Total          |         | Condition         |         |          |         |           |         |                                   |
|-----------------------------------------|----------------|---------|-------------------|---------|----------|---------|-----------|---------|-----------------------------------|
|                                         | <i>n</i> = 311 |         | Picture narrative |         | Picture  |         | Text-only |         |                                   |
|                                         |                |         |                   |         |          |         |           |         |                                   |
|                                         | <i>n</i>       | %       | <i>n</i>          | %       | <i>n</i> | %       | <i>n</i>  | %       |                                   |
| Smoking history                         |                |         |                   |         |          |         |           |         |                                   |
| Never smoker                            | 140            | 45.0    | 41                | 44.6    | 45       | 43.7    | 54        | 46.6    | $\chi^2(2, 311) = 0.19, p = .909$ |
| Ever smoker                             | 171            | 55.0    | 51                | 55.4    | 58       | 56.3    | 62        | 53.4    |                                   |
| Age when started                        |                |         |                   |         |          |         |           |         |                                   |
| <i>M (SD)</i>                           | 17.6           | (5.12)  | 17.9              | (4.96)  | 16.8     | (4.38)  | 18.3      | (5.85)  | $F(2, 158) = 1.27, p = .283$      |
| Amount per day                          |                |         |                   |         |          |         |           |         |                                   |
| <i>M (SD)</i>                           | 17.9           | (9.59)  | 16.7              | (11.04) | 18.4     | (8.75)  | 18.2      | (9.27)  | $F(2, 157) = 0.33, p = .722$      |
| Time since quitting                     |                |         |                   |         |          |         |           |         |                                   |
| <i>M (SD)</i>                           | 21.4           | (12.75) | 21.2              | (12.97) | 19.8     | (13.76) | 23.2      | (11.56) | $F(2, 125) = 0.80, p = .450$      |
| Lung Screening Eligibility <sup>a</sup> |                |         |                   |         |          |         |           |         |                                   |
| Not eligible                            | 229            | 75.1    | 70                | 79.5    | 70       | 68.6    | 89        | 77.4    | $\chi^2(2, 305) = 3.54, p = .171$ |
| Eligible                                | 76             | 24.9    | 18                | 20.5    | 32       | 31.4    | 26        | 22.6    |                                   |

Note. <sup>a</sup> Lung Cancer Screening Eligibility based on study criteria

Table 8-8. Confounding variables by study condition

|                                             |     | Total<br><i>n</i> = 311 |    | Condition                          |    |                           |     |                             |                                    |  |
|---------------------------------------------|-----|-------------------------|----|------------------------------------|----|---------------------------|-----|-----------------------------|------------------------------------|--|
|                                             |     |                         |    | Picture narrative<br><i>n</i> = 92 |    | Picture<br><i>n</i> = 103 |     | Text-only<br><i>n</i> = 116 |                                    |  |
|                                             |     | <i>n</i>                | %  | <i>n</i>                           | %  | <i>n</i>                  | %   | <i>n</i>                    | %                                  |  |
| Questionnaire modality                      |     |                         |    |                                    |    |                           |     |                             |                                    |  |
| Print                                       | 274 | 88.1                    | 79 | 85.9                               | 89 | 86.4                      | 106 | 91.4                        | $\chi^2(2, 311) = 1.91, p = .385$  |  |
| Online                                      | 37  | 11.9                    | 13 | 14.1                               | 14 | 13.6                      | 10  | 8.6                         |                                    |  |
| Time spent reading                          |     |                         |    |                                    |    |                           |     |                             |                                    |  |
| Less than 2 minutes                         | 26  | 8.4                     | 6  | 6.5                                | 12 | 11.8                      | 8   | 7.0                         | $\chi^2(4, 308) = 6.46, p = .167$  |  |
| Between 2 to 10 minutes                     | 186 | 60.4                    | 60 | 65.2                               | 64 | 62.7                      | 62  | 54.4                        |                                    |  |
| More than 10 minutes                        | 96  | 31.2                    | 26 | 28.3                               | 26 | 25.5                      | 44  | 38.6                        |                                    |  |
| Health information proficiency <sup>a</sup> |     |                         |    |                                    |    |                           |     |                             |                                    |  |
| No, never                                   | 119 | 38.5                    | 22 | 23.9                               | 52 | 51.0                      | 45  | 39.1                        | $\chi^2(4, 309) = 17.23, p = .002$ |  |
| Yes, sometimes                              | 164 | 53.1                    | 62 | 67.4                               | 45 | 44.1                      | 57  | 49.6                        |                                    |  |
| Yes, often                                  | 26  | 8.4                     | 8  | 8.7                                | 5  | 4.9                       | 13  | 11.3                        |                                    |  |
| Previous lung cancer awareness              |     |                         |    |                                    |    |                           |     |                             |                                    |  |
| None                                        | 50  | 16.2                    | 7  | 7.6                                | 22 | 21.6                      | 21  | 18.4                        | $\chi^2(4, 308) = 13.10, p = .011$ |  |
| A little                                    | 206 | 66.9                    | 67 | 72.8                               | 58 | 56.9                      | 81  | 71.1                        |                                    |  |
| A lot                                       | 52  | 16.9                    | 18 | 19.6                               | 22 | 21.6                      | 12  | 10.5                        |                                    |  |
| Previous cancer screening awareness         |     |                         |    |                                    |    |                           |     |                             |                                    |  |
| None                                        | 65  | 21.2                    | 18 | 19.6                               | 19 | 18.6                      | 28  | 24.8                        | $\chi^2(4, 307) = 1.70, p = .791$  |  |
| A little                                    | 197 | 64.2                    | 60 | 65.2                               | 69 | 67.6                      | 68  | 60.2                        |                                    |  |
| A lot                                       | 45  | 14.7                    | 14 | 15.2                               | 14 | 13.7                      | 17  | 15.0                        |                                    |  |

Note. <sup>a</sup> Operationalised by difficulty reading or understanding health and medical information.

Table 8-9. Continuous primary outcomes by study condition

|                      | Condition         |          |           | Kruskal-Wallis tests         |
|----------------------|-------------------|----------|-----------|------------------------------|
|                      | Picture narrative | Picture  | Text-only |                              |
| LCS Knowledge scores |                   |          |           |                              |
| <i>N</i>             | 68                | 68       | 74        | $H(2, 210) = 6.87, p = .032$ |
| <i>Mean</i>          | 14.7              | 15.6     | 15.3      |                              |
| <i>SD</i>            | 2.11              | 1.92     | 2.26      |                              |
| <i>Median</i>        | 14.5              | 16.0     | 16.0      |                              |
| <i>Min. to Max.</i>  | 10 to 19          | 10 to 19 | 10 to 19  |                              |
| Design Appeal scores |                   |          |           |                              |
| <i>N</i>             | 75                | 84       | 103       | $H(2, 262) = 2.55, p = .279$ |
| <i>Mean</i>          | 8.8               | 8.7      | 8.7       |                              |
| <i>SD</i>            | 0.59              | 1.00     | 0.48      |                              |
| <i>Median</i>        | 9                 | 9        | 9         |                              |
| <i>Min. to Max.</i>  | 6 to 9            | 2 to 9   | 7 to 9    |                              |

Table 8-10. Nominal primary outcomes by study condition

|                                          | Total |      | Condition         |      |         |       |           |       | Pearson's Chi-squared tests       |
|------------------------------------------|-------|------|-------------------|------|---------|-------|-----------|-------|-----------------------------------|
|                                          | n     | %    | Picture narrative |      | Picture |       | Text-only |       |                                   |
|                                          |       |      | n                 | %    | n       | %     | n         | %     |                                   |
|                                          |       |      |                   |      |         |       |           |       |                                   |
| LCS Eligibility self-assessment accuracy |       |      |                   |      |         |       |           |       |                                   |
| Correct                                  | 86    | 32.6 | 18                | 23.1 | 32      | 38.6  | 36        | 35.0  | $\chi^2(2, 264) = 4.82, p = .090$ |
| Incorrect or unsure                      | 178   | 67.4 | 60                | 76.9 | 51      | 61.4  | 67        | 65.0  |                                   |
| LCS Attitudes                            |       |      |                   |      |         |       |           |       |                                   |
| Fear <sup>a</sup>                        |       |      |                   |      |         |       |           |       |                                   |
| Disagree/strongly disagree               | 207   | 73.7 | 64                | 78.0 | 65      | 69.1  | 78        | 74.3  | $\chi^2(2, 281) = 1.82, p = .402$ |
| Agree/strongly agree                     | 74    | 26.3 | 18                | 22.0 | 29      | 30.9  | 27        | 25.7  |                                   |
| Fatalism <sup>b</sup>                    |       |      |                   |      |         |       |           |       |                                   |
| Disagree/strongly disagree               | 272   | 95.1 | 81                | 95.3 | 90      | 93.8  | 101       | 96.2  | ---                               |
| Agree/strongly agree                     | 14    | 4.9  | 4                 | 4.7  | 6       | 6.3   | 4         | 3.8   |                                   |
| Benefits <sup>c</sup>                    |       |      |                   |      |         |       |           |       |                                   |
| Disagree/strongly disagree               | 3     | 1.0  | 3                 | 3.5  | 0       | .     | 0         | .     | ---                               |
| Agree/strongly agree                     | 288   | 99.0 | 83                | 96.5 | 96      | 100.0 | 109       | 100.0 |                                   |
| Worry <sup>d</sup>                       |       |      |                   |      |         |       |           |       |                                   |
| Disagree/strongly disagree               | 258   | 92.5 | 74                | 92.5 | 87      | 92.6  | 97        | 92.4  | $\chi^2(2, 279) < 0.01, p = .999$ |
| Agree/strongly agree                     | 21    | 7.5  | 6                 | 7.5  | 7       | 7.4   | 8         | 7.6   |                                   |

Note. LCS = Lung Cancer Screening. <sup>a</sup> 'I wouldn't want to know if I had lung cancer'. <sup>b</sup> 'I don't think there is any point going for lung cancer screening because it won't affect the outcome'. <sup>c</sup> 'If lung cancer is found early, there's a better chance of successful treatment and survival'. <sup>d</sup> 'I would be so worried about what might be found by the screening that I would prefer not to go'.

## Chapter 9. Discussion

### 9.1 Justification for the thesis and summary of the research aims

This thesis uses the term ‘picture narrative’ to refer to static visual portrayals of narrative created with intention using graphic techniques and with iconographic images (i.e., pictures) as an essential mode of communication. Picture narratives are often used in Health Communication, most notably in the form of comics (McNicol, 2017). However, they have not been extensively evaluated (Noe & Levin, 2020). The multimodal nature of picture narratives (as an integration of pictures, text and narrative) equips this form with many affordances that can support engagement with health information materials (Sones, 1944), support aspects of decision-making (such as comprehension, Houts et al., 2006; Schubbe et al 2020, and reduced counter arguing, Green, 2006), and support behavioural enactment (through symbolic modelling, Bandura & Menlove, 1968, and mental simulation, Green, 2006). For these reasons, I wanted to test the effectiveness of using picture narratives in a health communication context.

Lung screening presented a timely and important issue through which to test the use of picture narrative in the communication of health information. Lung cancer is the third most common cause of death in Scotland (National Records of Scotland, 2018). Lung screening using low-dose computer tomography has been found to improve early detection and improve cancer outcomes (Field et al., 2021). An implementation trial of such a programme is currently underway in England (National Cancer Programme, 2019) and it looks likely that a UK-wide lung cancer screening (LCS) programme will proceed this. The UK National Screening Committee (2022) are currently running a public consultation on lung screening.

Print materials are often provided to invitees to cancer screening, presenting an opportunity to apply picture narratives in the context of lung screening. All cancer screening programmes are challenged by low uptake (not having enough people participating in screening to make it worthwhile; Weller & Campbell, 2009), uninformed uptake (having people participating without being suitably informed; van den Bergh et al., 2009) and inequitable uptake (having disparities in participation rates across different demographic groups; Douglas et al., 2016; McRonald et al., 2014; Solmi et al., 2015). Informed choice

is currently a policy of the UK National Screening Committee (2018) and a necessary condition for empowering individuals in the face of an elective medical test that brings risks and uncertainty (Schapira et al., 2016).

Achieving equitable participation is a particularly important goal in the context of lung screening, as people from more socioeconomically deprived areas are much more likely to die from lung cancer (Powell, 2019; Tweed et al., 2018). Additionally, people in this population have been found to be more likely to avoid information about cancer (R. F. McCloud et al., 2013; Morris et al., 2013) and less likely to participate in LCS (Baldwin et al., 2021). Therefore, the success of lung screening information materials may be best measured in terms of whether they can support informed and equitable participation.

Health literacy (which refers to an individual's "ability to find, understand, and use information and services to inform health-related decisions and actions"; Santana et al., 2021, p. S259) is lower in areas of high socioeconomic deprivation (Zhu et al., 2021). Therefore, it is particularly important that the LCS information provided is accessible to this population and can facilitate understanding. It was believed that the use of picture narratives in LCS information materials could improve the accessibility and supportiveness of the information, based on the many affordances outlined above.

For the LCS information materials to be perceived as relevant, appropriate and comprehensible to those who are being invited to participate in the screening, it is necessary that materials are culturally sensitive (i.e., respect the practices and values of the reader; Brooks et al., 2019) and specific (i.e., align with the communication needs of, and communication conventions used by, the reader; V. Hoffmann, 2002). Therefore, this project developed the picture narratives for a particular target audience. The target audience were people living in low resource areas in Glasgow who met a broad definition of the eligibility criteria for lung screening (current or previous heavy smoking within the past 15 years and aged between 50 and 75 years old). This target audience is a priority population for LCS, and for the provision of accessible and supportive LCS information, due to disparities found in lung cancer mortality (ScotPHO, 2021; Tweed et al., 2018), and screening uptake (Douglas et al., 2016; Field, Duffy, Baldwin, Brain, et al., 2016; Solmi et al., 2015) for this population.

To ensure the benefits of LCS can be fully realised, the objective of this thesis was to systematically develop and test picture narrative LCS information, as an effective and equitable strategy for communicating about lung screening with people likely to be invited.

## **9.2 Summary of findings**

### **9.2.1 What content and design characteristics should be used in picture narratives of lung cancer screening information for invitees within the target audience?**

#### **9.2.1.1 Exploration**

A content analysis was conducted to evaluate the use of pictures and picture narratives in print information materials produced for invitees to any one of the three available UK cancer screening programmes (breast, bowel and cervical; Study 1). Forty-four print information materials produced between 2009 and November 2019 were identified and included in the analysis. These cases were analysed to assess the extent to which picture narratives have so far been used in these materials. Very few examples of picture narratives were found to be used within the sample, indicating their infrequent use in practice. The study was also conducted to build an understanding into the different ways in which pictures have been, and can be, used in print cancer screening information. In parsing the function, content and style of the pictures identified in the sample material, through rigorous development of the coding frame, I was able to better understand which picture design elements are most relevant to consider for the context of cancer screening information. I identified the following four main types of pictures used in print information, in terms of their function; 1) pictures identifying a brand of organisation (which I have referred to as Logos), 2) pictures indicating the type of information to proceed it in the text (which I have referred to as icons, based on the use in computing), 3) pictures used to display visual content or convey an aspect without communicating a coherent message, and 4) pictures that communicate a coherent message. Picture narratives fall into this fourth type of picture, as they necessarily communicate a coherent message (i.e., the narrative).

The content analysis also assessed picture content and style, as these are the two main avenues through which pictures can be analysed (Willats, 1997). Most display-type pictures across the sample were photographic, while most message-type pictures were

digital illustrations. The pictures were very rarely analogue illustrations (i.e., looked to be drawn by hand). The coding categories developed through this analysis provided a useful framework for delineating between the different content that could be presented with the picture narrative and the different visual styles that could be applied to the picture narratives. Additionally, I was able to take several of the examples found in this study as reference materials for the community-based design workshop (Study 3). I also used the categories I developed in the analysis to select a range of content and styles for the workshop participants to see.

Study 2 was an analysis of portrayals related to LCS within comics – a popular medium that makes use of the picture narrative form. This study was carried out to investigate common images and symbols used in picture narrative representations of cancer, with the assumption that these would more likely be recognisable to the target audience and would, therefore, support comprehension of LCS information, if used in the designs. Fifty-three comics were identified that included cancer as a main aspect of the narrative and that were available in English. First, I identified all instances where lung cancer and early detection were included in the comics. I also assessed the prevalence of other types of cancer present in the sample, and of the types of cancer narratives (i.e., the ways in which the narratives related to cancer) that were present. I found three examples of comics that contained narrative portrayals of lung cancer, and six examples of comics with a cancer early detection message. Most of the comics about cancer aimed at an adult audience were autobiographic, while only a small proportion had an explanation-type narrative (a genre of cancer comics was found in which the characters provide educational information or instruction without other narrative elements, such as plot or place). This aspect of the study provides an account of cancer comics written in the English language, published before 2021, and building on the work of Rhode and Connor (2012).

Following on from the quantitative description of the contents of the comics, I conducted a qualitative thematic analysis to explore reoccurring ways in which cancer was represented within the comics. Thirty-two of the fifty-three comics identified were available to me and included in this analysis. A key finding was that cancer was not often visualised as a tumour and representations of cancer, in general, were markedly absent from the comics. The analysis produced six main themes that were able to summarise the different ways in which cancer was represented within the comics. These were, as the word ‘cancer’, as an anthropomorphic character, as an x-ray image, as a drawing (within the drawing), through

the shapes and colours used, and as visual symbolic representations. The examples of cancer portrayed through picture narrative form identified in this analysis were used as reference materials while designing the picture narrative LCS information in subsequent chapters.

Study 3 was a community-based design workshop exploring LCS information design preferences and LCS perceptions within the target audience, with the intention to use the findings to inform the design decisions for the picture narrative LCS information tested in Studies 4 and 5. The aim was to explore ways to increase the engagingness, acceptability, accessibility, and supportiveness of the LCS information being developed, in a collaborative way with members of the target audience. The workshop was held in a community centre within a low-resource area of Glasgow (an area with high levels of socioeconomic deprivation based on the SIMD). I organised and facilitated this workshop in collaboration with a community development volunteer working at the community centre. Nineteen people participated in the workshop, all of whom were living in low-resource neighbourhoods. Eleven of the participants met the eligibility criteria being used for the UK Lung Health Checks (between 55 and 75 years old and have ever smoked; National Cancer Programme, 2019), with another participant approaching the eligible age. Audio recordings of participants' discussions were collected and analysed alongside posters produced by participants during the workshop and written notes made by helpers on each table at the workshop. The data were analysed inductively using thematic analysis, following Braun and Clarke's (2006) guidance. Five themes were developed that report the design features which participants considered important for print LCS information, these were: information amount and relevance, practical considerations, realism, the use of colour, and visuals that were accepted and recognised. Three themes were developed that captured participants' main perceptions surrounding LCS, these were: diagnostic pathway over screening, getting yourself checked out and knowing your body, and description of lung cancer.

#### **9.2.1.2 Creation**

The next phase of the research was to develop example picture narrative LCS information that could be used in an empirical study to substantiate the claim that picture narratives would be an effective format for supporting equitable and informed uptake in a LCS programme. The findings from each aspect of the 'exploration' design phase (i.e., review of design guidelines and mechanisms behind effective communication, alongside Studies

1, 2 and 3) were collected together to produce guiding principles for designing the picture narrative LCS information. These guiding principles were comprehensive, owing to the breadth of exploration leading up to this stage. Chapter 7 described the creative process carried out to develop the picture narratives based on these guiding principles. This section of the thesis orientates itself with practice-based research, where I (as the designer) gleaned insight into the capacity of picture narrative form for LCS communication through a period of creation and reflection. From this, I created prototypes for the example picture narrative LCS information, with the support of a professional artist.

In Study 4, I carried out usability testing of the developed prototypes with members of the target audience to identify aspects of the picture narratives that were inaccessible, to be able to make improvements to the designs. The usability testing was also used as an opportunity to assess whether the picture narrative designs were deemed acceptable to members of the target audience, to determine if it would be feasible to use the designs in a larger study of their impact on LCS communication outcomes. The usability testing was conducted using interviews with eight participants who were all between the ages of 50 and 70, had a history of heavy smoking and were living in areas of Glasgow in the 1st, 2nd or 3rd SIMD quintiles (i.e., medium to high levels of deprivation). The interviews contained two parts; a think-aloud test, followed by semi-structured interview questions prompting further feedback on the designs. These interviews were analysed using qualitative content analysis, focusing on whether design elements were recognisable and acceptable. The analysis also checked for indications of readability issues. Recognition was assessed across two levels: perception of the depictions, and interpretation of the messages. This approach was guided by the interest in ensuring the picture narratives looked to the audience as they were intended to look and conveyed the message to the audience that they were intended to convey. Through this study, I was able to identify aspects of the picture narratives that were not recognised by the participants and needed adapting to improve the ability/capacity of the picture narratives to communicate the intended message. Importantly, it was determined that the picture narrative designs were considered acceptable to the population and, therefore, would be appropriate for testing in a large-scale study of effectiveness.

## **9.2.2 Can picture narratives be used to support the effective communication of lung cancer screening information for invitees, in the interest of supporting informed and equitable uptake?**

### **9.2.2.1 Evaluation**

Study 5 was a questionnaire study of parallel three-arm randomised controlled trial design used to compare the developed picture narrative LCS information (intervention condition) with the same LCS information in a ‘text with pictures’ format (control condition 1) and ‘text without pictures’ format (control condition 2). The primary aim of the study was to determine whether using a picture narrative format to inform people about lung screening was effective in supporting LCS understanding and decision-making. This was tested by assessing whether the picture narrative condition increased LCS knowledge (via a 29-item true-false measure), improved self-identification of LCS eligibility (by comparing reported eligibility with actual eligibility), and reduced barrier attitudes towards LCS (via a 4-item 4-point Likert-style measure). Post hoc tests identified that picture narrative format produced worse outcomes in terms of LCS knowledge score and eligibility self-assessment accuracy.

It is worth noting that, in Study 5, although LCS knowledge scores were adequate for all conditions, only 32.6% of participants gave a correct assessment of their LCS eligibility (based on the description given in the materials used in the study). This study cannot determine whether this was due to lack of attention or comprehension, or whether something else was occurring which led to people reporting they were eligible when they were not.

The second, equally important, aim was to assess whether using the picture narrative format could reduce disparities in information provision across socioeconomic groups, by looking at whether the picture narrative condition produced a smaller gap within the communication outcomes (i.e., LCS knowledge, eligibility self-assessment accuracy, and LCS attitudes) for people experiencing low levels of socioeconomic deprivation compared to those experiencing high levels. The text-only format produced a statistically significant disparity in knowledge scores between participants with a low level of socioeconomic deprivation and those with a high level, while the format of text with pictures reduced this disparity. The difference in knowledge scores between socio-economic groups was also

smaller in the picture narrative condition compared to the text-only condition, but unfortunately, this was not to a statistically significant degree.

A third aim of the study was to explore whether participants' perceptions, in terms of design appeal, differed towards the different formats of LCS information and whether these perceptions drove an association between information format and knowledge acquisition. Design appeal was assessed using a 9-item 4-point Likert-style measure of appeal. LCS attitudes were predominantly positive and did not differ across the conditions. However, due to this lack of significant differences in design appeal across the conditions, and the unmet sample size requirement, meant it was not appropriate to test whether design appeal might explain difference in knowledge acquisition.

In addition to these three aims, the study assessed whether the picture narrative format would be deemed acceptable by the target population. Positive ratings of design appeal were taken to mean that the designs were considered acceptable. The picture narrative format was rated as equally appealing as the other two formats, which was predominantly positive. Therefore, I believe that using picture narratives (in a style similar to the ones developed through this thesis) as part of the LCS information materials would be considered acceptable to people living in Glasgow meeting the eligibility criteria for LCS.

## **9.3 Strengths and Limitations**

### **9.3.1 Novel approach**

This research took a novel and in-depth approach to exploring picture narrative health communication. From the discoveries made through conducting Studies 1 to 4 and the evidence collected in Study 5, the thesis contributes to a growing body of work looking into the use of comics in health communication, where there is a particular focus on building evidence into which characteristics of comics are most supportive for different communication aims and within which contexts (including audience and health topic; Noe & Levin, 2020). This thesis establishes a systematic and productive approach for developing picture narrative information for print health communication.

### **9.3.2 Timely and valuable**

This research is timely, with the NHS implementing Lung Health Checks through England in 2019 while I was completing the thesis. The Lung Health Checks are part of multi-

centre implementation trials to determine the best way to expand LCS to a nationwide screening programme (National Cancer Programme, 2019). Additionally, final results from the UK LCS trial have now been published, which report a reduction in mortality rates for people with high risk of getting lung cancer (Field et al., 2021).

The research in this thesis is also important as it attends to the need to reduce inequalities in access to cancer screening. It is well recognised that existing cancer screening programmes (breast, bowel, and cervical) suffer from inequitable rates of uptake across different socioeconomic groups (Douglas et al., 2016; McDonald et al., 2014; Solmi et al., 2015), with a Scottish Government Screening Inequalities Network existing to tackle this issue. The importance of ensuring equal access to LCS is compounded by the large disparities found in lung cancer outcomes across socioeconomic groups (e.g., morbidity and mortality; Powell, 2019). Equitable participant involvement was a priority outlined in the ESR/ERS statement paper on LCS (Kauczor et al., 2020).

The picture narrative LCS information developed through this thesis was specifically designed for people who would likely be eligible for LCS (based on the current recruitment strategy of the Lung Health Checks), living in Glasgow in areas with greatest rates of socioeconomic deprivation (referred to as the ‘target audience’ throughout the thesis). This target audience was selected based on greatest need, with Glasgow having the highest rates of lung cancer mortality in Scotland (National Records of Scotland, 2018; ScotPHO, 2018b). Focusing the design efforts on people within this target audience prioritised the perceptions and experiences of people who are most at risk of being marginalised by a LCS recruitment strategy.

### **9.3.3 Mixed method**

A study into the use of picture narrative in LCS information to support equitable and informed participation necessitated, and benefited from, a mixed-method approach. The phenomena under investigation included comics, health communication and people’s perceptions. These phenomena have been primarily dealt with within separate disciplines and using different research methods. Therefore, through adopting multiple disciplinary perspectives, I believe I was better able to produce a rigorous examination of the application of picture narratives in health communication within the context of LCS. Research is strengthened by the integration of multiple sources of knowledge (Bishop & Yardley, 2017), and I believe I produced a more useful holistic assessment of the use of

picture narratives in LCS information as a result. This approach required spending considerable time getting accustomed to the theory and concepts associated with each phenomena.

Something that I believe supported this mixed-method multi-disciplinary approach to the research was having a background in qualitative thematic analysis. I relied heavily upon the principle of searching for reoccurring patterns, throughout the thesis, even where the phenomena under investigation were vastly different (for example, comics compared to interview data). In doing so, I could make use of the guidelines around maintaining research integrity when conducting such qualitative analyses.

#### **9.3.4 Stakeholder involvement**

A strength of this project was that I engaged with stakeholders at multiple points through the project, including expert feedback, consultation with community workers and piloting study procedures. I also included the key stakeholder group (the target audience) in the development of the picture narrative designs. However, an important stakeholder group who were absent through this project were health communication practitioners and cancer screening programme organisers. This would be a necessary step, if the designs developed through this thesis were to be integrated into the information provision strategy used by a LCS programme. However, it is likely that this stakeholder group will become interested in being involved only once picture narratives have been demonstrated to be effective.

#### **9.3.5 Study 1**

The search for the cancer screening information materials only included materials produced for the screening programmes on a national level. This might not represent the information materials being used by individual clinics or across neighbourhoods. Although, within the context of the UK, it is unlikely that individual clinics will be creating their own versions of the information materials, as standard information is provided by the screening programme organisers. Due to being a quantitative evaluation, a key strength of this analysis was that a naïve secondary coder (i.e., someone who had not been involved in the coding scheme development) was used and verified the validity of the coding scheme. This study situates itself within the wider research area of health communication. Unfortunately, with the focus being on the visual elements of the materials, I did not make use of the opportunity to investigate the presence of behavioural

change techniques within these materials, which might have produced useful information to feed back to screening programme organisers. Developing the coding scheme for this study required me to consider, and become acquainted with, the elements that make up an image in pictures used in health leaflet, which I believed helped inform my practice later when creating the picture narrative designs. I believe this analysis would have been strengthened by including qualitative evaluations of the cases of picture narratives that were found in the materials.

### 9.3.6 Study 2

Taking a thematic analysis approach to investigating the portrayals of cancer in comics is a relatively novel approach. There have only been two similar studies to my knowledge; Krakow's (2017) analysis of the narrative attributes of the comic *Ladies ... Wouldn't It Be Better to Know?*<sup>43</sup> and Lo-Fo-Wong et al's (2014) content analysis of portrayals of different types of distress in *Cancer Vixen*<sup>44</sup>. Such investigations are usually conducted through close readings of a few examples. For example, Girard's (2017) analysis of the visuals used in page 113 of the comic *Our Cancer Year*<sup>45</sup> and Todd's (2013) analysis of medical narratives across several comics, including *Cancer Vixen*.

One limitation of Study 2 was that a minority of the comics analysed were produced in the UK. This could mean they were less representative of the symbols and conventions used by people within the UK. This issue was remedied by following Study 2 with a community-based design workshop in which I presented examples of these comics (across a range of styles) to members of the target audience and gained insight into how the images were received (e.g., positively, negatively, with confusion, or ignored). Due to only finding four comics that included portrayals of lung cancer, this study was unable to determine if there were differences in the images associated with lung cancer compared to other types of cancer. Based on responses from the participants of the design workshop, there were indications that the target audience would associate lung cancer with a blackened lung due to the connection with smoking, which is likely not to be the case for other cancer types.

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<sup>43</sup> American cancer society, *Ladies ... Wouldn't It Be Better to Know?* (American cancer society; 1969)

<sup>44</sup> Marisa Acocella Marchetto, *Cancer Vixen: A True Story* (New York: Alfred A. Knopf, 2006)

<sup>45</sup> Joyce Brabner, Harvey Pekar and Frank Stack, *Our Cancer Year* (New York: Four Walls Eight Windows, 1994)

### 9.3.7 Study 3

Study 3 took a novel approach to data collection by making use of a community-based design workshop. The workshop provided insights into design elements that may be better received by the target audience and provided an opportunity to investigate the target audiences' perceptions surrounding LCS. To my knowledge, this method has not been used before to investigate LCS perceptions or with the population who took part. I therefore conducted follow-up interviews to evaluate the success of using this novel method from the perspective of the attendees and found the method was deemed acceptable and enjoyable. I reflect on the process in detail in Chapter 6 in the hope that this might guide other researchers wanting to follow the approach. Only one community-based design workshop was used, producing a small sample size. Therefore, the finding from this study should not be generalised to a wider population. However, the results were suitable for the purposes of informing the development of example picture narrative LCS information for the distinct target audience. Multiple data sources were used to inform the analysis (audio-recordings, participants' posters, helpers' notes, researcher's reflections, and follow-up interview) and the participants were very engaged during the workshop activities, which I believe led to a rich data set suitable for an in-depth qualitative analysis. One potential limitation of the study is that, due to recruiting through the community centre, the participants were unrepresentative of the target audience due to being more engaged and involved in their community. The demographic data collected suggested that they were a representative sample; also, representativeness was not an issue in this case as the findings were not intended to be generalised.

### 9.3.8 Study 4

I believe the approach taken in Study 4 could have benefited from the inclusion of a second researcher-designer to double-code the data during the analysis and to collaborate on the design modifications. This would have been more rigorous and could have identified any oversights I might have had when applying the design suggestions (created from the analysis findings) to the updated designs. A secondary coder would have been suitable in this instance, because a coding frame was used and applied to the data (Braun & Clarke, 2021a).

Due to project time constraints, and the more time intensive process of qualitative analysis, I decided to conduct the usability testing as a single phase. However, this is not in-line with

the design principle of iterative end-user testing and re-design, and I now feel it was a mistake not to run further usability tests before conducting the RCT evaluation questionnaire study (Study 5). There were some significant changes between the prototype design (used in interviews) and the final design (produced after interviews) that I felt would have benefited from further usability testing. For example, the section about the risks of screening (see Figure 9-1 and Figure 9-2).

Figure 9-1. Prototype used in usability testing

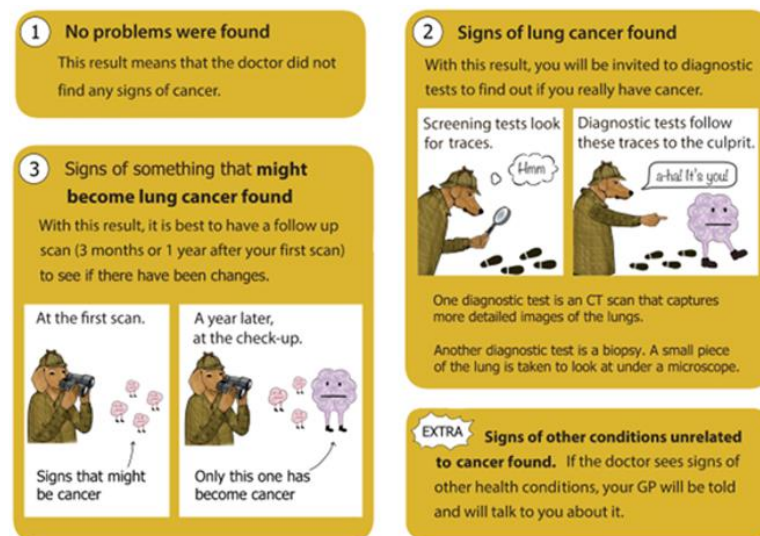
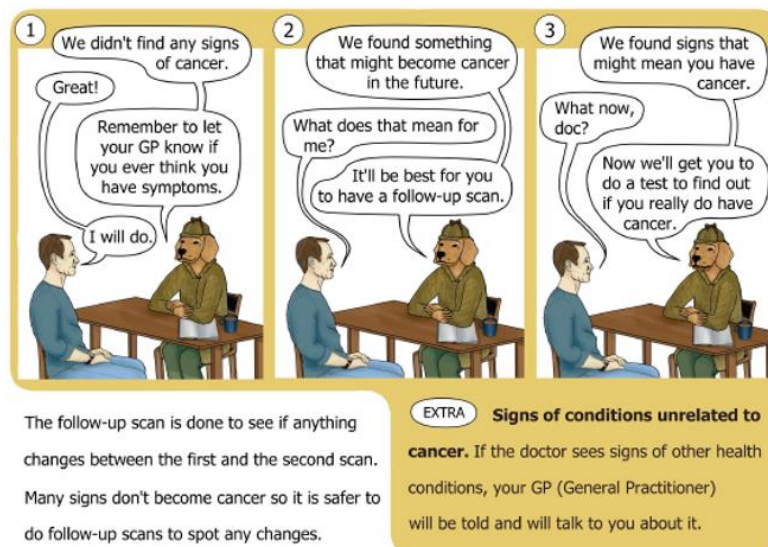


Figure 9-2. Design after usability testing



The target audience were not included during the development of the gist-based messages, which were used as the basis for the picture narrative designs, although Blalock and Reyna (2016) suggest this is an important step towards determining gist information. However, I did include expert review of this information. The intention of this thesis was not to

analyse the impact of using gist-based messages, but to use them as a theory informed approach to designing suitable LCS information that reduced burden on the readers.

### **9.3.9 Study 5**

One strength of Study 5 was the sample size achieved. Although the sample size was not large enough to run a mediation analysis of impact of design type on LCS knowledge through design appeal, it was large enough for the other statistical tests to be suitably powered.

There were two major limitations with this study that likely undermined the study's ability to test whether using a picture narrative format was able to reduce differences in knowledge acquisition across socioeconomic groups, and may also account for why the effect sizes found were small. It is likely that recruitment was biased towards people who find text-based health information easy to read, as people who find text heavy information inaccessible or overwhelming would have been put off from taking part in the study, due to the text only format of the invitation letter, participant information sheet, privacy notice and questionnaire. There is also a chance that self-selection bias occurred, where people who received the LCS information in a format that they found easy to read took part, while people who received the LCS information in a format they found difficult to read did not take part. To account for this, I produced a shorter version of the participant information sheet, with an option for participants to be sent the longer version or access it online, if desired. However, this was still four pages long, in order to meet all requirements of the ethics committee.

The text-based questionnaire was unlikely to adequately capture knowledge for people who find reading difficult. There is a chance that some participants were better able to acquire LCS knowledge from the picture narrative designs, but were not able to demonstrate this knowledge in the written questionnaire. There was indication of this, where participants from lower SIMD areas were more likely to complete the questionnaire incorrectly (e.g., not indicating false items with a cross and skipping pages or questions). As a result, the impact of using picture narrative on reducing communication disparities through supporting people who find text-heavy information inaccessible would not have been observed. Therefore, I would argue that the findings from Study 5 do not negate the potential effectiveness of providing information in a picture narrative format when inviting individuals to a LCS programme in order to support communication. However, more

research will need to be done to determine whether picture narratives do produce improvements in desired communication outcomes for people in more socioeconomically deprived areas.

There were other potential issues with the measures used in this study, with only the measure of LCS attitudes being based on a previously validated instrument. The results should, therefore, be interpreted with caution. Purposive sampling and in-person survey completion would have been more suitable for adequately testing the impact of design format on communication outcomes.

The approach of initially using a recruitment flier, rather than sending the participant pack, was relatively novel. This study found the recruitment flier achieved a much smaller response rate (2.7% vs 14.7%). This approach was used with the hope that it would reduce cost and paper waste, but the cost analysis found this approach did not improve costs.

I decided to conduct a study measuring effectiveness in order to align with what is considered higher quality evidence in the context of implementing new approaches in healthcare. This required using an ontologically consistent method, which relied on quantitative data and large sample sizes, to demonstrate reliability in the findings and to be able to make generalisations based on these. However, this approach limited my ability to glean deeper insights into the participants' perceptions to the different information formats; for example, whether design format had an impact on threat appraisal and avoidance. I suggest using alternative methods, such as vignette-based interviews, for assessing the impact of picture narratives on communication outcomes.

### **9.3.10 Orientated towards comics**

This thesis focusses predominantly on comics as a reference for the ways to develop and implement picture narrative in LCS information. There are other types of picture narratives that could have been made use of, such as murals or tapestries. However, comics are the most prominent modern medium to use picture narrative form, and are most likely to use conventions recognisable to the target audience, which justifies using them as I have.

### 9.3.11 Orientated towards white women

People from a white ethnic group and women were over-represented throughout the design phases. The comics analysed were disproportionally of white women characters and written by white female authors. The community-based design workshop was attended by only white British people, and by more women than men. Two of the three workshop helpers were white women. Both the artist and myself were white women. Finally, all participants in the usability interviews identified as white British, and only one of the participants was a man. Therefore, the picture narratives produced through this thesis are orientated toward white women. However, this did not seem to have an impact in relation to gender for the communication outcomes measured, with no significant difference found in LCS knowledge scores, eligibility self-assessment accuracy, or design appeal scores across men and women. On reflection, I believe I included a man as the main character in the picture narrative designs, knowing that men were less likely to engage with the topic and the research based on the experience I had with recruitment for Studies 3 and 4. Health information and related questionnaires often incur higher response from women than men, as was the case in Study 5. It would be interesting to know how much of a difference having a woman as the main character would have had on the communication outcomes.

I was unable to assess whether there were differences in outcomes across ethnic groups. However, with picture narrative comprehension being a product of both visual perception and cultural convention (theoretical basis outlined in Chapter 2), it is likely that people within different cultures will perceive and process the picture narratives differently. Therefore, as with all good health communication, the information ought to be tailored and assessed for cultural suitability (Brooks et al., 2019).

## 9.4 Implications of thesis for theory and practice

### 9.4.1 Theory

The use of comics in health promotion is often suggested as a mechanism for improving comprehension under the assumption that they may be easier to read. In this vein, the health comics developed for adults have so far been targeted at adults with low literacy or who have difficulty accessing more traditional forms of health information provision (Noe & Levin, 2020). However, this thesis identifies that this format has readability<sup>46</sup> issues that

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<sup>46</sup> a more suitable term in this might be pictorial or graphic accessibility

might be being overlooked. Even with an involved development process and usability testing, the picture narrative designs in this thesis were not as effective as having non-sequential pictures placed next to the text. As the same imagery was used in both conditions and the same text provided, I believe it was the need for an additional set of conventions for processing the picture narratives that may have made them unsuccessful.

A key finding from this thesis was that the information format of text accompanied by pictures produced better communication outcomes and reduced communication disparities across socioeconomic groups compared to a text-only format. What is interesting is that the textual information in both conditions was exactly the same and the sections of text were separated with different background colours in both. The inclusion of the pictures meant there was greater visual complexity and more information to process. I believe the concept of perceived information overload may provide an explanation for this finding (T. Lee et al., 2020). Alternatively, or additionally, pictures may have maintained engagement through visual appeal or enjoyment of seeing the illustrations. The pictures may also have worked as a quick indicator of what content is in the text next to it, acting as a placeholder for one's attention. This was found to be particularly supportive for a population for whom health information is less accessible or more burdensome (as identified by von Wagner et al., 2009).

Participants in Study 3 were concerned with the practical aspects of lung screening and were unconcerned with the recommendation to do screening, indicative of general acceptance of a future lung screening programme. As anticipated, participants indicate negative emotions associated with the thought of cancer, gave negative descriptions of cancer, and considered cancer screening to be a serious topic. This supports the idea that a LCS invitation focussed on cancer will be appraised as a health threat, which will lead some people to avoidance or dismissal of the information (outlined in the Common Sense Model; Leventhal et al., 2016). Another finding from Study 3 was a general misconception that screening is for symptomatic people, which ties into the misconception that lung cancer produces disenable symptoms. This has been found previously in other similar studies of LCS perceptions (Chapple et al., 2008; Hall et al., 2015; C. K. Palmer et al., 2014; Woof et al., 2020), reaffirming that this is an important belief for LCS communication efforts to counter.

Through Studies 3 and 4, I have identified that the comics conventions for speech balloons and thought bubbles, as well as the depiction of a narrative across several panels, was recognised by the target audience. Therefore, these basic comic conventions would be suitable to use. I also identified that a more realistic (not cartoonish) style would be more suitable.

The picture narratives for LCS information produced in this thesis included portrayals of cancer. However, there was minimal presence of depictions of cancer in the comics analysed and the information leaflets provided by the cancer screening programmes for people invited do not include images or descriptions of cancer. Additionally, to overcome fear and avoidance in people invited to screening, the LCS trials are using invitation materials that do not refer to cancer and instead refer to the screening as a test of lung health (Quaife et al., 2020). Information about lung cancer, including the possible test results, is being provided to participants when they attend the screening appointment. Therefore, it is at this point that the picture narratives created may be most suitable.

However, picture narrative could still be used to support people in attending the screening appointment. It was identified in the workshop that people were keen to be told about how to get to the screening, where it would be and what would take place. This information could effectively be presented as a picture narrative. Two good examples of this were identified during Study 1. Firstly, the leaflet created for the NHS Cancer Screening Programmes (2012). This picture narrative depicts the steps necessary for completing a self-completed bowel test, showing a man modelling the behaviour and in a line-drawn style. Notably, this picture narrative does not rely on people knowing how to read panel-to-panel, and instead indicates each step with a number and heading. Another example can be found in the cervical screening leaflet produced by NHS Cancer Screening Programmes (2016), which uses a sequence of 3 photographs showing, 1) a nurse, 2) the nurse talking to someone, and then 3) the person preparing to undress and the nurse pulling across a screen. The fact that the panels are circular likely distances this example from comics. It cannot be said what visual style (simple line drawing, realistic drawing or photographic) would be most suitable for certain populations. This question can only be answered through working with the population when designing the materials.

One of the qualities of comics that I identified as being potentially useful for cancer communication was the capacity of hand drawings to make a connection between the

source of the information and the reader (Chute & DeKoven, 2006). However, the content analysis showed this is underutilised. However, there have been moves to promote this capacity of illustration and comics to make this human connection (Alamalhodaie et al., 2020).

## **9.4.2 Practice**

### **9.4.2.1 Integrated print health information guidelines**

While preparing to develop the picture narrative LCS information, I rigorously identified and synthesised available guidance for print health information materials. The tool I developed from this synthesis extends previous guidance by incorporating behaviour change techniques suitable for including in a print leaflet. Additionally, greater importance is placed on pictorial accessibility, which I identified as missing in the available guidance. The tool can be found in Appendix 22.

### **9.4.2.2 Guidance on developing picture narrative for health communication**

Through this thesis, I have investigated how to incorporate knowledge from across disciplines, while taking into account local and cultural understanding, to inform the development of the picture narrative lung screening information. The final approach taken was to identify, synthesise and prioritise design suggestion through the different studies, with the researcher-designer (myself) as a key participant in, and conduit to, the processes. The description of the methods used to design the picture narrative LCS information offers a programme for collaborating with stakeholders, and uniting theory with context, when designing picture narrative health information.

### **9.4.2.3 Types of picture narratives**

While searching for the sample for Study 1, I identified that there were few examples of picture narratives being used in current screening information provision. With this, I was unable to make interpretations about the common ways picture narratives have been used. Therefore, the study looked instead at the use of pictures in general within these materials, to build an understanding into the visual lexicon used through pictures in contemporary UK cancer screening information. As a result, the analysis became orientated around pictures and neglected narrative. To account for this, I followed Study 1 with an analysis of comics which are predominantly narrative based. I was able to explore, to some degree, the different characteristics of narratives about lung cancer and early detection. However, this

study also became orientated around pictures, rather than narrative, by focussing on the visual aspects and images portrayed through the text and illustrations. I feel that this focus away from longform narrative was driven by my expectations for the final picture narrative designs, which I felt needed to fit into a print leaflet so as to mirror the cancer screening information leaflets used in current practice. The type of narrative used in the final designs I have created might be best considered as short-form picture narratives, where the narrative is based on connected characters and events without having a plot or storyline. Brame et al. (2011) present a good example of these two alternate types of picture narratives that can be adopted in health communication. They produced two comics-based pamphlets to raise awareness about testicular cancer and promote self-examination, where one was brief with no story, and the other was longer with a story about a couple's experience of testicular cancer diagnosis and treatment.

Whether you use a short or long-form picture narrative will have implications for the level of transportation experienced (this is, transportation into the story world; M. C. Green & Brock, 2000), which will likely have an impact on communication outcomes. In the context of producing a standard cancer screening information leaflet, I believe a long-form picture narrative would be unsuitable due to the additional pages and printing required. If health information providers wish to make use of a long-form narrative to take advantage of the affordances of narrative identified in Chapter 2, I believe it would be more cost effective and impactful to include this within a TV programme or by providing a video online (if the population have easy access to the internet). I also believe a long-form picture narrative could be most useful in the case of providing additional information for people who experience particular barriers to taking part. For example, a long-form picture narrative could be developed for people who are worried about doing the test. In this case, the picture narrative would help by being a personal, humanising (McNicol, 2014) and unthreatening form of communication. Another example would be developing a long-form picture narrative for people who have indicated that they would like to take part, but have been unable to overcome practical barriers, such as organising an appointment. In this case, a picture narrative could be used to model ways of overcoming the different barriers, which could thereby support self-efficacy and problem solving.

### **9.4.3 Future directions**

#### **9.4.3.1 Communication outcomes that were not investigated**

Fear-related avoidance and unfavourable cognitive reappraisal were two key mechanisms that are involved in LCS information engagement and decision-making, which I identified during my literature review. I designed the LCS picture narrative designs to target these factors. However, the impact of the designs on these two factors has not been evaluated within this thesis. Therefore, I would suggest the next step for this research would be to test the impact of using the picture narratives developed in the project on emotional appraisal of the health threat and coping-strategy adoption. In a similar vein, I identified that narrative transportation is particularly involved in the success of narratives having an impact on health communication outcomes. However, the design of the current study did not allow for measuring transportation. Additionally, my evaluation of the use of picture narratives for LCS communication maintains to neglect the potential of picture narratives for overcoming emotional barriers and for being more intimate and for humanising the information (Alamalhodaie et al., 2020; Chute & DeKoven, 2006). Therefore, it would be pertinent to investigate the extent to which the picture narrative designs could influence these outcomes.

#### **9.4.3.2 Comparing different picture narrative styles**

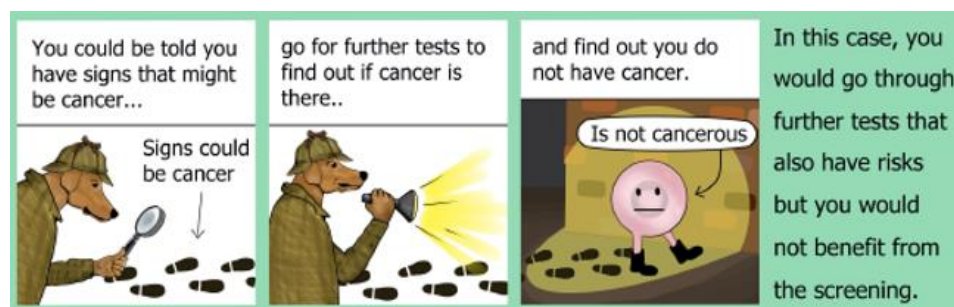
The picture narrative LCS information designed through this thesis only covered a select amount of LCS information. This included a description of the health condition, the testing process, the eligibility criteria, the benefits and harms, and the result possibilities. A future study could look at the usefulness of picture narrative for different information sections or messages, as it may be that picture narrative format is more effective for communicating procedural information than for explaining the link between early detection and improved outcomes. This thesis provides the groundwork for carrying out such research.

#### **9.4.3.3 Researcher-Designer reflections**

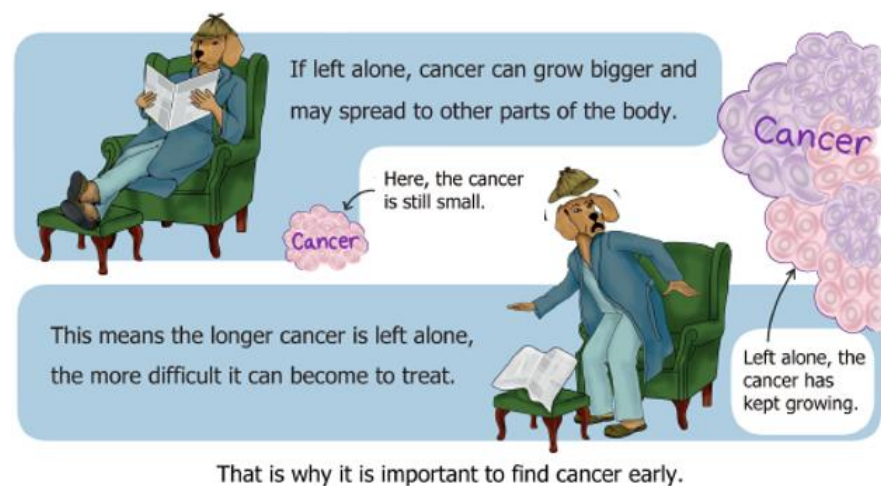
For the next step in my research, I am keen to carry out an analysis of the final versions of the picture narrative LCS designs created through the process of this thesis. There are already aspects of the designs that have caught my attention as being potentially interesting avenues for further investigating the phenomena of picture narratives in health information provision. For example, the designs use both a combination of traditional European comics style with uniform panels enclosed with a boarder (see Figure 9-3) and traditionally

Japanese comic style, where panels often do not have a uniform size, shape or position and often switch between being bordered and borderless (see Figure 9-4). I am interested to know why this design aspect occurred and what impact it might have on message reception. Another observation I have made during the design process is the potential usefulness of having a ‘primer’ image at the beginning of the communication, which can orient the reader to the conventions to be used within the picture narrative information materials. In the picture narrative LCS designs I created, this ‘primer’ is in the form of a two panel strip that uses thought bubbles and speech balloons (to indicate the following information will be making use of conventions associated with comics), with the dog character (to indicate this will be the main provider of information through the designs who is there to maintain continuity across the illustrations) pictured searching for signs with a magnifying glass (to indicated this is a detective character) (see Appendix 33).

*Figure 9-3. Uniform panelled picture narrative sequence*



*Figure 9-4. Borderless picture narrative sequence*



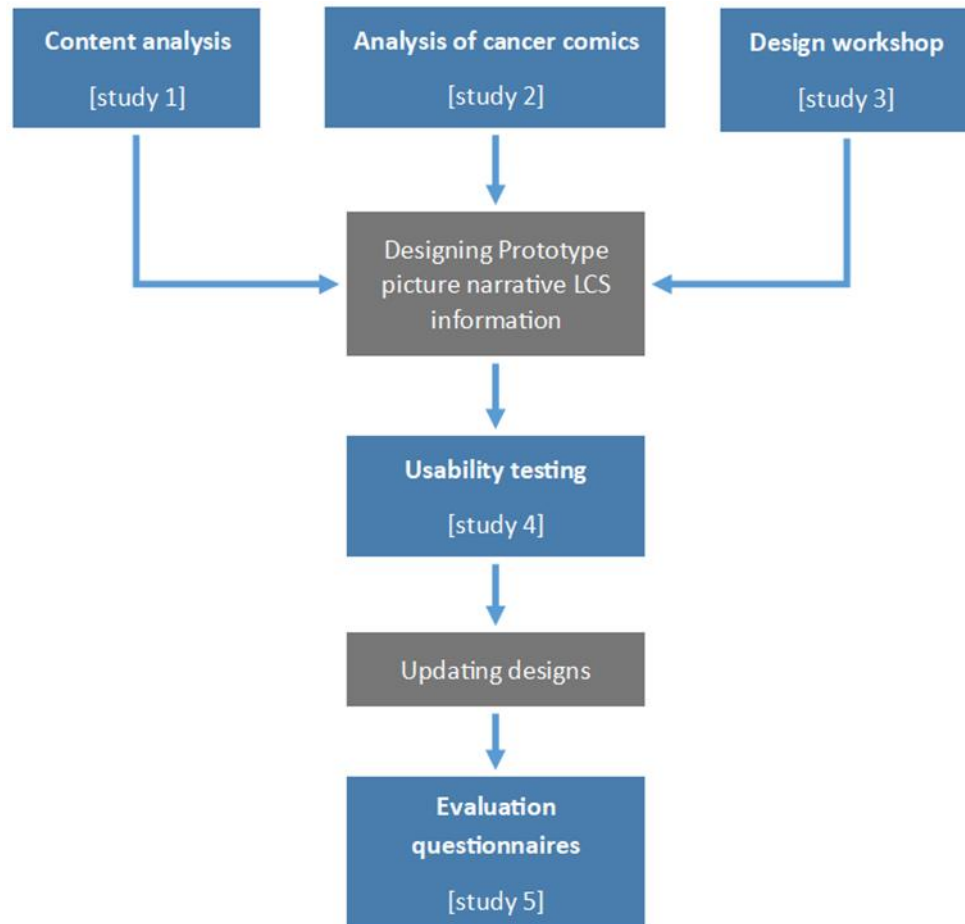
## 9.5 Concluding remarks

A traditional comic format may be considered inappropriate by future invitees to lung screening in the UK, due to dominant cultural views of the medium as being immature in combination with perceptions of lung cancer being a serious matter. However, this thesis demonstrates that the integration of picture narratives within a more traditional health information design, which would meet invitees' expectations of what health information should look like, could be an accepted and effective option for supporting informed decision-making and tackling disparities in cancer screening engagement found across sociodemographic groups. It is essential that such picture narrative designs are developed based on theory, evidence and with the involvement of the target population, and I believe that this thesis outlines a rigorous and effective methodology for achieving this.

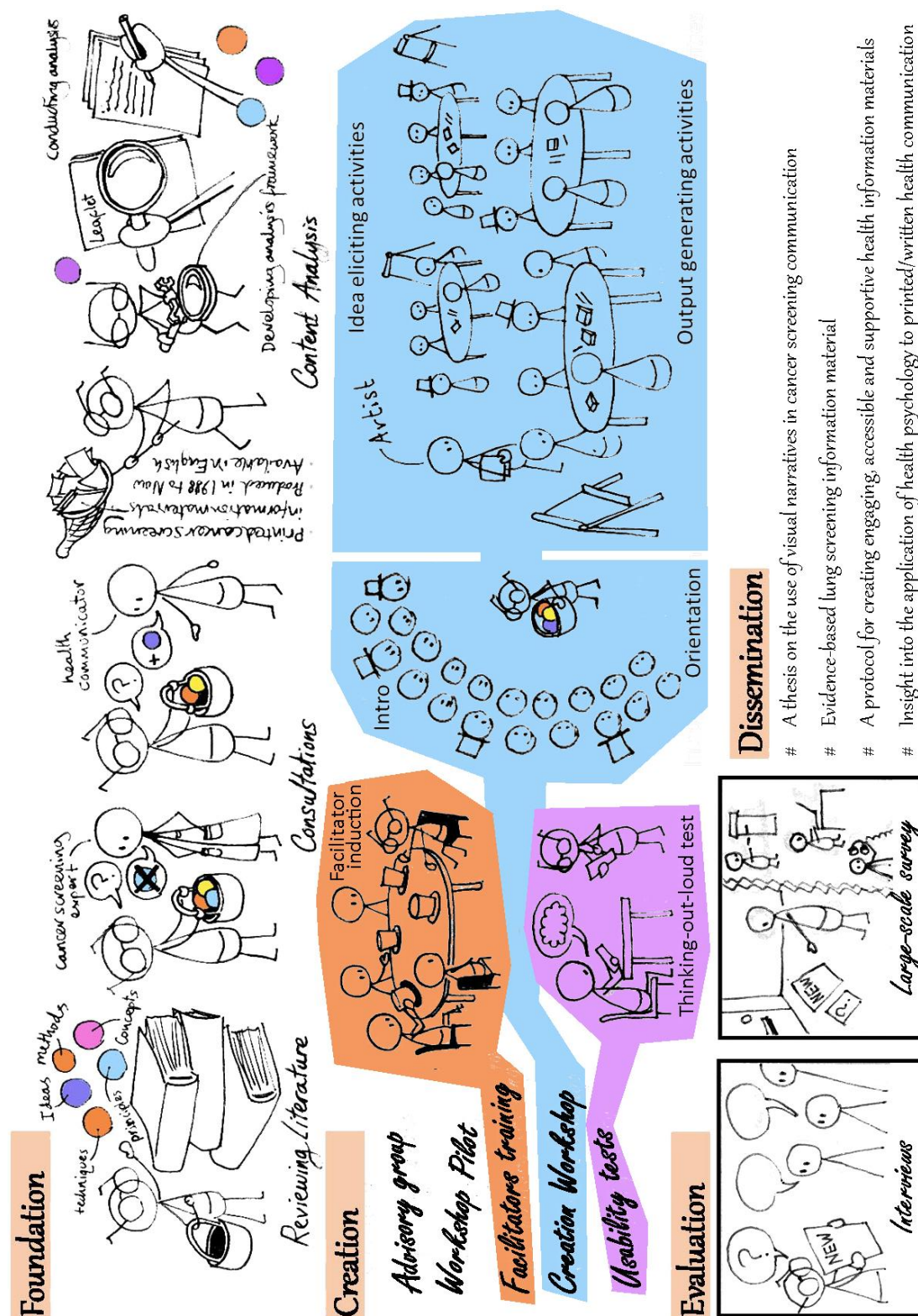
## Appendices

### Chapter 3 appendixes

#### Appendix 1: Overview of thesis studies



## Appendix 2: Original plan for the design process



## Chapter 4 Appendixes

### Appendix 3: Published paper from study 1 – Content analysis of UK cancer screening information leaflets

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#### Prevalence and Characteristics of Pictures in Cancer Screening Information: Content Analysis of UK Print Decision Support Materials

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##### ABSTRACT

This paper answers calls for further theoretical work into types of pictures used in health information. Pictures influence message reception, interpretation, and retention, making this an important area for research in health communication. A content analysis was used to produce a systematic and theory-orientated assessment of the use of pictures in cancer screening information materials ( $N = 44$ ) produced for invitees to either cervical, breast or bowel screening in the United Kingdom. The main categories investigated in this study were function, content and style of the pictures. Pictures used in cancer screening information materials were twice as likely to be used to demonstrate what something looked like or depict a situation (display pictures) than to convey a specific cancer screening message (message pictures). The messages being conveyed were predominantly related to screening procedures (51%) or outcomes (38%) rather than screening experiences (6%) or decisions (9%). Pictures were rarely used to portray a narrative in the materials ( $n = 12$ ). The paper brings conceptual clarity to the ways pictures can be, and have so far been used, to communicate cancer screening information. This study identifies that pictures conveying a cancer-related message, and pictures in the format of a narrative, should be used more often in print cancer screening communications.

Cancer is a leading cause of death by non-communicable disease in the United Kingdom (World Health Organization, 2018). Three centrally organized screening programmes (for breast, cervical and bowel cancer) have been established in the UK with the aim to increase the early detection of cancer, improve treatment outcomes and reduce mortality (Landy et al., 2016; Logan et al., 2012; Marmot et al., 2012). The primary mechanism for inviting eligible members of the general population to the screening is with posted letters (sent by mail) and these are accompanied by a leaflet providing additional information (Public Health England, 2018).

The UK National Screening Committee have asserted that personal informed choice, defined as making a decision “based on access to accessible, accurate, evidence-based information,” should be supported throughout the cancer screening programmes (UK National Screening Committee, 2018, p. 2). The invitation letter and accompanying leaflet are the first opportunity to support informed choice for invitees. The UK screening information leaflets need to be able to support engagement with, understanding of, and consideration of, the cancer screening information, to support informed choice. Therefore, it is important to build a strong understanding of factors impacting the success of print materials in providing cancer screening information.

##### The role of pictures in health information

Pictures can improve the chances of a text being read, as well as improve comprehension and recall of health information compared to presenting text alone (Houts et al., 2006; Schubbe et al.,

2020). Therefore, the use of pictures in cancer screening information leaflets could support informed choice by increasing engagement with, and improving understanding of, written information. In line with this, many guidelines, toolkits and assessment tools for print health education materials assert that pictures should be used in patient and public health information (see, Table 1).

However, there is limited guidance on what types of pictures to use, and under which conditions, to best facilitate different desired communication outcomes – reflecting a lack of available or consistent research findings. Most research into picture use in a health information context has not distinguished between different types of pictures, their effectiveness to communicate different types of message or their use in different health contexts (Jensen, 2011). Lack of clarity between types of pictures, as well as heterogeneity across study samples and contexts, is likely the reason why reviews of pictures in health information materials have concluded mixed results and why studies have difficulty replicating the results in applied settings (for example, Houts et al., 2006; Schubbe et al., 2020). Jensen (2011) determines that a more systematic investigation into the visual elements of health information communication is needed. To be able to investigate how elements within a picture impact the way health messages are received and consequent behavior change, it is necessary to have precise and shared ways of categorizing and describing these elements. This will also improve the communication of recommendations made to designers and providers of health materials.

The use of pictures in health communications is supported by the cognitive theory of multimedia learning which proposes that visual images have an active role in the process of meaning

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**Table 1.** Published guidelines and tools available for developing or evaluating print health information materials with items specific to using pictures.

| Citation                                        | Full title                                                          |
|-------------------------------------------------|---------------------------------------------------------------------|
| Guideline                                       |                                                                     |
| NCI (2018)                                      | Clear & Simple                                                      |
| Toolkits                                        |                                                                     |
| NHS (2003)                                      | Toolkit for producing patient information                           |
| CDC (2009) <sup>1,2</sup>                       | Simply Put V3                                                       |
| NWT Literacy Council (2015)                     | A plain language audit toolkit                                      |
| Assessment tools                                |                                                                     |
| BALD, Baker (1997)                              | Baker Able Leaflet Design                                           |
| BIDS, Bernier (1996)                            | Bernier Instructional Design Scale                                  |
| CDC (2019)                                      | Clear Communication Index                                           |
| Moody and Rose (2004) <sup>1</sup>              | ClearDOC index                                                      |
| CSAT, Guidry et al. (1998)                      | Cultural sensitivity assessment tool                                |
| EQIP, Moullet et al. (2004) <sup>2</sup>        | Ensuring Quality for Patients tool                                  |
| Kaphingst et al. (2012) <sup>1,2</sup>          | Health Literacy INDEX                                               |
| HLE2, Rudd et al. (2019)                        | Health Literacy Environment Assessment tool V2                      |
| PEMAT-P, Shoemaker et al. (2014) <sup>1,2</sup> | Patient Education Materials Assessment Tool for Printable materials |
| SAM-CAM, Helitzer et al. (2009)                 | Suitability and Comprehensibility Assessment of Materials           |
| TEMPED, Clayton (2009)                          | Tool to Evaluate Materials Used in Patient Education                |

<sup>1</sup>CDC (2009) toolkit has the most extensive guidance on using pictures in print health information materials; <sup>1</sup> advise keeping leaflets clear of irrelevant content; <sup>2</sup> advise keeping pictures clear of irrelevant content; NCI – National Cancer Institute, NHS – National Health Service, CDC – Centers for Disease Control and Prevention, NWT – Northwest Territories.

making and that message comprehension is supported when textual information is accompanied by visuals that are consistent with the message (Mayer, 1999). Where the goal is to increase understanding to support informed decision making, it is important that the pictures in cancer screening materials are relevant to the leaflet messages and contribute to comprehension of those messages. The use of pictures also supports the approach of Social Cognitive Theory, in modeling behaviors through showing people carrying out actions (Bandura, 1998). Modeling plays a key role in getting people to adopt new behaviors and is particularly relevant for cancer screening information as it includes instructions for completing screening and invitees often report practical barriers as a reason for not taking part (Kotzur et al., 2020).

In response to calls for more systematic investigations of pictures in health information, King (2015) conducted a content analysis of pictures present in cancer information materials produced in the United States of America (US) from four key health and cancer organizations. King (2015) found visual images were used more often in materials targeted to minority populations and materials about cancer prevention and detection. Also, pictures most often depicted people and behaviors being modeled/demonstrated. King (2015) considers these variations in picture use in terms of relevant theories but concludes that more theory-based research into the use of visual information in cancer screening material is required.

Content and style are key qualities to analyze when attempting to describe the technical elements of a picture (Willats, 1997). Picture content refers to what is being depicted within the picture and style refers to the methods of expression used to produce the picture. Additionally, function is an important quality to capture as it describes something about how the picture will be received and interpreted by the viewer. Picture function refers to the quality of the information provided by the picture (i.e., what the picture is doing as part of the information material). The categories of content, style and function, were used in the current study to guide a systematic and theory-led investigation of the use of pictures in recent UK cancer screening information materials.

The current study is a partial replication of King's (2015) study, applied to screening information materials in the UK. The aim is to describe current practice in the UK and consider this in terms of current visual communication theory, something that has not been done before. A comparison between the US and UK context will be valuable as, although similar in many ways (in culture, economics, politics and industry; Henrich et al., 2010), they have very different approaches to health care provision; healthcare is a nation-wide universal public service in the UK but not in the US. In addition, replication of King's (2015) study provides an opportunity for testing and refinement of the original coding frame.

## Aims

This study aims to extend the work of King (2015), on categorizing the use of pictures in print cancer screening information materials, in the UK context and to further develop empirically useful categories for describing pictures used in the cancer screening context.

The main objectives were as follows:

- Determine the extent to which pictures have been used in print cancer screening materials in the UK (Picture prevalence).
- Analyze the pictures by: content, style and function (Picture characteristics).
- Explore possible patterns in the way different picture characteristics have been used.

## Method

### Sample

#### Identifying and selecting the sample

The sample included any materials designed to be posted or handed to targeted readers, concerning any of the UK cancer screening programmes in operation at the time of the study (breast, bowel and cervical screening<sup>1</sup>) and, produced within

the ten years preceding the search date (i.e., 2009 or later). Only materials that had a version available in English were included. The sample did not include "Easy-read" materials designed specifically to be read with the support of another person. Where different versions of the same material were identified, the most recently published version was included in the sample.

Materials were identified through a hand search of the websites of seven UK cancer charities and public health organizations (National Health Service, nhs.uk; Macmillan, macmillan.org.uk; Cancer Research UK, cancerresearchuk.org; Bowel Cancer UK, bowelcanceruk.org.uk; Public Health England, gov.uk/government/organizations/public-health-england; NHS Wales, bowelscreening.wales.nhs.uk, Health & Social Care, cancerscreening.hscni.net). These seven organizations were selected as the main providers of advisory board approved and publicly trusted information about cancer or medical screening across the devolved nations (England, Wales, Scotland, Northern Ireland) in the UK. All materials were indicated on the websites as designed to be printed (e.g., described as leaflet/booklet or being in PDF print-ready format). The search was conducted during November 2019.

#### Final sample

There were 44 cases found during the search period that satisfied the inclusion criteria. Characteristics of the sample including cancer type, test types, provider, location, year produced and number of pages are reported in a data file accessible via Figshare (doi: 10.6084/m9.figshare.14483589).

#### Analysis

A basic content analysis (Drisko & Maschi, 2015) was used to give a systematic description of the prevalence and characteristics of pictures in the sample. Content analysis provides a systematic and replicable approach to summarizing the content of a sample of documents (Stemler, 2001).

#### Units of analysis: Pictures

All pictures in the materials were identified. The definition of picture was an image that visually resembles that which is being depicted, following Mitchell's (1986) definition, and the boundary of a picture was determined by the picture elements being self-contained, following Meynell's (2013) consideration of Willats (1997) description of a picture.

#### Coding manual development

A literature review was conducted to identify categories for usefully describing pictures in health information falling within the three picture elements; function, contents, and style. In addition, the primary researcher viewed, and made notes on, each picture as presented in its information material and in comparison to the other pictures. These notes were used to adapt, and add to, the categories identified from the literature to be suitable for the current study sample and to identify any additional categories where appropriate. A comparison between the categories used by King (2015) and the current study is provided in Table 2.

The coding manual was trialed and updated twice by LG and CH, for five pictures selected randomly from the sample. To test the validity of the coding manual, a new set of pictures was randomly selected and coded by the main researcher (LG) and an uninitiated coder (LF). Fifteen pictures were coded for contents and style, while 34 pictures were coded for function. Cohen's Kappa was used to test inter-rater reliability for the dichotomous codes. For the continuous codes, intra-class correlation estimates were calculated based on an absolute-agreement, 2-way mixed effects model. Most coding achieved good ( $n = 7$ ) to moderate ( $n = 11$ ) agreement (Altman, 1991). Twelve codes had too few occurrences across their variables for Kappa score to be calculated.<sup>2</sup>

#### Calculated variables

To determine the prevalence of picture use across the materials, the study recorded how often (frequency) pictures were used and how much surface space was dedicated to pictures

Table 2. Comparison of study characteristics between King (2015) and the current study.

|                        | King (2015)                                                                                                                                                                                            | Current study                                                                                                                                                                                                                                                                                                        |
|------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Sample</b>          |                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                      |
| Cases                  | Print cancer information material, United States (US).<br>$n = 147$ (25, related to cancer detection)                                                                                                  | Print cancer screening information materials, United Kingdom (UK).<br>$n = 44$                                                                                                                                                                                                                                       |
| Units                  | Images – Visual images and graphics, covering visual information, visual displays (graphs, charts and diagrams), pictures, computer renderings and technical medical imagery.<br>$n = 858$             | Pictures – A self-contained image that visually resembles the thing being depicted.<br>$n = 406$ (283, when logos excluded)                                                                                                                                                                                          |
| <b>Search strategy</b> |                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                      |
| Retrieval              | Requests made to organization.                                                                                                                                                                         | Hand search of organization websites.                                                                                                                                                                                                                                                                                |
| Dates                  | Between September 2010 and January 2011.                                                                                                                                                               | During November 2019.                                                                                                                                                                                                                                                                                                |
| Providers              | Four US national health organizations:<br>(1) American Cancer Society<br>(2) American Institute for Cancer Research<br>(3) Centers for Disease Control and Prevention<br>(4) National Cancer Institute | Seven UK health organizations that provide public information on the national cancer screening programmes <sup>2</sup> :<br>(1) National Health Service<br>(2) Macmillan<br>(3) Cancer Research UK<br>(4) Bowel Cancer UK<br>(5) Public Health England<br>(6) NHS Wales<br>(7) Health & Social Care Northern Ireland |

(Continued)

Table 2. (Continued).

|                      | King (2015)                                                                                                                                                                                                                               | Current study                                                                                                                                                                                                                                                                |
|----------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Inclusion criteria   | Produced anytime.<br>Available as single sheet unfolded (information sheet) or folded (pamphlet) or multiple sheets folded or bound (booklet).<br>Information was generally or specifically related to cancer.<br><br>Written in English. | Produced between 2009 and 2019.<br>Available as sheet unfolded (information sheet) or folded (leaflet) or multiple sheets folded or bound (booklet).<br>Information was about at least one of the nationally available cancer screening programmes.<br>Available in English. |
| Measurement          | Frequency: number of pages/panels with images out of total number of pages/panel.<br>Saturation: the surface area covered by images (units combined) out of the total surface area of the pamphlet (case).                                | Frequency: Quantity of pictures per case.<br>Coverage: percentage case surface area covered by rectangular regions containing the picture.<br>Mean document coverage.<br>Mean coverage per picture.                                                                          |
| Case characteristics |                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                              |
| Target population    | Sex.<br>Race/ethnicity.<br>Cancer site.<br>Cancer continuum.                                                                                                                                                                              | —                                                                                                                                                                                                                                                                            |
| Cancer topic         |                                                                                                                                                                                                                                           | Cancer site.<br>Cancer screening test.                                                                                                                                                                                                                                       |
| Unit characteristics |                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                              |
| Content              | Focal phenomena: people, objects, data.<br>(Where image content was primarily people) Sex.<br>Race/ethnicity.                                                                                                                             | Main depiction: none, scenery, a subject, an action, speech.<br>Quantity.                                                                                                                                                                                                    |
| People               |                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                              |
| Objects              | (Where image content was primarily objects) Object type.                                                                                                                                                                                  | Object type.                                                                                                                                                                                                                                                                 |
| Data displays        | (Where image content was primarily objects) Display type.                                                                                                                                                                                 | —                                                                                                                                                                                                                                                                            |
| Setting              | —                                                                                                                                                                                                                                         | Setting type.                                                                                                                                                                                                                                                                |
| Topic                | —                                                                                                                                                                                                                                         | Screening topic.                                                                                                                                                                                                                                                             |
| Message              | —                                                                                                                                                                                                                                         | (Where picture function was message) Screening message.                                                                                                                                                                                                                      |
| Point of view        | —                                                                                                                                                                                                                                         | Type of view.                                                                                                                                                                                                                                                                |
| Picture narrative    | —                                                                                                                                                                                                                                         | Presence.                                                                                                                                                                                                                                                                    |
| Style                | Composition: photographic, illustrated.                                                                                                                                                                                                   | Production: Photograph, Digital illustration, Analogue illustration.<br>Color or monochrome.<br>Marks.                                                                                                                                                                       |
| Word use             | —                                                                                                                                                                                                                                         | None or separate, Labeling, Sounds, Speech, Object, text.                                                                                                                                                                                                                    |
| Function             | Information conveyed: demonstrative/modeling, explanatory/describing, statistical/numerical information, comparison/juxtaposition, other.                                                                                                 | Picture function: Logos, Icons, Display, Message.                                                                                                                                                                                                                            |

\*At the time of data collection, NHS Scotland were using the information leaflets provided by Public Health England. NHS = National Health Service.

(coverage). Picture frequency was calculated across the entire sample (total number of pictures) and by case (number of pictures per print material). Picture coverage was calculated using the Nvivo 12 Pro region selection tool. The data were managed in SPSS v26.

$$\text{Mean Document coverage} = \frac{\sum \text{Coverage in each case}}{\text{number of cases}}$$

$$\text{Mean coverage per picture} = \frac{\sum \text{Coverage of each picture}}{\text{number of pictures}}$$

#### Coding categories

**Picture function.** The following four types of picture function were identified; Logos, Icons, Display pictures and Message pictures. Logos are pictures identifying a brand or organization. Icons are simple symbols that indicate the content of the text that follows. Display pictures are pictures that provide visual information without communicating a coherent message or functioning as a logo or icon (for example, to decorate the page, set the scene or show what something might look like). Message pictures are pictures used to communicate a coherent message (for example, explain how something works or a sequence of actions involved in completing a task). Logos and Icons are commonly used design terms while the terms

Display pictures and Message picture were developed for this analysis. See Supplementary material 1 for example picture extracts.

**Picture content.** The following categories of content were recorded for each picture; what the main depiction was (scenery, a subject, an action or speech, as well as, no depiction – which would be meaningless lines and shapes), the number of people, the types of objects (ranging from medical equipment to plants), the background setting (whether indoors, outdoors, medical, home, unclear or blank), what cancer screening topics were covered (ranging from anatomy to benefits of screening, as well as, no topic – indicating an entirely decorative picture), what cancer screening messages were included (ranging from procedural instruction to emotions experienced), the viewer's position within the picture's world (as part of it, as outside observer or having no presence) and whether the picture portrayed a narrative (a narrative being a sequence of connected events involving an actor and an action).

**Picture style.** The following methods of expression were recorded for each picture; how the picture had been produced (digitally, photographically, by hand or a mix), whether it was in color, what types of marks had been used (outline, fill, or a mix) and how words had been used (as labels, sounds, part of objects, parallel to the picture or within the picture).

Table 3. (Continued).

|                              | Display (n = 129) |      |               |      | Message (n = 53) |      |               |      |
|------------------------------|-------------------|------|---------------|------|------------------|------|---------------|------|
|                              | Frequency         |      | Mean Coverage |      | Frequency        |      | Mean Coverage |      |
|                              | n                 | %    | M%            | SD   | n                | %    | M%            | SD   |
| Anatomy                      | 26                | 20.2 | 0.97          | 1.03 | 4                | 7.5  | 1.68          | 1.20 |
| Signs of cancer              | 2                 | 1.6  | 0.50          | 0.39 | 0                | 0.0  | -             | -    |
| Cancer progression           | 0                 | 0.0  | -             | -    | 4                | 7.5  | 1.66          | 1.20 |
| Screening                    |                   |      |               |      |                  |      |               |      |
| - being invited              | 3                 | 2.3  | 1.25          | 0.90 | 1                | 1.9  | 2.39          | -    |
| - deciding to take part      | 2                 | 1.6  | 1.01          | 0.60 | 6                | 11.3 | 1.67          | 0.36 |
| - doing the test             | 50                | 38.8 | 1.86          | 2.56 | 17               | 32.1 | 4.00          | 7.15 |
| - receiving result           | 0                 | 0.0  | -             | -    | 1                | 1.9  | 1.43          | -    |
| - result possibilities       | 0                 | 0.0  | -             | -    | 15               | 28.3 | 1.05          | 0.58 |
| - benefits                   | 0                 | 0.0  | -             | -    | 14               | 26.4 | 1.48          | 0.87 |
| - adverse outcomes           | 0                 | 0.0  | -             | -    | 3                | 5.7  | 1.23          | 0.49 |
| Treatment                    | 0                 | 0.0  | -             | -    | 2                | 3.8  | 0.55          | 0.30 |
| Screening messages           |                   |      |               |      |                  |      |               |      |
| Procedure                    |                   |      | --            | --   | 27               | 50.9 | 2.97          | 5.81 |
| Outcomes                     |                   |      | --            | --   | 20               | 37.7 | 1.37          | 0.79 |
| Experiences                  |                   |      | --            | --   | 3                | 5.7  | 2.49          | 1.73 |
| Decisions                    |                   |      | --            | --   | 5                | 9.4  | 1.81          | 0.36 |
| Other                        |                   |      | --            | --   | 4                | 7.5  | 1.17          | 0.33 |
| Reader's Point of view       |                   |      |               |      |                  |      |               |      |
| Reader as part of situation  | 35                | 27.1 | 2.28          | 2.98 | 12               | 22.6 | 5.14          | 8.27 |
| Reader as outside observer   | 45                | 34.9 | 1.30          | 1.10 | 11               | 20.8 | 1.60          | 0.73 |
| Reader as having no presence | 47                | 36.4 | 1.10          | 1.06 | 30               | 56.6 | 1.16          | 0.91 |
| Picture narrative            |                   |      |               |      |                  |      |               |      |
| Yes                          | 1                 | 0.8  | 0.50          | -    | 12               | 22.6 | 5.28          | 8.23 |
| No                           | 128               | 99.2 | 1.51          | 1.86 | 41               | 77.4 | 1.24          | 0.81 |

<sup>a</sup>excluding alcohol. <sup>b</sup>excluding illicit drugs. <sup>c</sup>For display pictures, other included feces. For message pictures, other included a building, a post box, feces, a sun and clouds.

(n = 43/129). The second most common type of display picture did not portray a screening topic but did include people, objects and background settings (n = 23/129).

The most common type of message picture did not portray a narrative, portrayed a screening topic, contained no setting, contained no people and either contained objects (n = 26/53) or did not (i.e., lines and shapes not forming an object; n = 10/53).

#### Picture style

Logos were either digital illustrations (n = 107/123) or digital illustration in combination with analogue illustration (n = 16/123). They were more often in color (n = 76/123) and most often created with only fill markings (n = 88/123), with 23 being outline only and 12 having both marking styles. All logos had a word or words in them, such as the organization's or campaign's name.

Icons were entirely digitally illustrated (n = 101/101) and more often in color (n = 76/101). Icons were created with an even range of marking styles (Outline only = 34; Fill only = 32; Outline and Fill = 35). Only 15 (14.9%) icons contained words, and all were used as labels.

Display pictures were most often photographs (n = 74/129), followed by digital illustrations (n = 44/129), produced in color (n = 114/129), created without outline markings (fill only = 94/129), and contained no words (n = 80/129). Where words were used, they were for labeling (n = 28), were part of objects (n = 21), or were part of text (n = 4). There were no words used to portray sound or speech. When text was included (n = 4) it was situated parallel to the pictorial images (Table 4).

Message pictures were most often digital illustrations (n = 35/53). Most message pictures were produced in color (n = 44/53). There were 31 (58.5%) message pictures created with blocks of color (only fill markings) and 21 (39.6%) created in combination with an outline (outline and fill markings). Only one (1.9%) message picture was a line drawing without solid sections of color. Most message pictures included words (n = 44/53), with many (n = 28) containing text. The only type of words not used were sound words. The text was integrated with the pictorial images in 16 of the cases and parallel in the other 12 (Table 4).

#### Discussion

##### Picture prevalence in cancer screening information

Most of the print materials produced for the purpose of communicating UK cancer screening information to invitees followed health communications guidelines by including visual information, with the materials containing an average of 6 pictures and 7% surface area dedicated to pictures (after discounting logos). Health communication guidelines stipulate using pictures wherever they may support or facilitate communicating a message within a document. The materials in our sample contain very similar messages, following guidelines on what information should be told to invitees of a screening programme (National Quality Forum, 2016, p. 9; Public Health England, 2009). Therefore, it could be expected that similar numbers of pictures are used across the sample. However, the number of pictures used, and the size of the surface area dedicated to pictures, varied greatly across the materials.

Table 4. Frequencies of style in display and message pictures in print cancer screening materials.

|                       | Display (n = 129) |       |               |      | Message (n = 53) |      |               |      |
|-----------------------|-------------------|-------|---------------|------|------------------|------|---------------|------|
|                       | Frequency         |       | Mean Coverage |      | Frequency        |      | Mean Coverage |      |
|                       | n                 | %     | M%            | SD   | n                | %    | M%            | SD   |
| Production            |                   |       |               |      |                  |      |               |      |
| Photograph            | 74                | 57.4  | 1.56          | 1.75 | 6                | 11.3 | 3.52          | 2.72 |
| Digital illustration  | 44                | 34.1  | 1.06          | 1.04 | 35               | 66.0 | 2.18          | 5.01 |
| Analogue illustration | 7                 | 5.4   | 1.44          | 0.50 | 2                | 3.8  | 1.37          | 0.01 |
| Analogue & digital    | 1                 | 0.8   | 0.94          | -    | 2                | 3.8  | 0.22          | 0.01 |
| Photograph & digital  | 3                 | 2.3   | 6.78          | 6.11 | 8                | 15.1 | 1.71          | 1.19 |
| Color                 |                   |       |               |      |                  |      |               |      |
| Yes                   | 114               | 88.4  | 1.56          | 1.95 | 44               | 83.0 | 2.33          | 4.58 |
| No                    | 15                | 11.6  | 1.02          | 0.63 | 9                | 17.0 | 1.31          | 1.27 |
| Marks                 |                   |       |               |      |                  |      |               |      |
| Outline               | 2                 | 1.6   | 1.26          | 0.76 | 1                | 1.9  | 1.24          | -    |
| Fill                  | 94                | 72.9  | 1.66          | 2.08 | 31               | 58.5 | 2.27          | 5.31 |
| Outline & fill        | 33                | 25.6  | 1.05          | 0.95 | 21               | 39.6 | 2.02          | 1.95 |
| Word use              |                   |       |               |      |                  |      |               |      |
| None or separate      | 80                | 62.0  | 1.45          | 1.36 | 9                | 17.0 | 1.40          | 1.71 |
| Labeling              | 28                | 21.7  | 0.99          | 1.00 | 8                | 15.1 | 1.76          | 1.11 |
| Sounds                | 0                 | 0.0   | -             | -    | 0                | 0.0  | -             | -    |
| Speech                | 0                 | 0.0   | -             | -    | 5                | 9.4  | 2.32          | 1.27 |
| Object                | 21                | 16.3  | 2.35          | 3.50 | 9                | 17.0 | 4.83          | 9.74 |
| Text                  | 4                 | 3.1   | 3.84          | 5.65 | 28               | 52.8 | 2.77          | 5.66 |
| Integrated            | 0                 | 0.0   | -             | -    | 16               | 57.1 | 2.09          | 1.78 |
| Parallel              | 4                 | 100.0 | 3.84          | 5.65 | 12               | 43.0 | 3.69          | 8.52 |

King's (2015) study found a similar, but slightly greater, percentage of materials surface area to be covered by visual images in information materials about cancer detection in the US (11% vs 7%; Table 5), while both studies found the same average number of pictures per case ( $M = 6$ ). The larger surface area taken up by pictures in the US sample may be accounted for by the inclusion of data graphs in the unit of analysis and would suggest data graphs require more space. The similarity in picture prevalence suggests that picture placement across cancer information leaflets is similar across the two contexts. This may potentially come down to principles of composition, where designers in both countries are aiming for the same ratio of pictures to text and white space. King's (2015) sample had more pictures with people in them (57% vs 39%) and more photographs (57% vs 50%), suggesting US cancer organizations are more reliant on pictures of people and on photographs than providers of information about cancer screening in the UK when developing information materials. Taken together, this perhaps reflects different tones used in healthcare messages between the US and the UK. The private healthcare system of the US means that most healthcare needs to "sell itself" to the public, leading to US healthcare information having a tone of product advertisements that rely on images of attractive, healthy and happy looking people. The national healthcare

system of the UK positions health as a social responsibility (Brookes, 2021), leading to UK healthcare information having a tone of an instruction manual with educational diagrams and images of the tests, equipment and procedure.

### Contributions to theory

Firstly, this analysis described picture characteristics across three categories; content, style, and function. These categories remained a stable way of grouping the different variables that were analyzed. Working to capture each of these categories gives a holistic assessment of individual pictures that integrates a description of the informational (content) and esthetic (style) qualities and the picture's relationship to the leaflet message (function).

This study determined four useful distinctions (logo, icon, display, message) to describe the different functions of pictures present in cancer screening materials. Firstly, the acknowledgment of logos and icons as pictures with unique functions is an important contribution to the analysis of pictures in print information material. These visual images can often be overlooked in health communication research (for example, King, 2015). However, their presence will contribute to a viewer's overall interpretation of an information leaflet (for example,

Table 5. Comparison of study findings between King (2015) and the current study.

|                    | King (2015)                                                                                                                                 | Current study                                                                                                                                                     |
|--------------------|---------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Picture prevalence | Average of 6 pictures per case.<br>Pictures covered an average of 9.4% surface area of each case.<br>(10.6% for cancer detection materials) | Average of 9 pictures per case (6, when logos excluded)<br>Pictures covered an average of 7.3% surface area of each case (6.8%, when logos excluded)              |
| People             | People were the predominant feature of 57% pictures (496 vs 228 object and 134 data).                                                       | People were in 38.7% (70 vs 112 no people) of display (45.7%) and message (20.8%) pictures.                                                                       |
| Object             | Food or drink were the most common type of object in pictures predominantly featuring object (31.2%), followed by parts of people (22.6%).  | Parts of people were the most common type of object (44.0%) in display (45.0%) and message (41.5%) pictures, followed by medical or scientific equipment (34.6%). |
| Production         | Photographic production was used for 56.8% (487 vs 371 illustrative).                                                                       | Photographic production was used for 50% (91 vs 91 illustration) of display (59.7%) and message (26.4%) pictures.                                                 |

Pieters & Wedel, 2018) as well as contribute to the visual complexity of the material. Visual complexity being both the objective feature and subjective perception of visual information related to the quantity, variety, arrangement and regularity of the visual elements (Berlyne, 1958; Pieters et al., 2010). Therefore, icons and logos are also worth recognizing and accounting for in descriptions of print health information.

Secondly, the classification of display pictures versus message pictures is a novel approach to describing types of pictures in health communication. A strength of the two categories is that they depart from the affect and cognitive dichotomy promoted by some recent health communication research (Bol et al., 2014; Cho et al., 2018) and bring the focus on the properties of the information being provided. The categories of affective and cognitive pictures are suitable as experimental conditions. However, during coding scheme development it was identified that when used to describe pictures in a naturalistic context, these categories create a false dichotomy, as a single picture can both facilitate learning and induce an emotional response, and such cognitive and emotional information is processed in an integrated way (VanRullen & Thorpe, 2001). Therefore, these two qualities should be kept separate when assessing picture use in health information.

#### Implications for research

In addition to describing pictures used in cancer screening print materials, this study also set out to provide empirically useful categories for describing such pictures.

The coding scheme and questionnaire developed in this study achieved high inter-coder reliability rates between the primary researcher and a second coder who had not been involved in the development of the coding scheme and had never formally analyzed pictures before. Therefore, the coding scheme was a valid and understandable way of describing the pictures, giving support for the use of the coding questionnaire<sup>3</sup> in future studies which could be used to replicate the research in different contexts (e.g., with other health leaflets or repeated in the future to measure changes) to build the field of visual health communication research.

The coding scheme developed in this study provides a scaffolding for the development of a standardized classification system for research into pictures in print health communication. This would support a more systematic investigation into pictures used in health information communication – a need highlighted previously (Jensen, 2011). The categories could be used as the starting point for deciding and describing which picture characteristic are being manipulated in a study, to be able to untangle the impact different manipulations have on different communication outcomes.

#### Implications for practice

A large proportion of the pictures did not connect directly with messages within the materials as they did not include a cancer screening topic. With visual images being the initial point from which viewers make a judgment about the leaflet (due to the picture superiority effect, Geise & Baden, 2015), it will be important for the pictures to indicate the type of information

being provided or the relevance to the viewer. Pictures that do not connect with the target audience and do not communicate the relevance of the information will discourage people from reading the materials. Accordingly, many existing print health information guidelines advise keeping leaflets and pictures clear of irrelevant content (see, Table 1). Current practice was found to be inconsistent with the advice to keep pictures entirely relevant to the leaflet message.

Topics that were particularly missing from the pictures were being invited, deciding to take part ( $n = 8$ ), receiving result ( $n = 1$ ), result possibilities ( $n = 15$ ), screening benefits ( $n = 14$ ) and potential adverse outcomes ( $n = 3$ ). Future design work could focus on balancing the portions of pictures across these different screening topics. Shaffer and Zikmund-Fisher's (2013) taxonomy of screening narratives – identified while developing the coding scheme – was helpful in determining a broad range of screening topics capable of capturing the nuance of people's cancer screening experiences and decisions.

The pictures in the cancer screening materials analyzed in this study often did not portray an action and they seldom included people. Considering most of these pictures were about doing a screening test, more pictures should be showing an action being carried out as modeling behaviors is an important mechanism for learning and adopting new behavior (Bandura, 1998). Where the goal is to support informed choice, it is important that pictures of people modeling screening-related behaviors are used in cancer screening materials.

There were very few pictures that portrayed a narrative across the screening information materials. The success of comics (a media that uses spatially juxtaposed panels to portray a sequence of events or aspects; McCloud, 1994) in communicating health information (Noe & Levin, 2020) demonstrates the utility and suitability of using pictures that portray narratives for cancer screening communication efforts. Despite the low number of pictures used to portray a narrative across the cancer screening material analyzed, there were picture narrative examples for all the types of topics relevant to making and acting on a decision to screen (i.e., procedure, outcomes, experiences and decision dimensions). There were also picture narratives that included more than one type of topic, demonstrating the capacity and potential for picture narratives to communicate the entire range of cancer screening information within future leaflets. This content analysis identified that cancer screening information materials have underutilized picture narrative form.

A clear finding from this analysis is that cancer screening information materials include fewer, and have less surface area dedicated to, pictures that perform a message function compared to pictures that perform a display function, indicating that pictures are predominantly used to highlight or support the written messages rather than as a conduit of the messages themselves. In some situations, display pictures are the most suitable type of picture to use, as with anatomical drawing used to show what parts of the body look like. However, most messages within screening information materials go beyond showing what something looks like – from describing the process involved in doing the screening to the potential positive and negative outcomes of taking part. Therefore, cancer screening material designers should look to use a larger portion of pictures that convey coherent cancer screening messages.

Many of the display pictures were photographs of people. Such pictures do not need to be limited to a display function and future design work could focus on conveying relevant cancer screening messages through photographic pictures of people (for example, photos illustrated with symbols such as arrows and crosses or sequences of photos depicting speech, thought and behavioral enactment).

### Limitations

On reflection, there are some picture characteristic categories that could be useful for cancer screening picture researchers that were not included in the coding scheme in this paper. Although we coded whether any action was depicted in the picture and what the screening topic the picture was portraying, we did not specifically code for instances where a picture was modeling cancer screening behavior. This specificity may be necessary for studies considering the interaction between different picture characteristics (such as ethnicity cues and behavior being modeled) on communication outcomes (such as raising awareness or changing behavior). Details were not kept about the ethnicities of the models or how recognizable the household objects would be in different cultures. Researchers ought to measure these factors if looking into diversity or image relevance in relation to the ethnicities of the target audience. King (2015) demonstrates a way of measuring this. Picture structure (such as positioning) was not coded for. Structure is a key message feature (Shen & Bigsby, 2012) alongside the contents and the style of a picture but was not within the scope of the current analysis.

This study did not evaluate the characteristics of the picture portraying a narrative present as there were so few in the sample. A future analysis of the contents of health communication pictures could include a qualitative description of the picture narratives used. The sample included only materials that were publicly available online. Any materials developed locally by individual clinics have not been included. Therefore, the findings reflect the standards of the centralized screening programmes.

### Conclusions

This study provides a description of the types of pictures being used in current UK cancer screening information materials, and their prevalence. This has allowed for a reflection on current practices, with a consideration of where best practice guidelines are not being followed. This study has highlighted that the following types of pictures have been underused in recent cancer screening information materials produced in the UK: pictures that communicate a coherent message, picture that portray a narrative, pictures modeling a screening-specific behavior and pictures conveying experiences or decision dimensions involved in cancer screening participation.

The study offers researchers a theory-based context-appropriate coding scheme for describing the characteristics of a cancer screening information picture. This coding scheme could also be adapted to be used in other print health communication contexts and could be adopted in future studies to support a more systematic scientific investigation of pictures in health communication.

### Notes

1. Prostate cancer screening was not in operation and a lung screening programme was being trialed but not yet available as a UK-wide screening programme.
2. A full description of the coding categories, the decisions behind them and their related interrater reliability can be accessed via Figshare (doi: 10.6084/m9.figshare.17282543).
3. The coding questionnaire can be accessed via Figshare (10.6084/m9.figshare.17283044).

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No potential conflict of interest was reported by the author(s).

### Data availability statement

The data that support the findings of this study are openly available at <http://doi.org/10.6084/m9.figshare.14483589>.

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## Appendix 4: Coding manual of picture content and style in print screening materials

### Coding manual - Cancer screening leaflet pictures v1.2

\* Required

#### 1. Picture case reference number

Please type the number that is above the picture \*

Enter your answer

#### 2. Depictions

What is the main information being depicted in the picture?

Please select one of the following:

Note.

\*The term 'subject' does not mean topic and instead refers to 'things' such as objects or people.

\*If the picture is of two or more people who look like they might be talking but there is no depiction of what they are saying (e.g. no speech bubble or quoted text), select 'Action' rather than 'Speech'.

\*If the picture is of a speech bubble but there is no actor assigned to that speech bubble (i.e. in the picture the speech isn't coming from a person or object), the picture would be coded as Subject - as the speech in this instance is an object image rather than an action \*

- ☐ No depiction - for example, meaningless shapes
- ☐ Scenery - Only shows natural features of surroundings for example a landscape or a city scape AND there is no particular object/s or person/s that are the focus of the picture
- ☐ Subject/s - There is/are object/s and/or a person/people in the picture that are meant to be the focus of the picture (this includes pictures showing anatomy) AND there is no action or speech
- ☐ Action - A subject or subjects are engaging in a movement with a predictable purpose or outcome AND there is no speech
- ☐ Speech - A subject or subjects are producing speech, most likely depicted with a speech bubble above someone's head

#### 3. People

How many people are in the picture?

Please type the quantity:

Note.

Only count as a person if;

1) has at least a face (containing any identifiable feature of a face i.e. eyes, nose, mouth, eyebrows) or back of head (containing any identifiable feature of a back of a head i.e. hair, ears)  
AND

2) if part of body is present, that part of body is in an expected position relative to the face for a human body \*

Enter your answer

#### 4. Objects

What types of objects are in the picture?

Please select all of the following that apply \*

- ☐ Medical or scientific equipment - Anything produced for medical or scientific testing or that is required in a medical or scientific procedure (e.g. x-ray films, syringes)
- ☐ Medication/pills (excluding illicit drugs) - (e.g. packet of tablets, bottled prescription medicine)
- ☐ Food - include fruit if presented as food
- ☐ Sports or exercise equipment - Any equipment used for sports or exercise (e.g. running machine, tennis racket)
- ☐ Forests/trees/plants - include if they are a clear object in the picture
- ☐ Parts of people - (e.g. limbs, organs, anatomy)
- ☐ Microscopic organisms/molecules - (e.g. cells, viruses, proteins)
- ☐ Unhealthy products - (e.g. alcohol, tobacco, illicit drugs)
- ☐ Signs - (i.e. no entry, fire exit or road signs)
- ☐ Household items - Things you are likely to find in people's homes (e.g. house furniture, appliances (i.e. sink), basic DIY tools, communications and tech devices (i.e. phones, laptops, tablets))
- ☐ Other

#### 5. Setting

What is the setting of the picture?

Please select one of the following

Note.

\*If the outdoors can be seen through a window in the picture, then select one of the indoor option, because the picture is 'set' indoors if you are looking through a window to the outside. \*

- ☐ None - the background in the picture is either blank or a block of one colour
- ☐ Unknown - there is a background image in the picture but it might be too blurry or zoomed in to be able to tell what the setting is
- ☐ Indoors somewhere - the background looks like the setting is indoors but its unclear where
- ☐ Indoors home - the background looks like the setting is inside a home
- ☐ Indoors doctors - the background looks like its indoors in maybe a doctor's office or lounge or health clinic/centre
- ☐ Outdoors - the setting in the picture is outdoors

## 6. Screening topics

What topic is covered in the picture?

Please select all of the following that apply:

Note.

There may be other topics present but the options included are the ones that the research study is interested in \*

- ☐ No screening topic - none of the following topics described
- ☐ Anatomy - the picture is showing, describing or explaining some human anatomy
- ☐ Cancer progression - the picture depicts the way cancer develops at a cellular biological level
- ☐ Signs of cancer - the picture depicts the signs and symptoms someone may show if they have cancer
- ☐ Being invited to Screening - this may be someone receiving a letter invitation or an explanation of how people get invited
- ☐ Deciding to take part in Screening - this may be people asking questions about why they should do screening, talking about how they came to decide to do screening or it could be telling the viewer 'this is something/s to take into account if deciding to do screening
- ☐ Doing the Screening test - the picture depicts the procedure/screening process
- ☐ Receiving Screening results - depicts someone receiving their screening test results or describes how this might happen
- ☐ Screening result possibilities - the picture depicts one or more of the types of results people receive from doing a screening test (these are: no abnormality found, no cancer found, unclear test, abnormality found, cancer found)
- ☐ Screening benefits - picture includes information about, or a portrayal of, the benefits of screening
- ☐ Screening adverse outcomes - picture includes information about, or a portrayal of, the potential side effects and negative outcomes of doing screening
- ☐ Cancer treatment - the picture is showing, describing or explaining a treatment method or different treatments for cancer

## 7. Message

Is there a specific and clear message being communicated with the picture? and, if so, what is this  
Please select all that apply

Note.

Many pictures do not have a specific and clear message. For example, a photo of a person using a laptop or an anatomical drawing with the names of the organs. The only information these pictures tell you is 'what something, someone or a situation looks like'. In this case, please select 'there is no message'.

Pictures with a message tell you more than this. For example, a picture showing you the correct way to open a test kit or a picture of people talking and you can tell what each person is saying or a picture that tells you 'if you do [x], [y] will happen'. The information these pictures tell you ranges from 'how to do something' to 'what someone is thinking or feeling' to 'how something works or what might happen'. In this case, please select the type of message that is in the picture.

\*

☐ There is no message - (for example, when describing what the picture is trying to tell you, you might be able to say something like "here is a person looking at a laptop" but you couldn't go more conceptually complex than that)

☐ Procedure - The message is about technical details about doing the screening test. i.e. a description of the procedure

☐ Outcomes - The message is about consequences of participating or not participating in screening (For example: Physical Outcomes ("during the screening, they found a lump and cut it out there and then") or, Psychological Outcomes ("I was relieved when I got the results back")

☐ Experiences - The message is about people's experiences. These experiences could be Feelings (i.e. Emotions e.g. sad, stressed, worried) or, Visceral experience (i.e. Bodily sensations e.g. pain, discomfort, tingling) or, Time and energy (e.g. "I had to take time off work to go to the screening")

☐ Decisions - The message is about people's decisions or what factors are involved deciding to do screening. This could be Identifying important decision dimensions (e.g. "I needed to think about whether the stress of waiting for the results would be too much for me") or, Assigning weight to decision dimensions (e.g. "I didn't want to have the stress of waiting for the results but I also really didn't want the uncertainty of not knowing what the results might have been.") or, Consideration of strategies for information acquisition (e.g. "I went on to the internet and used a cancer charity website to find information and I asked some of my friends") or, Identifying important information/facts (e.g. "I found out that even if you get a result that says you are clear, it doesn't necessarily mean you don't have cancer.") or, Identifying important values (e.g. "I want to be there when my grandchildren grow up so that's why I did screening")

☐ Other

## 8. Viewer's position

What point of view does the viewer have within the picture?

Please select one of the following: \*

☐ Reader as part of what going on - Characters 'talk' to the viewer or 'look' at viewer (for example, you might feel a person in the picture is talking to you) Or, the 'camera' angle might be positioned in a way that put the viewer within the action (for example, picture looks like you are looking down at your own hands)

☐ Reader as outside observer - Use of point of view or images makes viewer feel they are watching the story. Or there is a narrator narrating. (for example, you might feel like you are looking in on a conversation)

☐ Reader as having no presence - The world in the picture doesn't involve or position the viewer. The above other views are not present

## 9. Picture narrative

Is the picture a picture narrative?

Note.

Picture narrative = a picture that portrays a sequence of (at least two) connected events (someone or something does something). Some examples:

- One person saying something then another person saying something.

- A person doing something and then the same person doing something else. \*

☐ Yes - is a picture narrative

☐ No - is not a picture narrative

## 10. Production

How was the picture made?

Please select all of the following that apply:

Note.

The picture could be a photograph that's been edited on a computer and then drawn over with a pen. In this case, all three of the options below should be selected \*

- ☐ Photograph - Looks created by a camera
- ☐ Digital illustration - Looks created on a computer crisp digitalised marks, shapes and lines
- ☐ Analogue illustration - Looks created not on a computer, such as hand drawn
- ☐ None of the above

## 11. Colour

Is the picture in colour? \*

- ☐ No - if picture is black, white and grey. Also, if the only colour present in the picture is the pages background colour. (i.e. the background of the picture is likely transparent)
- ☐ Yes

## 12. Markings

What markings make up the picture?

Please select all that apply.

Note.

\*A photograph that has not been edited digitally will be fill only because objects in the real world don't have lines drawn around their edges

\*Pictures can have one or both of the options below. \*

- ☐ Outline - The picture includes drawn outlines of the objects
- ☐ Fill - The picture includes solid blocks of colour or shading

## 13. Word use

Are there words in the picture and how are they used?

Please select all that apply \*

- ☐ No words - There are no words in the picture
- ☐ Labeling - There is a word or words being used to name subjects (i.e. objects or people)
- ☐ Sounds - There is a word or words depicting sound
- ☐ Is part of object - There is a word or words making up a part of an image within the picture i.e. the writing is part of an object in the the picture (for example, a picture that has an image of a calendar with a name of a month written on it)
- ☐ Text - There are words making up a sentence or sentences

Submit

## Chapter 5 Appendixes

### Appendix 5: Catalogue of cancer comics identified and reviewed

| Case Index | Title                                                                                       | Author/s (creative team)                                                                                         | Publisher/syndicate                                         | Country | Year |
|------------|---------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|---------|------|
| *1         | the death of captain marvel                                                                 | Jim Starlin                                                                                                      | Marvel comics                                               | US      | 1982 |
| 2          | Why, charlie brown, why? A story of what happens when a friend is very ill                  | Charles Schulz                                                                                                   | peanuts                                                     | US      | 1990 |
| *3         | Our Cancer Year                                                                             | Harvey Pekar and Joyce Brabner. Art by Frank Stack                                                               | Da Capo Press Inc; Gph edition                              | US      | 1994 |
| *5         | A lighter look at the "C" word: More cartoons and comments on cancer                        | Steve Gould                                                                                                      | Mondays                                                     | US      | 1997 |
| 6          | Luann (various)                                                                             | Greg Evans                                                                                                       | Universal Uclick                                            | US      | 1998 |
| 7          | Dykes to Watch Out For (various)                                                            | Alison Bechdel                                                                                                   | Firebrand Books.                                            | US      | 2003 |
| *8         | Janet and Me: An Illustrated Story of Love and Loss.                                        | Stan Mack                                                                                                        | Simon & Schuster                                            | US      | 2004 |
| 10         | Where's moms hair: a family journey through cancer                                          | Debbie Watters                                                                                                   | second story                                                | Canada  | 2005 |
| *11        | Mammoth: a pictorial odyssey of the adventures of a fourth grade teacher with breast cancer | Rosalind (Tucky) Fussell                                                                                         | author house                                                | US      | 2005 |
| *12        | a cartoonist's guide to prostate cancer                                                     | Paul Miller                                                                                                      | Xlibris Corporation                                         | US      | 2005 |
| *13        | Testicular Cancer Screening and Diagnosis: Get on the Ball!                                 | David Brame; Joyce Nyhof-Young                                                                                   | University Health Network                                   | Canada  | 2005 |
| *14        | Cancer Made Me a Shallower Person: A Memoir                                                 | Miriam englebert                                                                                                 | Harper                                                      | US      | 2006 |
| *15        | Cancer Vixen: A True Story                                                                  | Marisa Acocella Marchetto                                                                                        | Alfred A. Knopf; 1 edition                                  | US      | 2006 |
| *16        | Mom's Cancer                                                                                | Brian Fies                                                                                                       | Abrams; 01 edition                                          | US      | 2006 |
| 17         | captain cutaneum (various, 5)                                                               | Ruskin R Lines                                                                                                   | self-published                                              | US      | 2006 |
| *18        | Lisa's Story: The Other Shoe                                                                | Tom Batiuk                                                                                                       | Kent State university Press: literature and medicine series | US      | 2007 |
| 19         | My dad has cancer                                                                           | Emily Marie Boggs; Meredith Davis                                                                                | Xlibris                                                     | US      | 2007 |
| 21         | Captain Cure (various, 3)                                                                   | Ty Wakefield                                                                                                     | self-published (AR Comics)                                  | US      | 2008 |
| 22         | Marvel Divas (various)                                                                      | Roberto Aguirre-Sacasa and Tonci Zonjic                                                                          | Marvel comics                                               | US      | 2009 |
| *23        | between friends (various)                                                                   | Sandra Bell-Lundy                                                                                                | King Features Syndicate. Inc. World                         | Canada  | 2009 |
| 24         | Funky Winkerbean (3-26-09)                                                                  | Tom Batiuk                                                                                                       | Funky Winkerbean                                            | US      | 2009 |
| *25        | A Courageous Journey: A Couple's Experience with Testicular Cancer                          | David Brame, David Kolin, Peter Chung, Joyce Nyhof-Young                                                         | University Health Network                                   | Canada  | 2009 |
| 27         | Seeds                                                                                       | Ross Mackintosh (Author, Illustrator), Benjamin Shahrabani (Editor), Eddie Deighton (Editor), Jon Sloan (Editor) | Com.x                                                       | US      | 2011 |
| *28        | Tchao Günther / nipple war (various)                                                        | Lili Sohn                                                                                                        | self-published                                              | Canada  | 2014 |
| *29        | The Inflatable Woman                                                                        | Rachael Ball (Author)                                                                                            | Bloomsbury Publishing                                       | UK      | 2015 |
| *30        | the story of my tits                                                                        | Jennifer Hayden                                                                                                  | Top Shelf Productions                                       | US      | 2015 |
| *32        | cancer owl (various)                                                                        | Matthew Paul Mewhorter                                                                                           | online                                                      | US      | 2016 |

|     |                                                                            |                                                                                                               |                                                                                                                           |            |              |
|-----|----------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------|------------|--------------|
| *36 | Cancer Comics                                                              | Anna Moriarty Lev                                                                                             | wordpress.com                                                                                                             | US         | 2011         |
| *39 | John: Life is worth fighting for                                           | Luc Colemont [script]; Mario Boon [script, artwork]; Mariacristina Federico [colours]                         | Ballon Media/ European comics                                                                                             | Belgium    | 2019         |
| *40 | Relatively Indolent but Relentless: A Cancer Treatment Journal             | Matt Freedman                                                                                                 | Seven Stories Press.                                                                                                      | US         | 2014         |
| *41 | In-Between Days: a memoir about living with cancer                         | Teva Harrison                                                                                                 | House of Anansi Press Inc.                                                                                                | Canada     | 2017         |
| *42 | When David Lost His Voice                                                  | by Judith Vanistendael (Author, Illustrator), Nora Mahony (Translator)                                        | SelfMadeHero                                                                                                              | Belgium    | 2012         |
| *43 | Embroidered Cancer Comic                                                   | Sima Elizabeth Shefrin                                                                                        | Singing dragon                                                                                                            | Canada     | 2016         |
| 51  | Slow Death (Special Cancer and Medicine Issue, No 10)                      | various. Editor: Ron Turner                                                                                   | Publisher: Last Gasp                                                                                                      | US         | 1979         |
| *60 | About Betty's Boob                                                         | written by Vero Cazot and illustrated by Julie Rocheleau, Edward Gauvin (trans.) and Deron Bennett (letterer) | BOOM! Studios                                                                                                             | US/Belgium | 2018         |
| 61  | Regret: A Cancer Survivor's Story                                          | Stan Yan                                                                                                      | self-published                                                                                                            | US         | -            |
| 62  | Nistar                                                                     | by Shira Frimer, Tuohy Timothy (Editor), Josef Rubinstein (Illustrations)                                     | self-published                                                                                                            | US         | 2013         |
| 63  | Terminally Illin'                                                          | Kaylin Andres and collaborator Jon Solo                                                                       | Last Gasp                                                                                                                 | US         | 2012         |
| *68 | Medikidz series (various)                                                  | various                                                                                                       | Medikidz USA / Jumo health                                                                                                | US         | 2009 to 2018 |
| *69 | ladies wouldn't you like to know                                           |                                                                                                               | american cancer society                                                                                                   | US         | 1969         |
| *71 | Probably Nothing: A Diary of Not Your Average Nine Months                  | Matilda Tristram                                                                                              | Penguin/Viking                                                                                                            | UK         | 2013         |
| *74 | Kimiko does cancer                                                         | Kimiko Tobimatsu (author), Keet Geniza (illustrator)                                                          | Arsenal Pulp Press                                                                                                        | Canada     | 2020         |
| *75 | Doctor OBI Cancer Chronicles Vol. 1: Cervical cancer and the HPV vaccine   | Joshua Frankel (written by), Ian McGinty (drawn by)                                                           | global oncology                                                                                                           | Nigeria    | 2019         |
| *76 | CANCER, A COMIC STRIP: THE ADVENTURES OF CRAFTY UNCONTROLLED MUTANT CELLS. | Emma Conway                                                                                                   | SCQ THE SCIENCE CREATIVE QUARTERLY                                                                                        | Canada     | 2014         |
| *77 | A comic strip of my cancer experience                                      | Magalie                                                                                                       | magsblog.com                                                                                                              | Australia  | 2014         |
| *78 | Finding the funny; After the funny                                         | Jade Blue                                                                                                     | <a href="https://jadesdoodles.wordpress.com/finding-the-funny/">https://jadesdoodles.wordpress.com/finding-the-funny/</a> | UK         | 2017         |
| *79 | Then This Happened....: A Diary About Breast Cancer                        | Tom Ray                                                                                                       | American Bandito                                                                                                          | US         | 2018         |
| 80  | the domino effect                                                          | Joan Blaney, Pamela Campbell-Morris                                                                           | University of Leicester Health Matters project and The Centre for BME Health                                              | UK         | 2020         |
| 81  | An Elegy for Amelia Johnson                                                | Andrew Rostan                                                                                                 | BOOM! - Archaia                                                                                                           | US         | 2011         |
| 82  | Perrywinkle                                                                | Susie Gander, Robin Jones                                                                                     | self-published                                                                                                            | UK         | 2017         |
| 83  | Tumor                                                                      | Joshua Hale Fialkov                                                                                           | Oni Press                                                                                                                 | US         | 2009         |
| 84  | Lafayette: Our Cancer Year                                                 | Lafayette-West community, editor Rosanne Altstatt                                                             | Purdue University                                                                                                         | US         | 2011         |
| *85 | Smoking and Cancer                                                         | G educators                                                                                                   | Department of National Health and Welfare, Canada                                                                         | Canada     | 1963         |

Note. <sup>a</sup> Books created from comics that were originally comic strips

## Chapter 6 Appendixes

### Appendix 6: Study 3 - Workshop schedule

#### Start

Billy will talk about: 1) The plan for today, 2) Who the facilitators are, 3) What the consent form is. Then, you will be asked to sign a consent form.

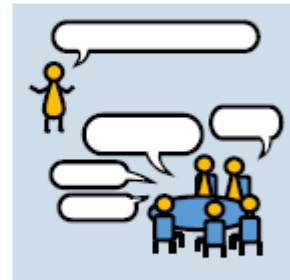
---

#### Part 1 - Sharing and exploring what we know and what we think

Lauren will talk about research findings and get you to think about these things:

- How to get and keep attention.
- How to help people make decisions and act on their decisions.
- What information people want about lung screening.

Tea break



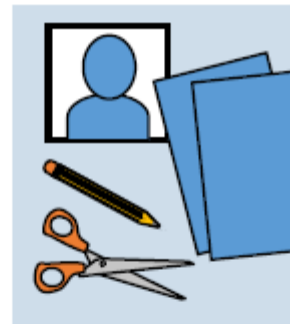

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#### Part 2 - Coming up with ideas for the leaflet

Billy will lead you through these activities:

- In groups, create a profile of someone invited to screening.
- Then, individually, come up with leaflet designs.
- Then, in groups, make a poster of leaflet design ideas.
- Then, describe your design ideas to the other groups.

Lunch break




---

#### Part 3 - Choosing your favourite ideas for the leaflet

Give opinions and feedback on leaflet ideas.

Tea break




---

**End** 2pm

Lauren will: 1) Give you info about the future of the project, 2) Ask for your feedback on the project, 3) give you £20 as a thank you.

## Appendix 7: Study 3 - Participant information sheet (short version)



### Community workshop to develop a health information leaflet

#### Short Participant Information Sheet

**What am I being invited to?** We are organising a workshop at PossilPoint community centre so that people from the community can be included in designing health leaflets that are meant for them. This is being done as part of a PhD student, Lauren Gatting's, research into health message design. She wants to show that involving the community in the design of leaflets will make them easier to read and more likely to be read. She also wants to see if a community workshop is a good way of doing this.

**Where and when the workshop will take place.** Possilpoint community centre, on January 22nd 2020, from 10 am to 2 pm.

**What you will do, if you decide to take part.** During the workshop, we will be coming up with design ideas for a leaflet about lung screening. The leaflet is going to be about lung screening because it is a particularly relevant health topic for people in your neighbourhood. You will be asked to give your thoughts and opinions in a way that best suits you (you could either say your thoughts or write them down or even draw them). There will be several people helping with taking notes and there will be an artist making drawings from what people say during the workshop.

**What you will get, if you take part.** A lunch will be provided and you will receive £20 as a thank you for taking part. With your permission, you will also be told about the results of the workshop and the leaflet that is made.

**How the workshop will be recorded.** During the workshop, there will be audio-recorders placed on each table to capture what people are saying. With everyone's permission, Lauren Gatting will take the audio-recordings from these devices and save them onto a secure password protected computer that only she will have access too. Also with your permission, Lauren will take photos of notes and drawing made during the workshop. She will listen to the recordings and look at the photos to help with writing about the workshop.

Your name will be kept only on the consent form that you fill out. The only way for your name to be linked with your other information will be through an identification number written at the top of you consent form that can then be used to identify your other data. Only the researcher and research quality regulators will have access to your consent form. Information from the workshop will be used in future reports and presentations, but you will not be personally identified (i.e. identified by name).

**Who is organising the workshop.** The workshop is being organised by Lauren Gatting as part of her PhD, which is being funded by the University of Glasgow's LKAS scholarship. The workshop will be run by Billy Aird who is being paid through this PhD funding.

**If you have any questions,** or would like more information, please contact Lauren Gatting either by email [L.gatting.1@research.gla.ac.uk](mailto:L.gatting.1@research.gla.ac.uk) or by telephone

There is also a long version information sheet. Contact Lauren Gating if you would like one of these.



## Community workshop to develop a health information leaflet

### Privacy notice

*The University of Glasgow will be what's known as the 'Data Controller' of your personal data processed in relation to Lauren Gating's PhD research project. This privacy notice will explain how The University of Glasgow will process your personal data.*

#### Why we will be processing your data

We are collecting personal data about your name, age, gender, ethnicity, socioeconomic status, general health status in order to describe the characteristics of the people who took part in the research. We will collect and process this data for this purpose only.

#### What is the legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is for research and public interest.

#### What will happen to your data

All the personal data you submit will only be processed by staff at the University of Glasgow in the United Kingdom. Your personal data will be saved in a pseudonymised form so that your name will not be directly linked to the other personal data you submit. Your data will be stored within a secure computer system. Your data will be stored 3 years by the primary researcher on the University of Glasgow computer system within a password-protected profile, while the research is being conducted. Your data will then be transferred and stored for ten years on the University of Glasgow's research repository to allow for any necessary quality assurance checks in the future. After this time, the data will be securely deleted.

#### What are your rights

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. You may also have the right to object to the processing of data and the right to data portability.

If you wish to exercise any of these rights, please submit your request via the [webform](https://www.gla.ac.uk/myglasgow/dpfooffice/gdpr/gdprrequests/) (<https://www.gla.ac.uk/myglasgow/dpfooffice/gdpr/gdprrequests/>) or contact [dp@gla.ac.uk](mailto:dp@gla.ac.uk).

#### Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer at [dataprotectionofficer@glasgow.ac.uk](mailto:dataprotectionofficer@glasgow.ac.uk)

If you are not satisfied with our response, you can complain to the Information Commissioner's Office (ICO) <https://ico.org.uk/>

## Appendix 8: Study 3 – Consent form



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

Centre Number:

Project Number:

Title of the project:

**Community workshop to develop a health information leaflet**

### Consent form

Name of Researcher: Lauren Gattig

Write your  
initials here

Please put your initials in the boxes next to each correct statement

|                                                                                                                                                                                                                                                                                                                                         |                          |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| I confirm that I have been given the Participant Information Sheet (version 1, dated 18/09/2019) and the Privacy Notice (version 1, dated 18/09/2019) and the researcher has gone through it with me, allowing me the opportunity to think about the above information and ask questions, and understand the answers I have been given. | <input type="checkbox"/> |
| I confirm that I know my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.                                                                                                                                                                      | <input type="checkbox"/> |
| I confirm that I understand that my information and things that I say in the workshop may be quoted in reports and articles that are published about the study, but my name or anything else that could tell people who I am will not be revealed.                                                                                      | <input type="checkbox"/> |
| I confirm that I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers.                                                                                                                               | <input type="checkbox"/> |
| I agree to the workshop being audio-recorded.                                                                                                                                                                                                                                                                                           | <input type="checkbox"/> |
| I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.                                                                                                                     | <input type="checkbox"/> |
| I agree to take part in the study.                                                                                                                                                                                                                                                                                                      | <input type="checkbox"/> |

| Name of participant (your name) | Date (today's date) | Signature |
|---------------------------------|---------------------|-----------|
| <br>                            | <br>                | <br>      |

To be completed by the researcher

| Name of researcher | Date | Signature |
|--------------------|------|-----------|
| <br>               | <br> | <br>      |

18/09/2019

LG\_WS\_Consent\_Form\_v1

## Appendix 9: Study 3 - Demographic questions

Participant ID: \_\_\_\_\_



**University of Glasgow** | College of Medical,  
Veterinary & Life Sciences

### Community workshop to develop a health information leaflet

## Demographic form

Q1) What is your age? \_\_\_\_\_ years

Q2) What is your sex? \_\_\_\_\_

Q3) What is your ethnicity? \_\_\_\_\_

The follow questions are to get an idea of your living situation:

Q4) What area of Glasgow do you live in? \_\_\_\_\_

Q5) Do you own or rent your accommodation?

- ☐ Owned outright
- ☐ Being bought on mortgage
- ☐ Rent from local authority
- ☐ Rent from housing association
- ☐ Rent from private landlord
- ☐ Other \_\_\_\_\_
- ☐ Not applicable

Q6) What type of accommodation do you live in?

- ☐ Whole house
- ☐ Flat or maisonette in block
- ☐ Assisted living accommodation
- ☐ Caravan/houseboat
- ☐ Other \_\_\_\_\_
- ☐ Not applicable

Q7) Do you live with a partner?

- ☐ Yes, Married
- ☐ Yes, Unmarried
- ☐ No, Never married
- ☐ No, Widowed
- ☐ No, Divorced or separated
- ☐ Other \_\_\_\_\_

More questions on the back

**Q8) What is your highest formal education qualification?**

- ☐ Highers / O-Grade / Certificate of Secondary Education
- ☐ Vocational qualifications / NVQ1+2
- ☐ Advanced Higher / A-level / NVQ3 / Certificate of Sixth Year Studies
- ☐ Bachelor Degree / NVQ4
- ☐ Masters / PhD
- ☐ Other \_\_\_\_\_
- ☐ No formal

**Q9) What type of employment do you have?**

- ☐ Retired
- ☐ Unemployed
- ☐ Part-time employment
- ☐ Full-time employment
- ☐ Self-employed
- ☐ Paid sick leave
- ☐ Unpaid sick leave

**Q10) How many cars or vans do you own? \_\_\_\_\_****Q11) In the last couple of months, how has your physical health been?**

- ☐ Excellent      ☐ Very good      ☐ Good      ☐ Fair/ok      ☐ Poor

**Q12) In the last couple of months, how has your mental health been? (this includes stress, depression, and problems with emotions)**

- ☐ Excellent      ☐ Very good      ☐ Good      ☐ Fair/ok      ☐ Poor

This is the end of the demographic questions.

Thank you for taking the time to answer them.

## Appendix 10: Study 3 - Participant information sheet (long version)



University of Glasgow | Institute of Health & Wellbeing

Administration Building, Gartnavel General Hospital, Glasgow G12 0XH

### Participant information sheet (long version)

**The title of the study is...** 'Community workshop to develop a health information leaflet'.

#### Introduction

You have been invited to take part in a workshop as part of a PhD student, Lauren Gattings's, research project. This letter gives you information about the study, to help you decide if you want to take part.

The researcher has an ethical duty to make sure that you know why the research is being done and what it will involve, before you agree to take part. So, please do tell the researcher, Lauren, if there is anything that does not make sense and feel free to ask me for more information. Their contact details are at the end of this letter.

#### What is the purpose of this study?

The study is part of a wider project looking at creating accessible, engaging and supportive health information, working with a community group.

#### Reasons for the study:

- To design a lung screening information leaflet that is engaging (likely to be read), accessible (easy to read and understand) and supportive (helps with making decision and planning to screen) for anyone invited to lung screening.
- To involve people who would be invited to lung screening to ensure the leaflet is helpful for people invited to screening in the future.
- To involve communities that are often underserved by health communication and cancer screening programmes to ensure the leaflet can help those with greatest need.

#### Outcomes that we hope to achieve:

- To produce a lung screening leaflet that is helpful for people who will most benefit from lung screening (50 to 70 year olds, with a smoking history that puts them at high risk) and is particularly helpful for people most often under-served in health care.
- To show one way that people from the community can be included in designing health leaflets that are meant for them.

#### Who is conducting the research?

The research is being carried out by Lauren Gattings from the Institute of Health and Wellbeing at the University of Glasgow, with funding from Lord Kelvin Adam Smith scholarship.

**Why we are inviting you.**

The workshop is for men and women aged between 50 and 65, who are or have been heavy smokers (smoking equivalent to ten cigarettes a day for 30 years or more and not stop smoking more than 15 years ago) and live in Possil, Glasgow. We are inviting you to participate in the workshop because you are a part of this group and have shown interest in taking part in the workshop.

**What you will be asked to do, if you take part in the study.**

You will be asked to go to Possilpoint community centre for the workshop. For about 2.5 hours of the workshop, you will be involved in designing a leaflet about lung screening (we have planned activities that will support the group in coming up with design ideas). For about 45 minutes there will be a lunch break. For the rest of the workshop time there will be several short breaks, an introduction to the day and a thank you at the end. After the workshop you will not be required to do anything further but we will send you the results of the study if you wish.

**Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you may receive now or in the future.

**Who has reviewed the study?**

The study has been reviewed and approved by the University of Glasgow MVLS Ethics committee. The aim of the ethics committee is to protect your safety, rights, wellbeing and dignity.

**Confidentiality**

All the information you give us is strictly confidential. All audio-recordings will be stored securely and your name will not be held with the recording. Notes will be taken from the recording and the recordings will then be destroyed. Your name will not be held with the notes. Only the research team will have access to the information.

**What happens to the information that is collected?**

With your permission, the workshop will be audio recorded so that the researcher can evaluate the success of the workshop. Lauren Gating will take the audio-recordings from these devices and save them onto a secure password protected computer that only she will have access too. Also with your permission, Lauren will take photos of notes and drawing made during the workshop. She will listen to the recordings and look at the photos to help with writing about the workshop.

Your name will be kept only on the consent form that you fill out. The only way for your name to be linked with your other information will be through an identification number written at the top of your consent form that can then be used to identify your other data. Only Lauren and research quality regulators will have access to your consent form. Your data will be stored within a secure computer system. Your data will be stored 3 years by the primary researcher on the University of Glasgow computer system within a password-protected profile, while the research is being conducted. The data will then be transferred and stored for ten years on the University of Glasgow's research repository to allow for any necessary quality assurance checks in the future. After this time, the data will be securely deleted.

Information from the workshop will be used in future reports and presentations, but you will not be personally identified (i.e. identified by name). The information collected should help to improve the information we give people about lung screening in the future and help them make decisions about taking part in the screening programmes. If you would like a copy of the published results of the research let the researcher know during the workshop or contact us at the address given below and we will be happy to send them to you.

**What will happen if I don't want to carry on with the study?**

At any time during the study, if you do not wish to carry on you may withdraw, without giving any reason. The data you submit can be excluded from the study and destroyed, on request.

**What are the possible benefits of taking part?**

You will receive £20 as a thank you for your time and a hot lunch. We hope that the workshop is an enjoyable social event. You will also be helping people in your community by designing a health leaflet that will be most helpful to them.

With the information you provide during the workshop, we hope to identify ways to improve the way information is given to people about lung screening to help them to decide whether to take part and support them in taking part if that is their decision.

**What are the possible drawbacks of taking part?**

It is possible that during the workshop you may find a topic sensitive or upsetting. You are free to ask the facilitator to move on to another subject or to take a break or stop. It is important for you to understand that you are not required to discuss anything that you do not want to and you should discuss only the things which you feel are relevant. You also have the right to leave at any time.

**If you have a complaint about any aspect of the study**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance (contact details below). If you are unsatisfied with the response and would like to speak to the Principle Investigator for the project, contact Kathryn Robb on 0141 211 0685.

**Further information and contact details**

If you have any questions about the study, please call or text Lauren Gating on or email [L.Gating.1@research.gla.ac.uk](mailto:L.Gating.1@research.gla.ac.uk)

**Thank you very much for considering taking part in our research.**

## Appendix 11: Study 3 - Discussion prompts

### Topic 1: How to get people's attention and keep it

1. What do they like and dislike in the example leaflets and why?
2. Ask if the following design suggestions are a good or bad idea and, if so, why and how:
  - using shock tactics
  - being personal
  - being relatable
  - using stories
  - using illustrations and diagrams
3. What pictures in the example leaflets do they like and dislike? And, why?
4. Other things they would put in the leaflet?
5. Are there other ways they would grab people's attention, to the leaflet?
6. Are there other ways they would keep people's attention, in the leaflet?

### Topic 2: What information people want about lung screening

7. Ask participants if they think each of the following types of information should be included. And why. And what do they think about these things.
  - Info about lungs
    - What they look like
    - How they work
  - Info about lung cancer
    - How many people get lung cancer
    - What it is and how it is caused
    - How curable it is
    - What affects curability
  - Info about early detection
    - That finding cancer early increases chances of survival
  - Info about the screening test
    - What the test machine looks like
    - How the test machine works
    - Chances of getting an incorrect result either
  - Info about drawbacks
    - Radiation tiny amounts from the test machine
    - Finding and treating some tumours that might never become life threatening
    - An incorrect result that says you have cancer when you don't
  - Info about treatment
8. What would be people's reasons for going for screening or not going for screening.
9. Do the leaflets do a good job at helping people make a decision about whether to do lung screening or not?
10. What have they heard about cancer screening?
11. What have they heard about lung cancer?

## Appendix 12: Study 3 - Example reference materials used during workshop

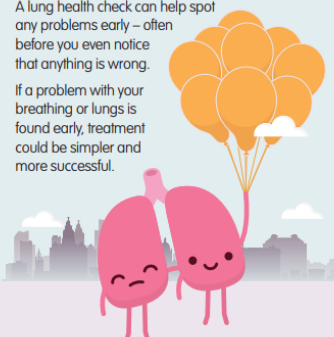
### LOOKING AFTER YOUR LUNGS

Your lungs work hard every minute of your life. As you get older it's worth having them checked out.

#### GOOD IDEA

A lung health check can help spot any problems early – often before you even notice that anything is wrong.

If a problem with your breathing or lungs is found early, treatment could be simpler and more successful.

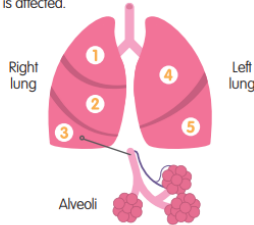


#### Michele's story

“Lung health checks are all about finding any problems with your lungs as early as possible, when there are more treatment options. And as a lung cancer survivor myself, I know how effective early treatment can be. That's why I'd encourage everyone to go for a lung health check – whether you think there's a problem or not.”

### YOUR LUNGS COULD BE EASIER TO FIX THAN YOU THINK

- You have two lungs, made up of 5 sections called lobes.
- Each lobe is made up of thousands of tiny grape-like sacs, called alveoli.
- If there is a problem on one bit of the lung, early treatment can focus just on the bit that is affected.



Any questions, please call the team on **0151 254 3032**.

Translation available on request  
 若有需要時將會翻譯成中文。  
 সস্ত্রম এন্ড অস্ট্রম করানোর ব্যবস্থা করা হবে।  
 अनुवाद करने पर अनुवाद करने की व्यवस्था की जाएगी।  
 घेनडी वरुन 'डे उरनम' वरुन 'अ' नरेगा  
 Marka la soo codsado ayaa la turjumi doona  
 درخواست کرنے پر ترجمہ فراہم کیا جائے گا۔  
 Tiumaczenie dostępne na prośbę  
 Braille, audio and other formats also available

This leaflet is a locally-adapted version of a leaflet originally created by the Department of Behavioural Science and Health at University College London (UCL) in partnership with Resonant Media, which is licensed under CC BY. Few design provided by Carbon Creative.




## M.O.T. FOR YOUR LUNGS

A new **FREE** NHS lung health check for people aged 58-75

### M.O.T. FOR YOUR LUNGS

People in the area aged 58 to 75 are being offered a new **FREE** NHS lung health check.

Run by specially trained nurses, they are an easy way to find out how well your lungs are working.

If needed, you'll get care and treatment to help breathe new life into your lungs.

The checks are for people aged 58 to 75 who have ever smoked, or who are in this age range and have a condition called COPD (Chronic Obstructive Pulmonary Disease).

**You are invited to a lung health check whether you feel fine or not.**



#### Jane's story

“I felt quite worried when I received a letter inviting me to have a lung health check because I have been a smoker in the past. But the nurse I saw was very reassuring and not judgemental at all.

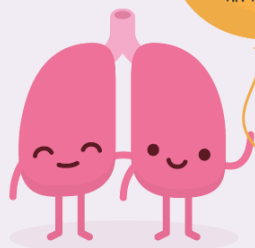
We had a chat about my general health and then she did a breathing test with me - the results were fine. I was so relieved, and I felt pleased that the lifestyle changes I've made have made a difference to my health.”

### BENEFITS OF THE LUNG HEALTH CHECK



- Talk through your questions and feel reassured
- Find out about having a breathing test or lung scan
- No judgements on smoking
- Local and easy to get to
- FREE to attend

**"THESE FREE LUNG HEALTH CHECKS ARE A GREAT WAY TO GIVE HARD-WORKING LUNGS AN M.O.T."**



**Deborah Fleetwood,**  
Nurse,  
Healthy Lungs Programme.

### WHAT YOU'LL GET

- First you'll be asked some questions about your breathing and about your overall lung health.
- Then you may be offered a breathing test. By blowing into a machine, you'll be told whether there are any problems that need taking care of.
- The nurse may also talk to you about having a lung scan to check for any early signs of lung cancer.
- You'll have plenty of time to chat to the nurse and ask any questions.
- You can bring a friend, family member or partner with you on the day if you want to.

#### MAKE AN APPOINTMENT NOW

To book an appointment for a **FREE** lung health check at a suitable time for you, please call **0151 254 3032**.

#### Steve's story

“I've been a smoker for almost 40 years, so attending a lung health check made complete sense to me.

During my appointment, I was offered a scan which showed some small shadows on my lungs called nodules. They told me these are fairly common, and thankfully it wasn't lung cancer. A second scan showed they had gone, but getting checked out helped put my mind at ease. I would definitely recommend it.”

Produced for the NHS Lung Health Checks. Designed by Carbon Creative based on original leaflet created Department of Behavioural Science and Health at University College London (UCL) in partnership with Resonant Media. 2019

[https://www.liverpoolccg.nhs.uk/media/3679/20550\\_liverpool-mot-for-your-lungs.pdf](https://www.liverpoolccg.nhs.uk/media/3679/20550_liverpool-mot-for-your-lungs.pdf)

## STEPS TO CONSIDER



**What's this going to cost me?**  
Lung cancer CT screening exams for eligible individuals are covered by insurance programs including Medicare / Medicaid, although insurance programs vary in the deductibles and co-pays. Contact your insurance plan for coverage details. If you are uninsured the cost can range from \$300-\$500\*  
\*In New York, the average cost of a pack of cigarettes is about \$74.00; a pack-a-day habit adds up to \$420 per month or \$5,040 per year.

**What's next?** Visit your doctor to talk about getting a low-dose CT scan to screen for lung cancer. You will discuss your complete health history and get a clear explanation about the possible benefits and risks. Ask your doctor for a referral to a screening center experienced in reviewing low-dose CT scan and lung cancer early detection. Use the cut-off below to help you discuss this with your doctor.

Get here and take with you when you visit your doctor:

- 1 Because of my age and smoking history, I would like to talk about getting a low-dose CT scan for lung cancer screening.
- 2 Can you explain the benefits and risks of this procedure?
- 3 Please refer me to a screening center experienced in reviewing low-dose CT scan and lung cancer early detection.

For more information visit **nysmokefree.com** or call **1-866-NY-QUITS** (1-866-497-8437)  
Looking to talk to other smokers trying to quit? Or talk to a Quit Coach online? Join the smoke-free community: **qunity.nysmokefree.com**  
Or join on on...   
Social support can increase your chance of quitting successfully by **50%**.  
So get social!

## LUNG CANCER SCREENING

**Early detection saves lives.**

New York State Smokers' Quitline / nysmokefree.com / 1-866-497-8437  
Developed by Roswell Park Cancer Institute Services at Roswell Park Cancer Institute / Buffalo, NY

## WHY SPIRAL CT SCAN?



**Screening for lung cancer is here and it can save your life!** The evidence is in; a low-dose CT scan is the only proven way to detect signs of lung cancer before there are any symptoms in people at high risk. Lung cancer is most treatable when it is found in the earliest stages.

### Why all the excitement?

-  Because lives can be saved, especially since lung cancer kills more people each year than all major cancers combined...
-  and now we know that low-dose CT scan is a proven way to detect lung cancer early when it is most treatable and curable...
-  this means many lives each year will be saved by early detection using low-dose CT lung cancer screening... one can be yours!

## ADVICE FROM A SURVIVOR



*If I hadn't been screened for lung cancer, I probably wouldn't be here today.*  
**Charlene,**  
Lung Cancer Survivor

**Should I get the low-dose CT scan lung cancer screening?** Low-dose CT scan for lung cancer is recommended if you answer yes to the following 3 statements used to identify those at high risk.

- ☒ I am 55 to 75 years old
- ☒ I am a current or former smoker who quit within 15 years
- ☒ Do you smoke or did you quit less than 15 years ago?

**Do you meet some, but not all the examples above? Talk to your doctor.**



Your doctor will answer any questions you may have concerning the low-dose CT scan, and whether it's right for you.

## INFORMATION ABOUT YOUR CT SCAN

**What is getting a low-dose CT scan like?** The scan is a low dose of radiation, similar to what you might be exposed to from a chest x-ray.

- 1 The CT scan takes a 360-degree picture of your lungs.
- 2 You hold your breath for seconds.
- 3 Non-invasive, painless and takes about 10 minutes.

**What you need to know.** Like all screening tests, there are pros and cons to consider. Talk with your doctor.

 **PRO**  
Lung cancer screening can reduce the risk of dying from lung cancer by catching and treating it early.

 **CON**  
There is a chance of a "false alarm." This means the results look like a dangerous cancer but it isn't and this leads to many tests.

**Old News Worth Repeating...** Smoking is the number one risk factor for lung cancer and is linked to 90% of lung cancers. Quitting smoking remains the single best way to reduce your risk of lung cancer.

### WHAT YOU'LL GET

First you'll be asked some questions about your breathing and how you feel to find out about your overall lung health.

Then by blowing into two hand-held machines, you'll be told whether there are any problems that need taking care of.

The nurse may also talk to you about early signs of lung cancer, and will ask if they can take samples of blood, breath, sputum and cheek cells (by rubbing a swab along the inside of the cheek). You can decide about this on the day or later.

You'll have plenty of time to chat to the nurse and ask any questions. Bring a friend, family member or partner with you on the day if you want to.

"These lung checks are a brilliant idea - a great way to give hard-working lungs a service"

Bernie, Nurse  
University College Hospital

### LUNG HEALTH CHECKS

GPs in the local area are inviting people aged 60 to 75 for the Lung Health Check.

Look out for an invitation in the post.

For more information call our freephone advice service on 0800 [redacted] or call/text 07469 [redacted] or email us at [redacted]

If you are unable to read this leaflet because English is not your first language, please ask someone who speaks English to telephone the Freephone helpline on 0800 [redacted] for further information and help.

Bangla: [redacted]

Turkish: [redacted]

### M.O.T. FOR YOUR LUNGS

A new NHS Lung Health Check for people aged 60 to 75

Please read if you are aged 60-75

### M.O.T. FOR YOUR LUNGS

People aged 60 to 75 are being offered a new LUNG HEALTH CHECK.

Run by specially trained nurses, they are an easy way to find out how well your lungs are working.

And, if needed, you'll get care and treatment to help breathe new life into your lungs.

The checks are for people aged 60 to 75 who have ever smoked. You are invited whether you feel fine or not, and whether or not you have any lung problems.

You can bring a friend, family member or partner with you, if you'd like.

"If they can give me some extra years with my grandkids, I might even be lucky enough to be able to walk them down the aisle."

Bernard, 69, London

### BENEFITS OF THE LUNG HEALTH CHECK

- ✓ Free
- ✓ Local and easy to get to (at either the Homerton or University College Hospital)
- ✓ Talk through your questions over a cup of tea
- ✓ Find out about having a lung scan
- ✓ No judgements on smoking

"I started smoking when I was 14. When you go back 40-odd years, we didn't know that cigarettes caused all these problems. It's good to know no one is going to give me a hard time at the Lung Health Check."

Maggie, 60, London

### LOOKING AFTER YOUR LUNGS

#### HOW THE NHS CAN HELP

Your lungs work hard every minute of your life.

As you get older, it's worth checking things out.

#### GOOD IDEA

The Lung Health Check can spot problems early - often before you notice anything, when treatment could be simpler and more successful.

#### YOUR LUNGS COULD BE EASIER TO FIX THAN YOU THINK

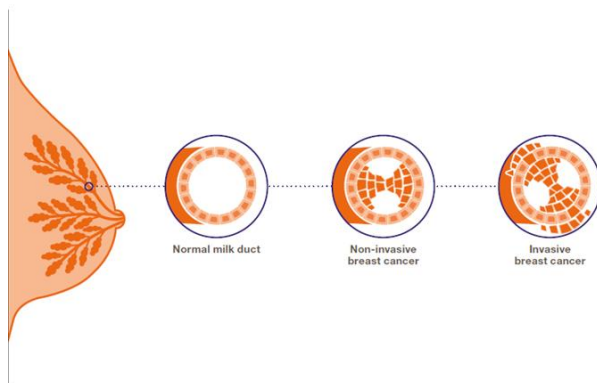
You have two lungs, made up of 5 sections called lobes.

Each lobe is made up of thousands of tiny grape-like sacs, called alveoli.

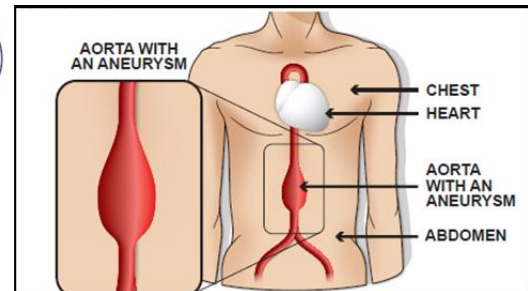
If there is a problem on one bit of the lung, early treatment can focus just on the bit that is affected.

Included as supplementary materials in Quaife et al (2020)

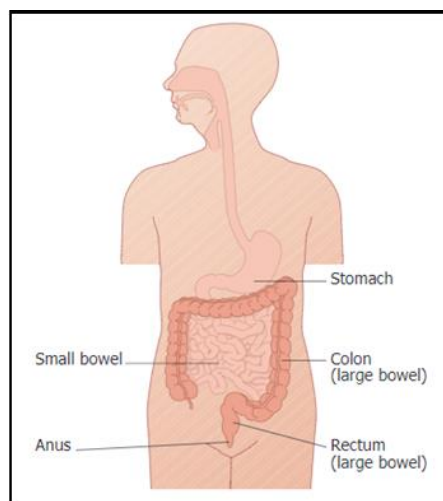
A)



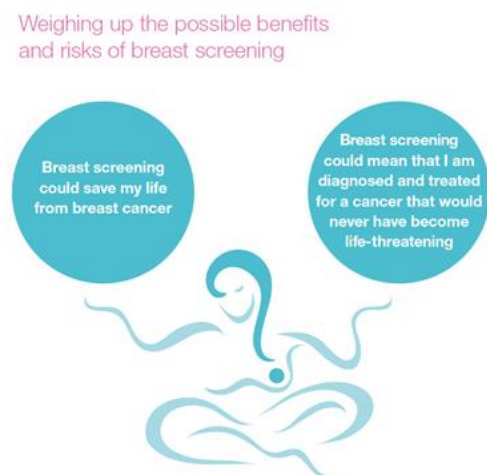
B)



C)



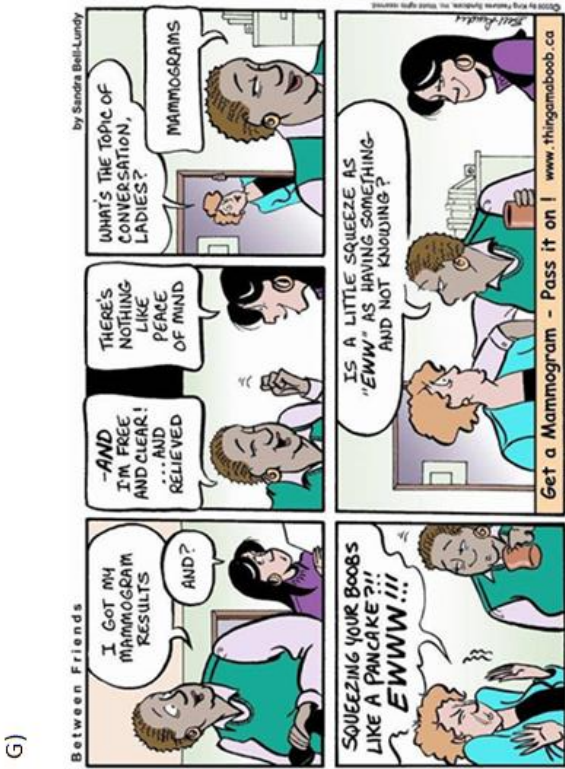
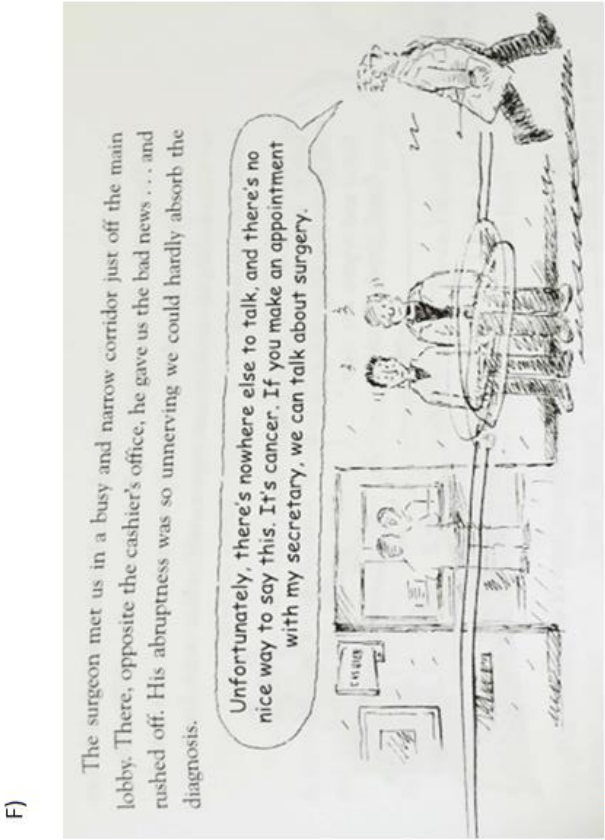
D)



E)



- A) Public Health England. (2019). NHS breast screening: Helping you decide. *Public Health England*. Page 8
- B) Public Health England. (2019). AAA screening: information for health professional. *gov.uk*. Accessed 25 March 2022 from <https://www.gov.uk/government/publications/abdominal-aortic-aneurysm-screening-how-it-works/aaa-screening-information-for-health-professionals>
- C) NHS Cancer Screening Programmes. (2016). BOWEL CANCER SCREENING: The Facts. *Department of Health*. Page 4
- D) Public Health England. (2019). NHS breast screening: Helping you decide. *Public Health England*. Page 10
- E) Kari Moden, *Silhouettes of Hope* (2010) - produced for the American Cancer Society



- F) Luc Colemont and Mario Boon, *John: Life is worth fighting for* (Belgium: Europe comics, 2019), page 16
- G) Sandra Bell-Lundy, *Between Friends* (Canada: King Features Syndicate, Inc., 2009)
- H) Stan Mack, *Janet and Me: An Illustrated Story of Love and Loss* (New York: Simon & Schuster, 2004), page 15

# Appendix 13: Study 3 - Participant's posters

Workshop table 1

## Cancer affects any age

## TRUG STORIES

### Michael's story

Michael has been a smoker for 20 years. He has been told by his doctor that he has a high risk of developing lung cancer. He is now looking for ways to quit smoking and reduce his risk of developing lung cancer.

### YOUR LUNGS COULD BE LARGER THAN YOU THINK

Each time you breathe in, you take in a tiny amount of dust or smoke. Over time, this can build up in your lungs and make them smaller. This can lead to lung disease and even lung cancer.

### Steve's story

Steve has been a smoker for 30 years. He has been told by his doctor that he has a high risk of developing lung cancer. He is now looking for ways to quit smoking and reduce his risk of developing lung cancer.

## LUNG Cancer screening (a CT scan test)

### The facts

- Lung cancer is the leading cause of cancer death in the UK.
- Most lung cancers are found in people who have smoked or who are currently smoking.
- Lung cancer screening can find small lung nodules before they become big enough to cause problems.
- Lung cancer screening can help you to live longer.

## Get Screened!!

# LUNG CANCER SCREENING

## Early saves lives

## CONTACT

### my smokefree.com

1-866-MY-QUIT  
quit@my smokefree.com

### BENEFITS OF THE LUNG HEALTH CHECK

- ✓ It's free
- ✓ It's local and easy to get to
- ✓ Talk through your questions
- ✓ Find out about having a lung scan

### For more information on smoking, please contact:

1-866-MY-QUIT  
quit@my smokefree.com

Workshop table 2

① Cancer affects EVERYONE

② MAKE AN APPOINTMENT NOW  
 Book an appointment for a FREE  
 Lung Health Check at your local  
 GP, 0115 951 1111 or 0800 000 0000

HEALTHY CANCER ④

③ YOUR LUNGS COULD BE EASIER TO FIX THAN YOU THINK  
 The lungs have a large, spongy, air-filled structure.  
 Each lung is made up of thousands of tiny  
 groups like sacs, called alveoli.  
 If there is a problem in one of the lungs,  
 both lungs can take over the work for the  
 affected lung.

Signs + Symptoms

- cough
- breathing problems
- tired, fatigue
- losing weight
- exhausted
- gaining weight

My life my health  
 My life my health  
 My life my health

⑦ I just had a check up.  
 My lungs are healthy

⑥ Daddy don't do it!

BENEFITS OF THE LUNG HEALTH CHECK

- ✓ It's free
- ✓ It's local and easy to get to
- ✓ Talk through your questions
- ✓ Find out about having a lung scan
- ✓ No judgement on smoking

LOOKING AFTER YOUR LUNGS  
 What you can do to keep your lungs healthy

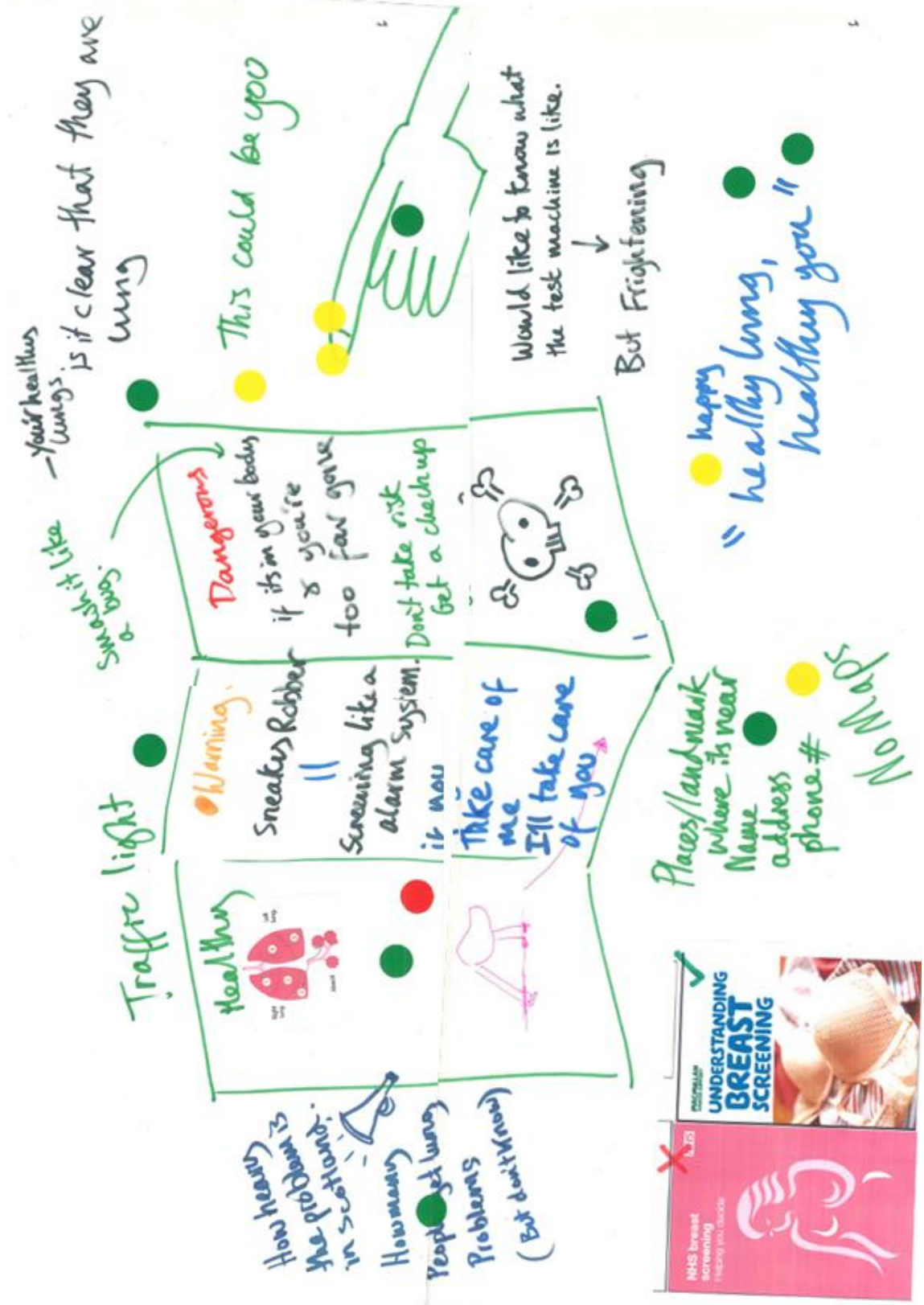
GYM

- diet
- exercise
- aware of your body

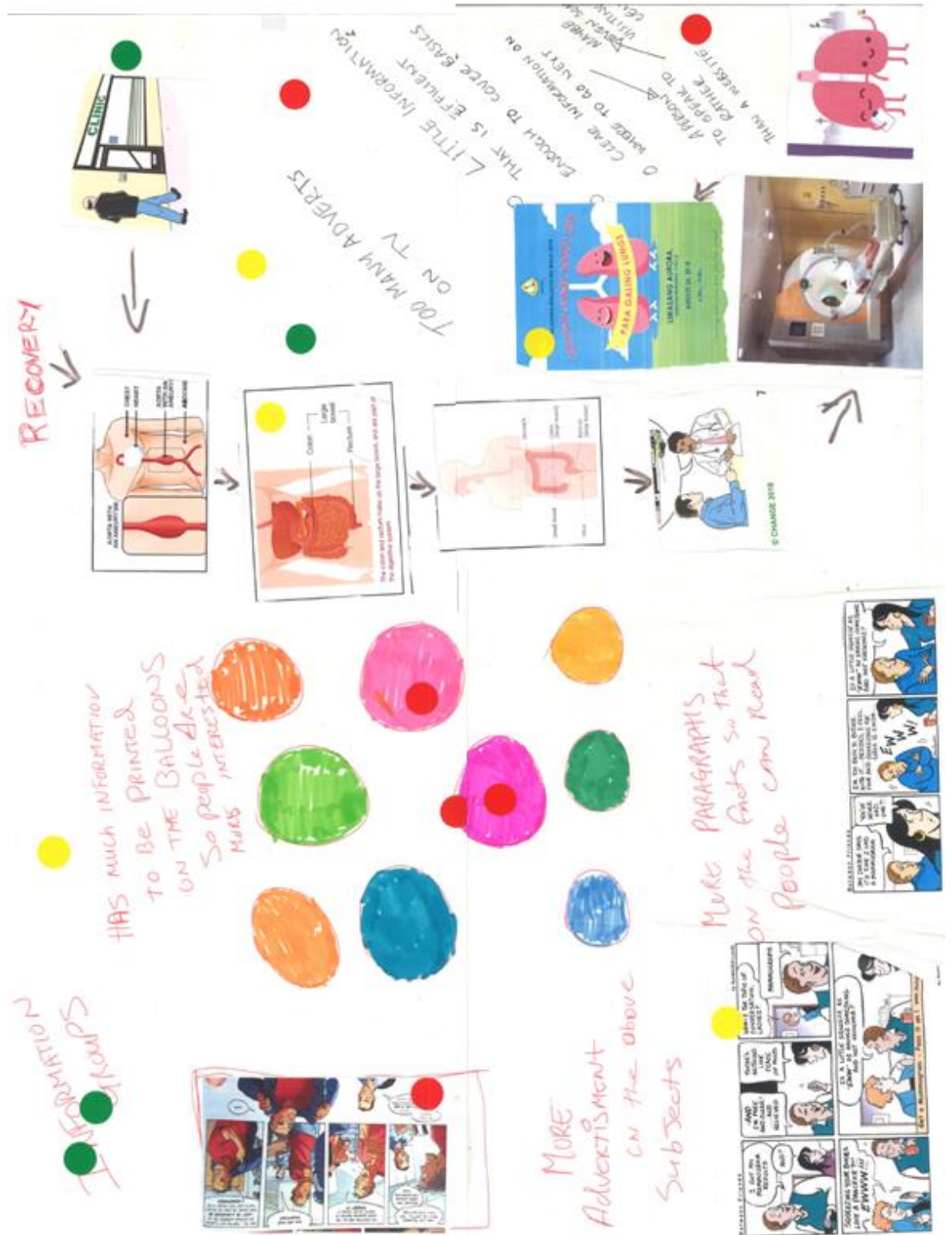
⑨

⑩ HOLIDAY

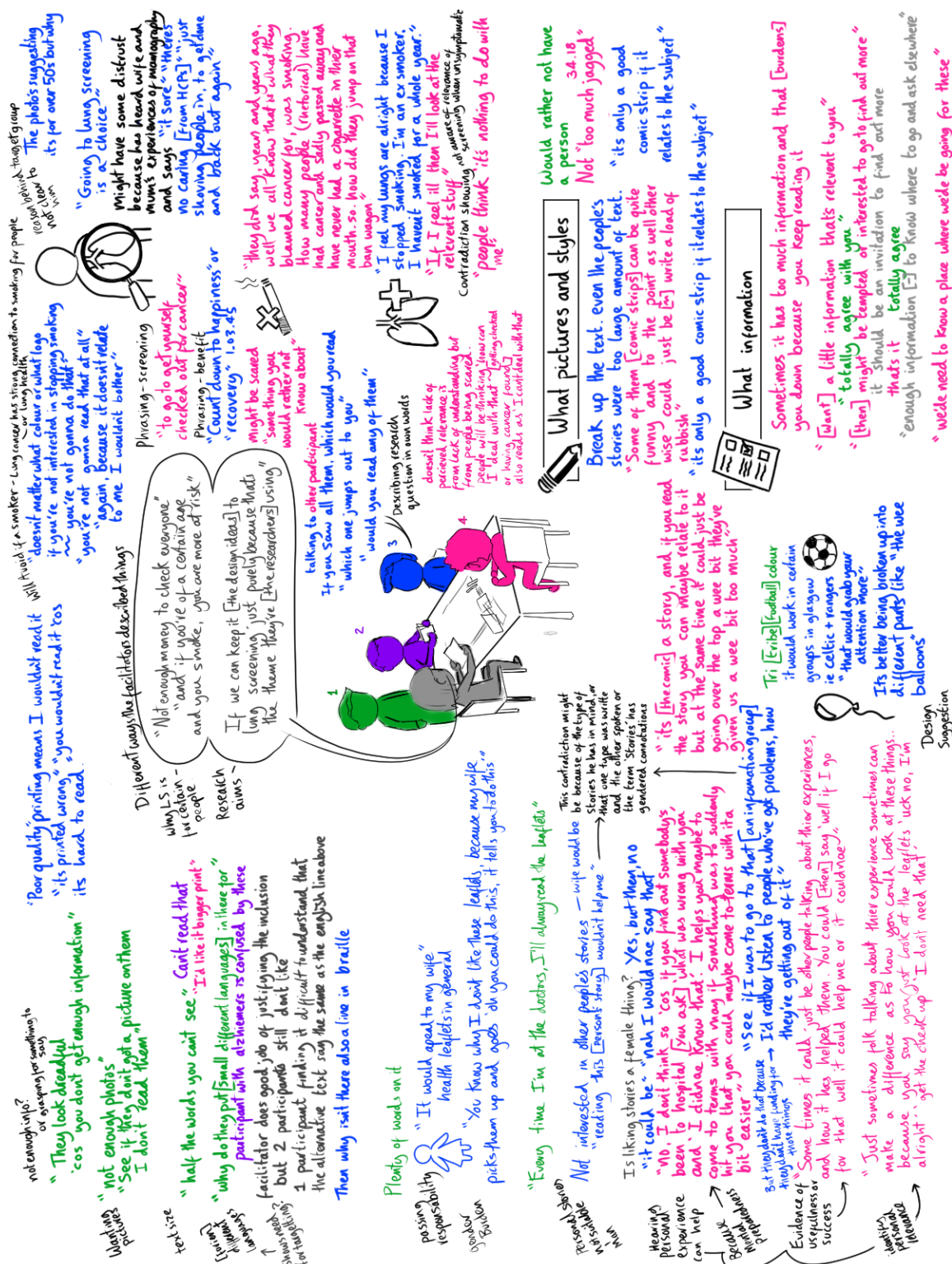
Workshop table 3



Workshop table 4



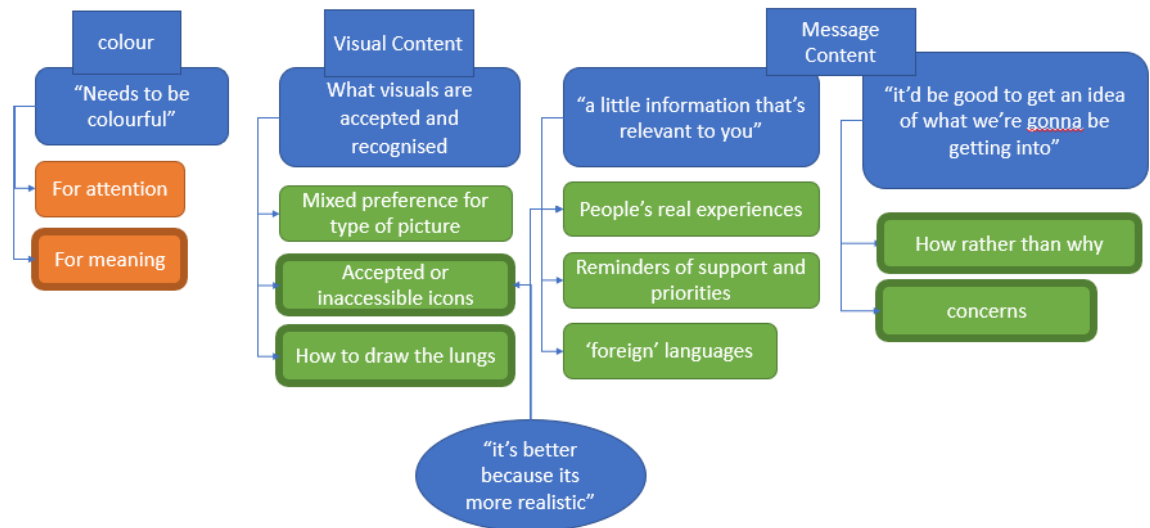
## Appendix 14: Study 3 - Example transcript poster



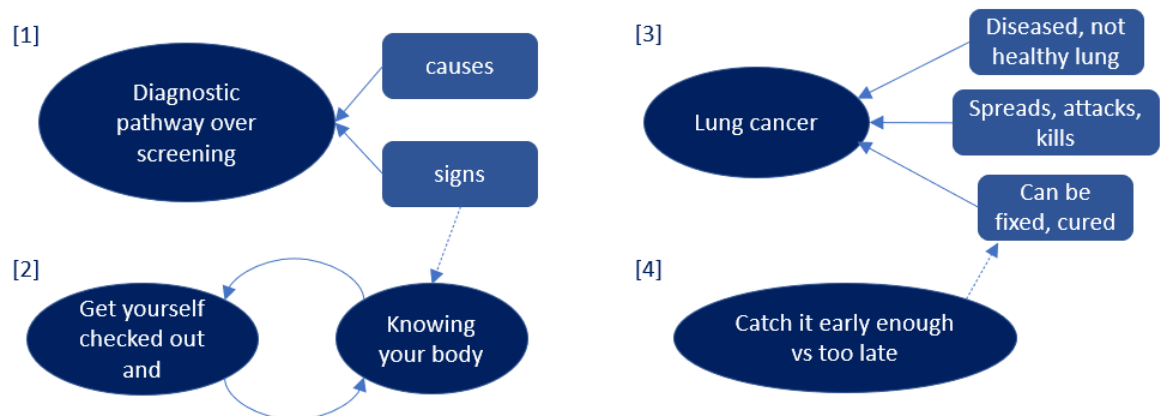
*Note.* Each colour indicates a different participant. Text in black are researcher's notes and some codes

## Appendix 15: Study 3 - Thematic maps

Developing themes for participant design preferences



Developing themes for perceptions surrounding lung cancer screening



## Appendix 16: Study 3 - Participant and helper evaluation interview topic guide

- Have you thought much about the workshop since Wednesday?
  - If yes, what were your thoughts about it?
- What did you think about the way there were 4 groups and each one had a volunteer helper?
- What did you think about the different activities completed within the workshop?
  - at the start where you were asked to fill out the consent form and the questions?
  - where I talked and used the projector?
  - where you were in your groups talking to each other?
  - where you were putting your ideas onto a poster?
  - where two people from each group talked about their poster to the rest of the group?
  - where you were asked to stick red yellow and green stickers on the posters?
- Is there any other feedback you want to give about the workshop?
- What do you think about people getting paid to take part in research like this?
- Was this like anything you had done before?
- Do you think the workshop changed the way you think about health leaflets now?
- One thing that people said in the workshop, was to make the leaflet like an 'invitation to more information'? How do you feel about this? Should it be an awareness raising leaflet or a leaflet telling people to go to lung screening and how to get there or a leaflet that gives people information about it so they can decide whether they want to go?

## Appendix 17: Study 3 - Artist evaluation interview topic guide

- Have you thought much about the workshop since it happened?
  - If yes, what were your thoughts about it?
- What did you think about the different roles of the people supporting the workshop?
  - The role of the facilitator?
  - The role of the helpers?
  - The role of the researcher?
  - What did you think about your role?
    - For each: Were there benefits, challenges? Was it suitable, helpful, problematic?
- What did you think about the different activities completed within the workshop?
  - where I talked and used the projector?
  - where participants were in your groups talking to each other?
  - where participants were putting your ideas onto a poster?
  - where people from each group talked about their poster to the rest of the group?
  - where participants stuck stickers on parts of posters they liked, didn't like or weren't sure of
    - For each: Was it clear, useful, burdensome, problematic?
- What did you think about the organisation leading up to the workshop?
- Is there any other feedback you want to give about the workshop?

## Appendix 18: Study 3 - Table of workshop feedback interview extracts

| Workshop element                    | Feedback                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|-------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| General                             | <p><u>Workshop was enjoyable</u></p> <p>P6: "it was really good, i thoroughly enjoyed it" "i really really enjoyed it"</p> <p>P9: "the actual experience is really good and [03:51] thoroughly enjoyed it, it was one of the better ones i've been to in a long time"</p> <p>P11: "i thoroughly enjoyed it, it was good, i cannae think of anything that would-"</p> <p>P13: "i really enjoyed myself last week it was brilliant"</p> <p>P16: "was ok (ok [laughs]) it was middle of the road" "so and so good but it wasnae bad" "it kept my interest"</p> <p>P17: "the whole of the workshop was quite good and I think it was well presented and well run"</p> <p>P18: Good because "bring people out" and a chance to talk</p> <p>Facilitator: "i think on the day it went really well"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Organisation leading up to workshop | <p><u>Helper and facilitator felt organisation with them worked</u></p> <p>Facilitator: "i thought it worked" "the way it was organised was really good"</p> <p>Helper: I feel like it was enough</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Four groups around tables           | <p><u>Good to allow everyone to be heard</u></p> <p>P11: "it was good because it, it meant because it was small groups everybody got an input (yeh, yeh) whereas if it was a big group [that wouldn't] happen"</p> <p>P17 "I thought that was really good yeah because I think if it had been bigger groups you would have been shouting over each other"</p> <p>Facilitator "i think splitting them up into their own- own wee groups then that let them have their own wee say"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Workshop team                       | <p><u>The helpers encouraged and supported participants while also keeping them on task</u></p> <p>P9: "i know some people have problems with writing and reading skills, so having a helper there you feel less pressured" "when we're sort of getting stuck a wee bit in thinking she's like 'well how do you d-' and then she's like that getting you thinking again"</p> <p>P16: "when she gave us ideas mhm (yeh) so it- so it was alright"</p> <p>P17: "that was good as well because more so for myself because [I could] Ask for help and that's thanks to the fact that there was someone there specifically for that" "she didn't try and push (mhm) her ideas on you (mhm) which was well good"</p> <p>Facilitator: "she was working really well to try and get the other people in the group to get their say across cos" "I thought she-d done really well"</p> <p>Artist: "were kind of really crucial to kind of keep the groups like kind of on topic"</p> <p><u>Familiarity with facilitator was good</u></p> <p>Helper: "with somebody they knew and trusted was facilitating I think that worked really well"</p> <p>Artist: "[main facilitator] was great because I think he was really important to kind of be able to like relay like a bit of trust and kind of encouragement from people um somebody who knows the participants but isn't directly involved with asking the questions"</p> <p><u>Artist gained useful insight from being included</u></p> <p>Artist: "I was lucky because I had the vantage point of being able to float between all the groups and so like I was able to get a bit more insight into the different levels of engagement of different people different ideas"</p> |
| Information provision               | <p><u>Enough information with slight difference by table</u></p> <p>P9: "I thought the information we received was enough I don't think we'd have needed any more information really"</p> <p>P11: "i think we were well informed, you know, what it was about"</p> <p>R: "did you think that you could ask for more information if you wanted?" P13: "aye i could aye aye"</p> <p>P17: "I think it was explained to us but I thought it could be explained slightly better"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Consent and demographic forms       | <p><u>Participants were used to completing forms and found them acceptable</u></p> <p>P9: "its like most things its- it- its just one of the- its part and parcel with the- whatever you do no matter what you do, your gonna have to have one of these forms to fill out"</p> <p>P6: "we filled out ones today {at their group meeting}"</p> <p>P11: "if its got to be done, its got to be done. its just part of, life nowaday"</p> <p>P13: "no its alright i feel fine aye"</p> <p>P16: "i don't usually like filling forms out but if its got to be done its got to be done"</p> <p>P17: "that was okay"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Researcher's presentation           | <p><u>Presentation was good to set the scene and was not too long</u></p> <p>P6: "that was good"</p> <p>P9: "aye good yeh, fine" "when its short and concise like that then its ideal"</p> <p>P11: "i think it was important you had to stand up there and explain to us"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |

|                              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                              | <p>P13: "fine, fine you done a great job, aye"</p> <p>P16: "cos i think a wee bit further- another five minutes that would have been too much"</p> <p>R: "did you think that it was too much information all at once?" P17: "no"</p> <p>Artist: "it was good to kind of set the the scene for the day"</p> <p>Helper: "you didn't talk for too long at all you didn't lose people you went over what was meant to be done"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Discussion activity          | <p><u>Discussion allowed time to settle in and warm up</u></p> <p>P11: "it turned out a lot of people didn't know each other (mhm) and it was a way of getting communication going (yeh) yeh [coughs] just getting to know each other" "it made everybody a bit more at ease with each other"</p> <p>Artist: "having that time to settle into their activity and talk about the subject was probably the most important part of that"</p> <p><u>Discussion was a chance to establish group dynamics and expectations</u></p> <p>Artist: "thats kind of when the style of groups came to be established they got sunk into themselves and they kind of decided what you meant" "I think that helped the facilitators understand the group dynamics and how they would kind of approach maybe doing the prompts and stuff"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Poster creation activity     | <p><u>Poster making was enjoyed</u></p> <p>P11: "that was excellent (yeh?) yeh that was excellent yeh"</p> <p>P13: "I liked to get involved in making things and thingmy things up you know how- that was quite interesting"</p> <p>P16: "a lot of fun (yeh you thought it was) it was a lot of fun"</p> <p>P17: "that was quite good that was quite enjoyable"</p> <p>Artist: "I really really enjoyed it and I think from the experience I picked up from all of them they did too"</p> <p>Helper: "it was just organised chaos but that's exactly what that kind of work is and they really enjoyed it"</p> <p><u>Useful activity for artist</u></p> <p>Artist: "that's where I picked up the most information about what groups actually wanted and what they felt was important"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| Poster presentation activity | <p><u>It was good to see other groups ideas</u></p> <p>P6: "when it was all stuck up (R: yeh, yeh yeh) and then they read through their table, their table, their table and went around them all to explain how everybody was feeling about this, it was really good"</p> <p>P9: "yeh I thought it was good as well cos it lets you see other peoples ideas" "I thought was really good, it was excellent"</p> <p><u>Presenting pushed peoples comfort zones</u></p> <p>P6: "they did do well cos [name] doesn't usually talk"</p> <p>P11: "I thought it was good because it encouraged people who's never done it before to go up and then- to take part in it" "gave her confidence to come and do it"</p> <p>P13: "see i'm not really good at speaking in front of people, i'm bit para that way, you know what i mean so [-] that why i had to say to lassy you take here, i'll get the first bit you do the second bit cos' i was [-] getting a bit red"</p> <p>P17: "[people were] like "well I don't wanna go up" "I don't wanna go up""</p> <p>Helper: "he was all bold as brass to talk and then lost his bottle" "not a single one of those people up there looked uncomfortable" "they were a bit kind of like "oh I don't know what I'm saying" but they didn't look massively uncomfortable"</p> <p><u>It was an opportunity to acknowledge contributions and be proud</u></p> <p>Artist: "it was so nice I felt like it was such a good opportunity to like empower them right members of the groups could feel that their contributions were really important"</p> <p>Helper: "getting them to speak about their posters and talk it through was just reiterating like consistently throughout the day reiterating that we want you to give us a copy of your thoughts"</p> |
| Sticker activity             | <p><u>Evaluating other people's work not liked</u></p> <p>Artist: "it was intimidating [for people] I do remember that kind of frozen pause of 'are you seriously telling me I can tell someone that's bad'"</p> <p><u>Chance to mingle and see other people's work</u></p> <p>Artist: "it also kind of got people out of their chairs as well and engaging with the work of other tables where they might not have wanted to get up and go look at what somebody else had done" "from my perspective it seemed like it was really positive"</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

## Chapter 7 Appendixes

### Appendix 19: Text information for test picture narrative lung screening designs

#### **What is lung screening**

##### ***What is the purpose of lung screening?***

The purpose of lung screening is to find lung cancer at an earlier stage, when it is easiest to treat and can be cured. This will help fewer people die from lung cancer.

Lung cancer is a clump of cells in the lung that are growing in an unrestricted way. At an early stage, the clump of cells is small and in one place in a lung. When lung cancer is found at an early stage, it is easier to treat and can be cured.

If left untreated, the clump of cells will keep growing and bits may break off and spread to other parts of the body, and we call this late-stage cancer. When lung cancer is found at a late stage, it is difficult to treat and, in most cases, cannot be cured.

Lung screening would be the best way of finding lung cancer at an early stage because it involves testing people before they have symptoms. Lung cancer does not cause any obvious symptoms and the lungs do not feel pain, which means people and their doctor rarely figure out they have lung cancer until it is at a late stage.

##### ***What happens during lung screening?***

People who take part in lung screening would have their bodies, from their shoulders to their waist, scanned in a doughnut shaped machine called a CT scanner. You lie on a flat surface that slowly moves, feet first, through the centre of the machine. The scanner creates images of inside of the persons lungs. A doctor then looks at these images to check for any signs of lung cancer.

#### **Who is lung screening for and why**

Lung screening would be specifically offered to people who have a high chance of having lung cancer because this makes them likely to benefit.

Two things that give us a high chance of having lung cancer is how old we are and how much we smoke.

##### ***Age***

The older we get, the more likely we are to have lung cancer. People over 60 years old are far more likely to have lung cancer than people under 60.

##### ***Smoking***

The more cigarettes we smoke and the more years we smoke for, the more likely we are to have lung cancer. People who smoke more than 10 cigarettes a day for over 30 years are much more likely to get lung cancer than people who have smoked less than this.

If you stop smoking, your chances of getting lung cancer become smaller over time. After 15 years of quitting smoking, your chances of getting lung cancer are the same as someone who has never smoked.

##### ***Before symptoms appear***

You should not wait until you have symptoms before going for screening because the early stages of cancer do not show any symptoms.

#### **What are the potential results of lung screening**

When someone has done the lung screening, they will be given one of the following three possible results:

Result 1 = No problems were found

This result means that the doctor could not find any signs of cancer.

Result 2 = Signs of cancer were found

With this result, you will be invited to diagnostic tests to find out if you really have cancer. One diagnostic test is an increased CT scan that captures more detailed images of the lungs. Another

diagnostic test is a biopsy which is where some cells are taken from the lung and looked at under a microscope.

Result 3 = Signs of a clump of cells that might become lung cancer were found

With this result, it is best to have a follow up scan 3-months or a year after your first scan to see if the clump of cells has change. If the clump of cells has changed, you will be sent for diagnostic tests. If the clump of cells has not changed, you can be relatively confident that it will not become cancerous.

Separate result = Signs of other conditions unrelated to cancer were found

When looking at the images of the lungs, the doctor might find signs of other conditions unrelated to cancer. If you get this result, your GP will be told and will contact you about it.

### **What risks come with lung screening**

The following are things people should know before making a decision to do lung screening.

#### ***Radiation***

The CT scanner uses radiation when scanning the lungs. Being exposed to radiation has the potential to cause cancer. However, the amount of radiation used in one CT scan is very low compared to the amount needed to cause cancer. The CT scan uses 1.4 units of radiation. The amount of radiation a person would need to encounter in a year for it to cause cancer is 100 units.

#### ***Stress***

For some people, going to screening, waiting for results and getting a result that suggests they have cancer can be distressing.

#### ***Being sent for diagnostic tests but not actually having cancer***

Most people who have a screening test that found signs of cancer go on to do a diagnostic test and find out that they do not have lung cancer. Diagnostic testing comes with its own risks, such as more radiation and having biopsies, and can cause extra worry for people.

#### ***Being treated for lung cancer that would have never caused any harm***

Some of the lung cancers found with the screening test grow so slowly that they would not cause the person problems during their lifetime if left untreated. However, there is currently no way of knowing which cancer will grow slowly so all people get treatment. This means some people will go through unnecessary cancer treatment.

#### ***Being told you do not have lung cancer when you actually do***

Like most tests, the screening test is not perfect, and sometimes a lung cancer is missed. It is extremely rare for a lung cancer to be missed, but important to be aware of.

## Appendix 20: All available guidance on using pictures in print health materials

| Citation                                                                | Guidance on pictures                 |
|-------------------------------------------------------------------------|--------------------------------------|
| Guideline                                                               |                                      |
| NCI Clear & Simple, 1994, 2003, 2018                                    | 1, 3, 4a, 7, 11, 11a, 11b, 14, 15    |
| Toolkits                                                                |                                      |
| CDC Simply Put V3, 2009                                                 | 2c, 2d, 3, 6, 7, 7a, 8, 9, 11, 14-17 |
| NHS Toolkit for producing patient information, 2003                     | 18, 19                               |
| NWT Literacy Council, 2015                                              | 2a                                   |
| Assessment tools                                                        |                                      |
| BALD, Baker, 1997                                                       | 1, 2, 6                              |
| BIDS, Bernier, 1996                                                     | 1, 7,                                |
| CDC Clear Communication Index, 2014, 2019                               | 1-8, 10, 15                          |
| ClearDOC index, Moody & Rose, 2004                                      | 2, 15                                |
| CSAT, Guidry et al., 1998                                               | 5, 11, 15                            |
| DISCERN, Charnock et al., 1999                                          | -                                    |
| EQIP, Moulton et al., 2004                                              | 1, 2, 15                             |
| Health Literacy INDEX, Kaphingst et al., 2012                           | 2b, 7, 9, 12, 15                     |
| HLE2, Rudd et al., 2007, 2019                                           | 6, 7, 10                             |
| PEMAT-P, Shoemaker et al., 2014                                         | 2a, 3, 9                             |
| RAIN, Singh, 1994                                                       | -                                    |
| SAM+CAM, Helitzer et al., 2009<br>(updated from SAM, Doak et al., 1996) | 1-8, 11, 13, 15                      |
| TEMPtED, Clayton, 2009                                                  | 5, 7, 10, 15                         |

1. Easy-to-understand what the image is of or about.
2. Relevant to the message of leaflet.
  - a. Used whenever they could make content more easily understood or make instruction for action easier to follow.
  - b. Either present a physical record of an event, demonstrate an action or behaviour, or serve as evidence of a claim related to the subject or content of the resource.
  - c. Help emphasize or explain the text
  - d. They show what the audience should do rather than what they should not do
3. Uncluttered and not containing irrelevant images.
4. Colour use enhances realism and/or has purpose.
  - a. Colour palette is appealing to audience.
5. The cover picture portrays the purpose of the materials.
6. Adjacent to related messages in text.
7. Have a caption or legend to explain picture, describe act shown, tell what to look at.
  - a. Pictures in a sequence are numbered
8. If an anatomical body part is shown, it is placed in context (within whole woman, etc.).
9. *Have good visual quality.*
10. *Present key messages so the reader can grasp the key ideas, independent of text.*
11. *They are familiar and easily recognisable to the target audience.*
  - a. *They are meaningful to the audience*
  - b. *They are appropriate for the age of the audience*
12. *Help a reader understand invisible or abstract ideas related to the subject or content of the resource.*
13. *They should not have text "wrapped around" them [SAM+CAM]*
14. They relate to only one message.
15. Cues such as arrows and highlighting are used
16. Photographs are used for images of "real life" events, people, and emotions. Drawings are used for showing procedures, depicting socially sensitive issues and explaining an invisible or hard-to-see event. Cartoons are used for humour or a casual tone.
17. If a small object is shown, it is shown with another object for scale
18. They are not clip art

19. They are not covered with other design elements

## Appendix 21: Identifying application of behaviour change techniques to print health materials

| Behaviour change techniques <sup>a</sup>                             | Most appropriate practical application <sup>b</sup> | Additional action required <sup>c</sup> | Mechanism <sup>d</sup> |
|----------------------------------------------------------------------|-----------------------------------------------------|-----------------------------------------|------------------------|
| 01.1. Goal setting (behaviour)                                       | reader interaction                                  | Y                                       | technical support      |
| 01.2. Problem solving                                                | reader interaction                                  | Y                                       | technical support      |
| 01.3. Goal setting (outcome)                                         | reader interaction                                  | Y                                       | technical support      |
| 01.4. Action planning                                                | reader interaction                                  | Y                                       | technical support      |
| 01.6. Discrepancy between current behaviour and goal                 | reader interaction                                  | Y                                       | technical support      |
| 01.8. Behavioural contract                                           | reader interaction                                  | Y                                       | investment             |
| 01.9. Commitment                                                     | reader interaction                                  | Y                                       | investment             |
| 02.3. Self-monitoring of behaviour                                   | guide reader                                        | Y                                       | investment             |
| 02.4. Self-monitoring of outcome(s) of behaviour                     | guide reader                                        | Y                                       | investment             |
| 03.1. Social support (unspecified)                                   | guide reader                                        | Y                                       | practical support      |
| <b>04.1. Instruction on how to perform the behaviour</b>             | show/tell                                           |                                         | technical support      |
| <b>04.2. Information about Antecedents</b>                           | show/tell                                           | Y                                       | practical support      |
| 04.3. Re-attribution                                                 | guide reader                                        | Y                                       | perception             |
| <b>05.1. Information about health consequences</b>                   | show/tell                                           |                                         | investment             |
| <b>05.2. Salience of consequences</b>                                | show/tell                                           |                                         | investment             |
| <b>05.3. Information about social and environmental consequences</b> | show/tell                                           |                                         | investment             |
| <b>05.5. Anticipated regret (maybe include)</b>                      | show/tell                                           |                                         | investment             |
| <b>05.6. Information about emotional consequences</b>                | show/tell                                           |                                         | investment             |
| <b>06.2. Social comparison (maybe include)</b>                       | show/tell                                           |                                         | investment             |
| <b>06.3. Information about others' approval (maybe include)</b>      | show/tell                                           |                                         | investment             |
| 07.1. Prompts/cues                                                   | guide reader                                        | Y                                       | practical support      |
| 07.5. Remove aversive stimulus                                       | guide reader                                        | Y                                       | practical support      |
| 07.7. Exposure                                                       | guide reader                                        | Y                                       | practical support      |
| 08.7. Graded tasks                                                   | guide reader                                        | Y                                       | practical support      |
| <b>09.1. Credible source</b>                                         | execute                                             |                                         | investment             |
| <b>09.2. Pros and cons</b>                                           | show/tell                                           |                                         | investment             |
| <b>09.3. Comparative imagining of future outcomes</b>                | execute                                             |                                         | investment             |
| <b>10.06. Non-specific incentive (maybe include)</b>                 | show/tell                                           |                                         | investment             |

|                                                                     |                    |   |                   |
|---------------------------------------------------------------------|--------------------|---|-------------------|
| <b>10.07. Self-incentive</b>                                        | show/tell          |   | investment        |
| 10.09. Self-reward                                                  | reader interaction | Y | investment        |
| 10.11. Future punishment                                            | reader interaction | Y | investment        |
| <b>11.2. Reduce negative emotions or increase positive emotions</b> | execute            |   | emotion           |
| <b>11.3. Conserving mental resources</b>                            | execute            |   | emotion           |
| 12.1. Restructuring the physical environment                        | guide reader       | Y | practical support |
| 12.2. Restructuring the social environment                          | guide reader       | Y | practical support |
| 12.3. Avoidance/reducing exposure to cues for the behaviour         | guide reader       | Y | practical support |
| 12.5. Adding objects to the environment                             | guide reader       | Y | practical support |
| <b>13.1. Identification of self as role model</b>                   | show/tell          |   | investment        |
| <b>13.2. Framing/reframing</b>                                      | execute            |   | perception        |
| <b>13.4. Valued self-identify</b>                                   | show/tell          |   | investment        |
| <b>13.5. Identity associated with changed behaviour</b>             | show/tell          |   | investment        |
| 15.1. Verbal persuasion about capability                            | guide reader       | Y | confidence        |
| 15.2. Mental rehearsal of successful performance                    | guide reader       | Y | confidence        |
| 15.3. Focus on past success                                         | guide reader       | Y | confidence        |
| <b>15.4. Self-talk</b>                                              | execute            |   | confidence        |
| <b>16.3. Vicarious consequences</b>                                 | show/tell          |   | investment        |

*Note.* Behaviour change techniques that are not feasible to incorporate into a one-off leaflet have been excluded. Y = yes

<sup>a</sup> taken from Michie et al (2013)

<sup>b</sup> here mode of delivery is in print leaflet sent with invitation

<sup>c</sup> Is additional action required from receiver beyond the immediate interaction with the leaflet? (an indicator of level of suitability to print communication)

<sup>d</sup> The mechanisms through which I believe the impact on behaviour can be explained.

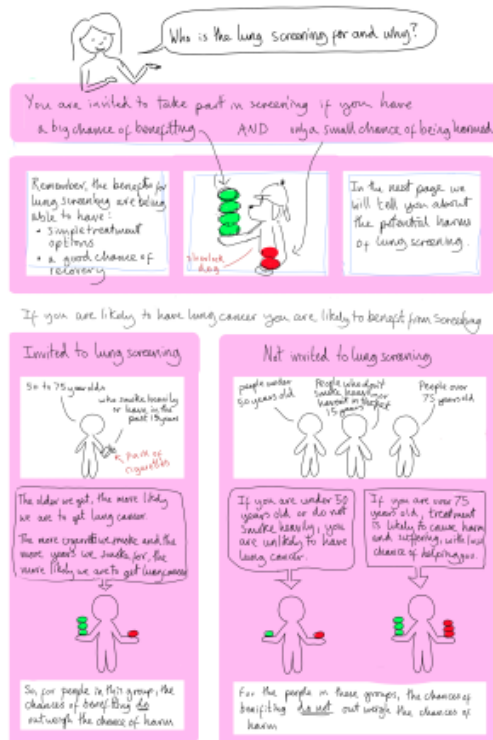
## Appendix 22: Synthesis of guidance from print health materials evaluation tools

|                                         |                               | Assessment tool                                                                                                             |
|-----------------------------------------|-------------------------------|-----------------------------------------------------------------------------------------------------------------------------|
| Domain                                  | Construct                     | date                                                                                                                        |
| ENGAGING - the ability to be engaging   | <i>Attention</i>              | advice column format                                                                                                        |
|                                         |                               | frequently asked questions (FAQ) format                                                                                     |
|                                         |                               | heading or subheading in the resource uses a teaser                                                                         |
|                                         |                               | The resource gives a specific place to respond                                                                              |
|                                         |                               | Provides examples then encourage to think of own situation                                                                  |
|                                         |                               | use of story to convey message                                                                                              |
|                                         | <i>Interaction</i>            | Questions to which reader responds (i.e. a quiz)                                                                            |
|                                         |                               | Asks reader to compare/contrast two or more 'items' (e.g. two pictures, two sentences)                                      |
|                                         |                               | Present cases and have reader pick best solution                                                                            |
|                                         |                               | Have reader complete a story                                                                                                |
|                                         |                               | Have things reader can cut out (i.e. coupons)                                                                               |
|                                         |                               | other not specified                                                                                                         |
|                                         | <i>Tone</i>                   | positive/negative message framing                                                                                           |
|                                         |                               | gain/loss message framing                                                                                                   |
|                                         |                               | problem-/solution-focused message framing                                                                                   |
|                                         |                               | addresses user directly                                                                                                     |
|                                         |                               | Consistent use of verbal immediacy (e.g. 'this', 'these' and 'here', present tense)                                         |
| ACCESSIBLE - the ability to be accessed | <i>Layout</i>                 | Visual cuing devices (bold, boxes, arrows [bullet points]) direct attention to specific points/key content.                 |
|                                         |                               | Use of colour supports message (not distract).                                                                              |
|                                         |                               | Paper has non-gloss or low-gloss surface.                                                                                   |
|                                         |                               | Advance organizers included                                                                                                 |
|                                         |                               | No more than 5 items in a list are presented without another subheading or "chunk".                                         |
|                                         | <i>verbal literacy demand</i> | Sentences are simple                                                                                                        |
|                                         |                               | Sentences are written in active, direct style                                                                               |
|                                         |                               | Sentences written in personal, conversational style.                                                                        |
|                                         |                               | does not use abstract and uncommon words or concepts                                                                        |
|                                         |                               | Does not use abbreviations, acronyms or medical terms (unless necessary, then given first with unknown term in parentheses) |
|                                         |                               | Examples are given to explain or clarify difficult words, concepts or category words                                        |
|                                         |                               | Explanatory/illustrative expressions (e.g. 'every year') are used instead of value judgment words (e.g. 'regularly')        |
|                                         |                               | Metaphors, similes, analogies, when used, help explain or clarify rather than confuse                                       |
|                                         |                               | nouns (e.g. 'the x') are used instead of ambiguous pronouns (e.g. 'it')                                                     |
|                                         |                               | sentences give more familiar concepts/context before introducing new information                                            |
|                                         |                               | A summary clearly reviews or retells the key messages/points in words, examples and/or visuals.                             |
|                                         |                               | Limited scope presented                                                                                                     |
|                                         |                               | section topics are introduced                                                                                               |

|                                                                                           |                                                      |                                                                                                                                                    |
|-------------------------------------------------------------------------------------------|------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                           |                                                      | sequencing of info organized logically and consistent throughout material                                                                          |
|                                                                                           |                                                      | composition of text is clear                                                                                                                       |
|                                                                                           |                                                      | type face used is clear                                                                                                                            |
|                                                                                           |                                                      | Reading Grade Level                                                                                                                                |
|                                                                                           | <i>numerical literacy demand</i>                     | Very limited use of precents, other than 100%                                                                                                      |
|                                                                                           |                                                      | Text does not require user to make calculations                                                                                                    |
|                                                                                           |                                                      | Numerical probabilities, where given, are also explained with words or graphics?                                                                   |
|                                                                                           |                                                      | Amounts/costs/rates have helpers like "same as, less/ more than," or "greater than" to help readers determine meaning of numbers.                  |
|                                                                                           |                                                      | Frequencies (3 out of 10,000) used rather than probabilities (.0003).                                                                              |
|                                                                                           | <i>graphical 'technical diagram' literacy demand</i> | Throughout text: use of charts, graphs, tables is limited                                                                                          |
|                                                                                           |                                                      | Documents are simple and easy to understand                                                                                                        |
|                                                                                           |                                                      | Documents have explanatory captions                                                                                                                |
|                                                                                           |                                                      | leaflet includes an explanation/example of how to us the document                                                                                  |
|                                                                                           | <i>graphic literacy demand</i>                       | easy-to-understand what the image is of or about                                                                                                   |
|                                                                                           |                                                      | If an anatomical illustration is used, it is placed in context (within whole woman, etc.)                                                          |
|                                                                                           |                                                      | images are relevant to message of the leaflet                                                                                                      |
|                                                                                           |                                                      | images are adjacent to related messages in text                                                                                                    |
|                                                                                           |                                                      | images have legends to explain picture, describe act shown, tell what to look at                                                                   |
|                                                                                           |                                                      | Colour use enhances realism and/or has purpose                                                                                                     |
|                                                                                           |                                                      | images are able to present key messages visually, independent of text                                                                              |
|                                                                                           |                                                      | the images are uncluttered                                                                                                                         |
|                                                                                           |                                                      | what is the visual quality of the images                                                                                                           |
|                                                                                           | <i>population suitability</i>                        | presents information that is relevant, understandable, and appropriate (respectful) for the target audience                                        |
|                                                                                           |                                                      | uses language (words, phrases, and expressions) common and relevant to target audience                                                             |
|                                                                                           |                                                      | graphics are familiar, relevant, and easily recognisable to the target audience                                                                    |
| ACCEPTABLE - the ability to give satisfaction sufficient to meet a demand or requirement. | <i>Credibility</i>                                   | is all the information included relevant to the message                                                                                            |
|                                                                                           |                                                      | does the document contain the date it was produced                                                                                                 |
|                                                                                           |                                                      | was it produced within the last 2 years                                                                                                            |
|                                                                                           |                                                      | does the material explain what authoritative sources, such as subject matter experts and agency spokespersons, know and don't know about the topic |
|                                                                                           |                                                      | Provide contact information for feedback (telephone email fax publisher etc)                                                                       |
|                                                                                           |                                                      | Does the document contain contact details for supporting information or services?                                                                  |
|                                                                                           |                                                      | does the document say whether patients and/or their families were involved or consulted in this production?                                        |
|                                                                                           |                                                      | Does the material address both the risks and benefits of the recommended behaviours?                                                               |
|                                                                                           | <i>cultural sensitivity</i>                          | Is the racial or ethnic group described as a high-risk or as the intended readers of the information?                                              |

|                                                   |                              |                                                                                         |
|---------------------------------------------------|------------------------------|-----------------------------------------------------------------------------------------|
| SUPPORTIVE -<br>the ability to<br>provide support |                              | Does the information address the perceptions of intended racial or ethnic group?        |
|                                                   |                              | The message(s) is(are) linked to sources credible to the intended audience.             |
|                                                   | <i>Purpose<br/>[clarity]</i> | graphics represent the target audience                                                  |
|                                                   |                              | it is possible to determine the purpose from a glance?                                  |
|                                                   |                              | the cover graphic portrays the purpose of the materials                                 |
|                                                   |                              | the purpose of the leaflet is explicitly stated (or clear)                              |
|                                                   |                              | the purpose of the leaflet remains consistent through out                               |
|                                                   |                              | explains the nature of the risk                                                         |
|                                                   | <i>Investment</i>            | Thrust of the material is application of knowledge aimed at desirable reader behaviour. |
|                                                   |                              | the purpose of the target behaviour/s is described                                      |
|                                                   |                              | Includes expected benefits from the target behaviour/s                                  |
|                                                   |                              | Addresses potential barriers/costs to be overcome for the target behaviour/s            |
|                                                   |                              | Includes information about health consequences                                          |
|                                                   | <i>Practical</i>             | tangible tools are provided for target behaviour/s                                      |
|                                                   |                              | tangible tools are provided for making a decision                                       |
|                                                   | <i>Technical</i>             | manageable, explicit steps are given for target behaviour/s                             |
|                                                   |                              | the information is accurate                                                             |
| PERSUASIVE<br>(may wish to<br>avoid)              |                              | Repetition (done in purposive manner)                                                   |
|                                                   |                              | Focuses on Values &/or lifestyle                                                        |
|                                                   |                              | Includes clear symbols (of tradition, family, sex, power, etc.) with emotional intent   |
|                                                   |                              | Focuses on fear                                                                         |
|                                                   |                              | Includes testimonials                                                                   |
|                                                   |                              | Focuses on reader's Leadership qualities (be firm, bold, strong, confident)             |
|                                                   |                              | Suggests everyone's doing it                                                            |

## Appendix 23: Sketch of test designs v1



**Appendix 24: Prototype designs (with letters identifying gist-based message content listed in Table 7-3)**

**A** What's the point of lung screening?

If you find cancer early, it can be easier to treat. This will mean less suffering.

Searching for signs of cancer

**B** If left alone, cancer can grow bigger and may spread to other parts of the body.

left alone, the cancer has kept growing

here, the cancer is still small

CANCER

This means the longer cancer is left alone, the more difficult it can become to treat.

**C** That is why it is important to find cancer early. And you can find cancer early with screening.

**D** People often say that they will go to screening if they think there is something wrong but...

**E** Lung cancer does not cause obvious symptoms when small.

Hi Doc, I have a cough.

Well, many things can cause that.

**F** And human lungs do not feel pain.

we have no feelings

That is why screening is done for people who do not have symptoms.

## So.. What is lung screening?

G

It takes place at either a hospital or a clinic and is done using a CT scanner.



You lie down on a plastic bed which slowly moves through the centre of the scanner.

The scanner is a thin hoop.

The scanner creates images of our lungs.

A doctor then looks at these images.



To check for any signs of cancer.

The doctor will then give you one of these three possible results:

H

### 1 No problems were found

This result means that the doctor did not find any signs of cancer.

### 3 Signs of something that **might** become lung cancer found

With this result, it is best to have a follow up scan (3 months or 1 year after your first scan) to see if there have been changes.

At the first scan.



Signs that might be cancer

A year later, at the check-up.



Only this one has become cancer

### 2 Signs of lung cancer found

With this result, you will be invited to diagnostic tests to find out if you really have cancer.

Screening tests look for traces.



Diagnostic tests follow these traces to the culprit.



One diagnostic test is an CT scan that captures more detailed images of the lungs.

Another diagnostic test is a biopsy. A small piece of the lung is taken to look at under a microscope.

EXTRA

**Signs of other conditions unrelated to cancer found.** If the doctor sees signs of other health conditions, your GP will be told and will talk to you about it.

I



## Who is lung screening for and why?

Remember, the benefits of screening are from improving your chances of:



Simpler treatment options

Less suffering

Longer life

J

You have a higher chance of benefitting from lung screening...

if you are more likely  
to have lung cancer



if you are more likely  
to benefit from  
treatment



The main things that increase our chances of getting lung cancer are:



Being older



Heavy smoking

smoking an average of  
10 cigarettes a day  
for 20 years.



You would be invited if you are...

over 50 and have smoked heavily  
within the past 15 years

and  
are under 75 years old.

you have a  
high chance of  
getting lung cancer.



you have a  
high chance of  
benefitting from treatment.

## What risks come with doing lung screening?

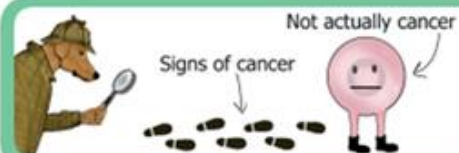
K

Like many medical tests, the lung screening test does not always give the correct result.



- ① The test might find signs of cancer that turn out not to be cancer.

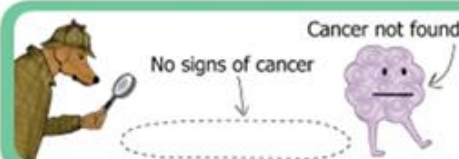
L



In these cases, the person would have gone through diagnostic testing which comes with its own risks.

- ② The test might not find signs of a cancer that is actually there.

M

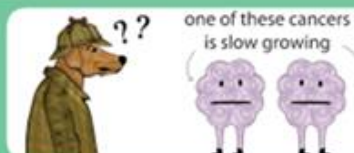


These cases are extremely rare but worth being aware of.

- ③ The test might find a cancer that is the type that grows slowly

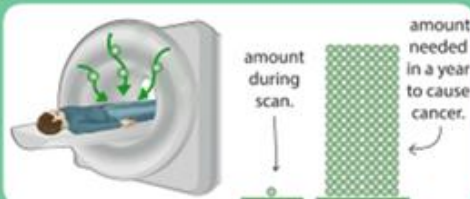
N

Some cancers grow so slowly they would not cause the person problems in their lifetime. People with this type of cancer will still be given treatment because we cannot tell if a cancer is slow growing.



### ④ Radiation

In the scanner you will have a small amount of radiation pass through you



However, the amount of radiation is very low compared to the amount that can cause cancer.

### ⑤ Stress



Different parts of the screening can be stressful for people.

Going to the screening  
Centre



Waiting for the results



Receiving the results.



P

**Appendix 25: Study 4 - Recruitment flier**

[Front]

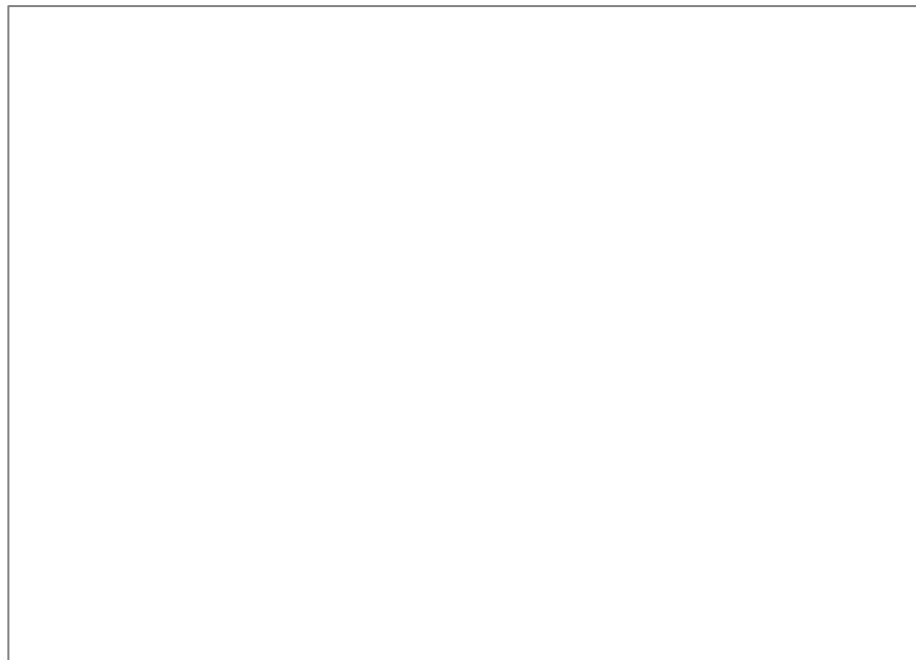


University  
of Glasgow

A research student at the University of Glasgow, called Lauren Gating, is looking for people to interview. She is designing information about lung screening and would like feedback to make the designs more attractive and easier to understand.

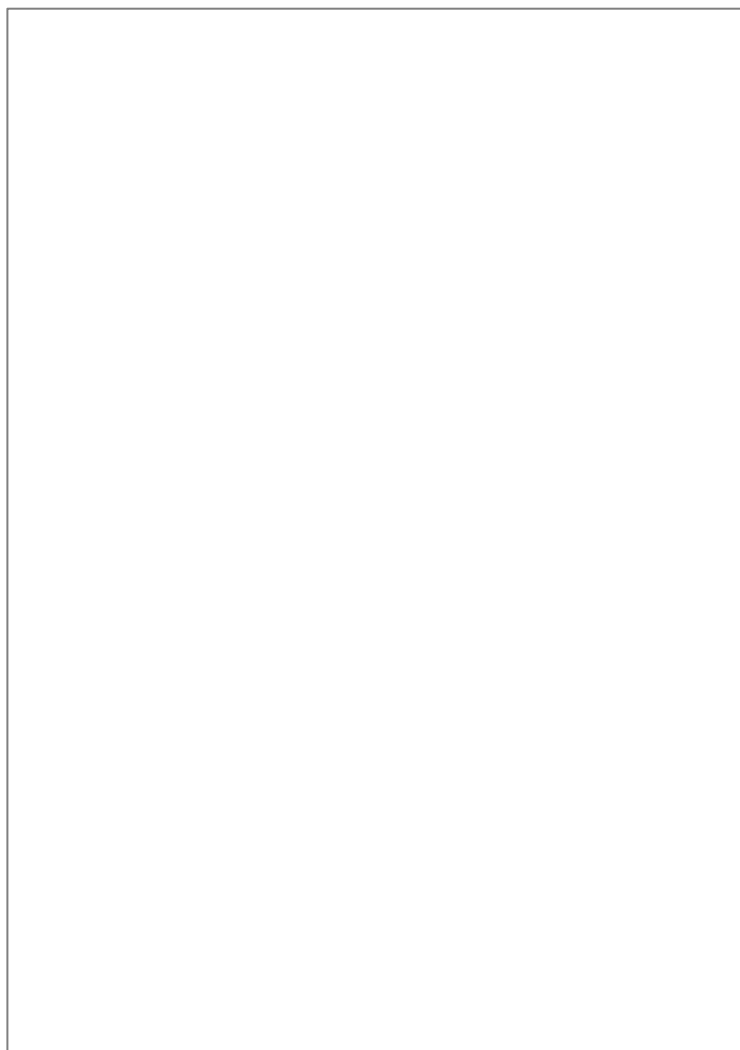
The interview can be by phone or video-call, will take 30 minutes and you will be given £10 as a thank you.

[Back]



**Appendix 26: Study 4 - Recruitment poster**

[Print version]



[Social media version]

**Appendix 27: Study 4 – Participant letter**

## Appendix 28: Study 4 - Participant information sheet and privacy notice



Administration Building, Gartnavel General Hospital, Glasgow G12 0XH

### Participant information sheet

*The title of the study is...* 'Making lung screening information that is engaging and supportive: Your feedback needed'.

#### Introduction

A research student at the University of Glasgow, Lauren Gating, is inviting people to give feedback on designs of lung screening information to make sure the designs are attractive and easy to understand. This letter gives you information about the study, to help you decide if you want to take part.

The researcher has an ethical duty to make sure that you know why the research is being done and what it will involve, before you agree to take part. So, please do tell the researcher, Lauren, if there is anything that does not make sense and feel free to ask Lauren for more information by using the contact details at the end of this letter.

#### What is the purpose of this study?

This study is one part of Lauren's wider project looking at creating health information for the public that is *Engaging* so that it is likely to be read, *Accessible* so that it is easy to read and understand, and *Supportive* so that it can help with making a decision and carrying out that decision. In this study we are specifically looking at making information about lung screening that would be given to people invited to do lung screening.

#### Aim of the study:

- To get feedback about the designs of lung screening information aimed at people who would be invited to lung screening (50 to 75-year olds, with a heavy smoking history) and who would most benefit from good communication about lung screening (living in neighbourhoods with low access to health care and low adoption of screening programmes), to ensure the designs are suitable and understandable for people in this group.

*Reasons for the study:*

- To design lung screening information that is attractive and easy to understand, particularly for people most likely to benefit from screening and most often under-served in health care.
- To involve people who would be invited to lung screening to ensure the designs are helpful for people invited to screening in the future.
- To involve people from communities that are often under-served in health care and cancer screening programmes to ensure the designs are helpful for those with greatest need.

**Who is being invited to take part in this study?**

Lauren is looking for feedback from between seven to ten people who are able to judge the suitability and understandability of the designs, by being part of the group that the designs are being created for and/or by working closely with people in this group. The designs are being created for people aged between 50 and 75 years old, who are heavy smokers or have been in the past (smoking equivalent to ten cigarettes a day for 30 years or more and not stop smoking more than 15 years ago), and who live in a neighbourhood in Glasgow with lower access to health services (identified using the Scottish Index of Multiple Deprivation).

**Do you have to take part?**

No, it is up to you to decide whether or not to take part. This will not affect the standard of care you may receive now or in the future and will not affect your opportunity to take part in other research in the future.

**What will you be asked to do if you take part in the study?**

All participants will be sent four pages of designs of information about lung screening, created by the research team. Participants will have the option to receive these in the post or via email. Participants will then have the option to either have an interview with Lauren or to send written feedback.

*If participants choose to be interviewed:*

The interview can be done via telephone, online video-call, text message depending on what the participant prefers. During the interview, participants will be asked to give verbal consent (this is, participants confirm they have been given the information about the study,

understand this information and agree to take part). Participants will then be asked questions to find out if the designs are acceptable, attractive, and understandable to them and/or the people they work with.

Participants will also be asked about their age, gender, ethnicity, living situation and smoking history. This information will be used by Lauren to make sure the people taking part in this study are diverse while also being part of the intended group of people for this study. It is estimated that the interviews will take around 30 minutes. Participants will not be required to answer any questions they do not feel comfortable answering and they will be able to pause or stop the interview at any time.

*If participants choose to give written feedback:*

The written feedback can be sent to Lauren via email or in the post. Participants will be asked to provide at least ten different statements about their opinion on the designs and whether they think the designs are acceptable, attractive and understandable. Participants can ask for a list of suggestion of things to write about to help with this. Participants will also be asked to fill in a consent form and a demographics form and to send these Lauren along with the feedback. The consent form is kept as a record that participants understood what was involved in the study and agreed to take part. The demographic form will ask about the participant's age, gender, ethnicity, living situation and smoking history and will be used by to determine if the people taking part in this study are diverse and are part of the intended group of people for this study.

**What if you change your mind about taking part?**

If you do not wish to carry on during the study, you can withdraw at any time (stop participating) and without giving any reason. The data you submit can be removed from the study, on request.

**Will the information you give remain confidential and private?**

All information participants give during the study will be kept strictly confidential. All audio-recordings will be stored securely and participants' names will not be held with the recording. Participants names and contact details will be kept in a secure file separate to any other information you provide for the study and will be deleted once you have been contacted about the interview or written feedback. Only Lauren will have access to this file.

The other data that you provide for the study will be saved with an identification code unique to you, this means the data is pseudonymous and means we can identify and remove your data on your request without needing to store your name. The researcher will delete any section of interview audio-recording in which you disclose any information that could make you identifiable. For more detailed information on how the data in this study will be managed, we have written a privacy notice that will be given to participants before taking part in the study and that you can request from Lauren at any time.

#### **What happens to the information that is collected?**

The interviews will be audio-recorded with the permission of the participant. Lauren will use these recordings, after the interview, to make notes about what was said. Lauren will use these notes, and any written feedback provided by participants, to make a detailed summary of the feedback and suggested ways of improving the designs. The audio-recordings will be made on a handheld recording device. After each interview, Lauren will take the audio-recordings from these devices and save them onto a secure password protected computer that only she will have access too.

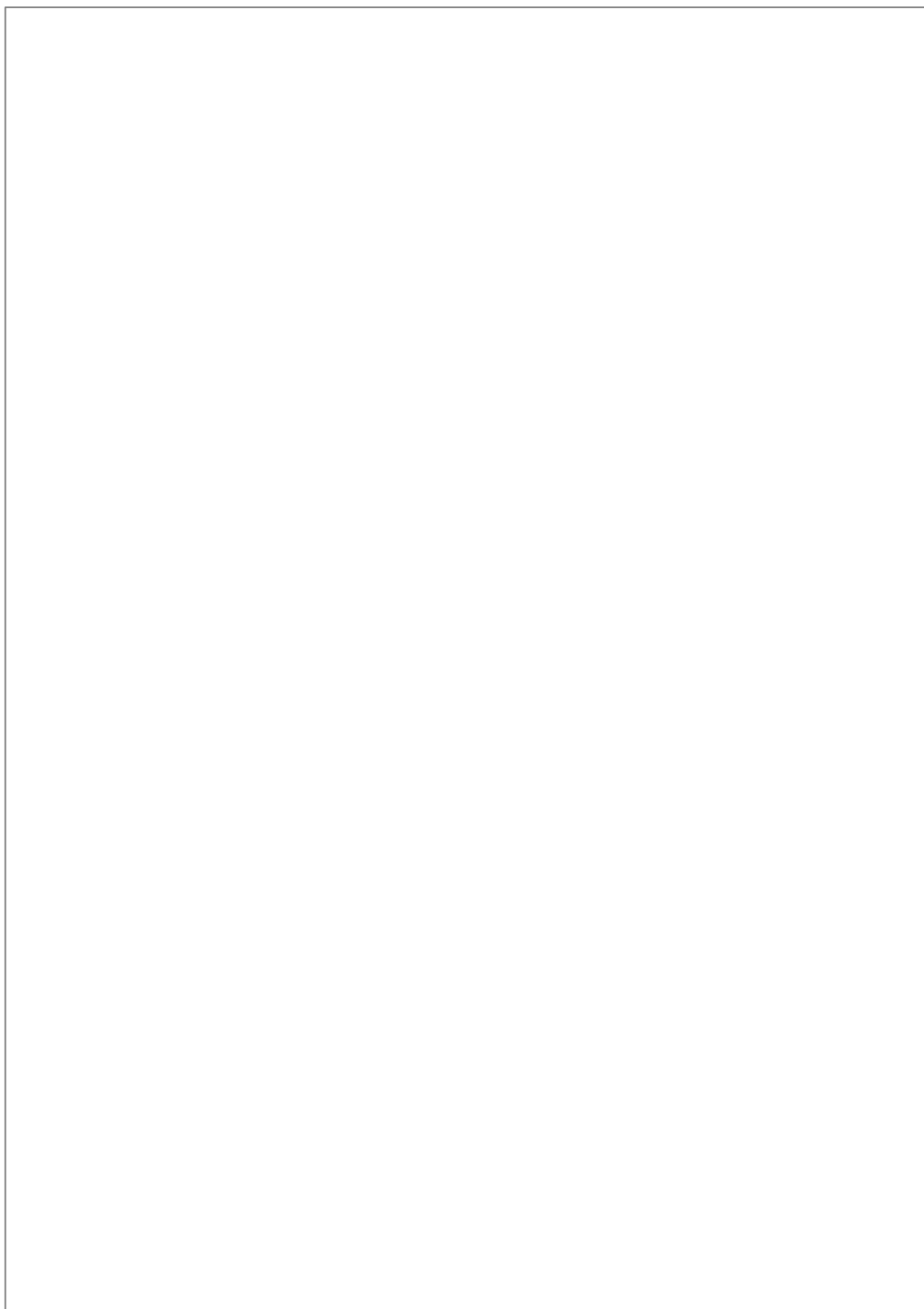
Information collected during this study will be used in Lauren's PhD thesis and may be used in future reports and presentations. You will never be personally identified (i.e. identified by name) without having given permission. The information collected should help to improve the information given to people about lung screening in the future and help them make decisions about taking part in the screening programmes. Participants can be sent a copy of any published results from this study by letting the researcher know during or after the study.

#### **How will the information be stored?**

Your data will be stored within a secure computer system. Your data will be stored for up to 2 years by the primary researcher on the University of Glasgow computer system within a password-protected profile, while the research is being conducted. The data will then be transferred and stored for ten years on the University of Glasgow's research repository to allow for any necessary quality assurance checks in the future. After this time, the data will be securely deleted.

#### **What are the possible benefits of taking part?**

Participants will have the choice to receive £10 either as a gift voucher, as cash or as a charity donation. This is as compensations for their time and as a thank you. By taking part,



**Study title:** Designing lung screening information that is engaging and supportive

## Privacy notice

*The University of Glasgow will be what's known as the 'Data Controller' of your personal data processed in relation to Lauren Gating's PhD research project. This privacy notice will explain how The University of Glasgow will process your personal data.*

### Why we will be processing your data

We are collecting personal data about your name, age, gender, ethnicity, socioeconomic status, smoking status in order to describe the characteristics of the people who took part in the research. We will also be processing your contact details to be able to send you the study materials and hold an interview with you (name, address and telephone number, where appropriate). We will collect and process this data for these purposes only.

### What is the legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is for research and public interest.

### What we do with it and who we share it with

All the personal data you submit will only be processed by staff at the University of Glasgow in the United Kingdom. Your personal data will be saved in a pseudonymised form so that your name will not be directly linked to the other personal data you submit. Your data will be stored within a secure computer system. The researcher is going to remove from the interview audio-recording any section of recording in which you disclose any information that could make you identifiable. This is to protect your identity in the unlikely case of a security breach.

### How long we keep it for

Any contact details we may collect from you in order to send you the study materials or conduct the interview, will be securely deleted once the interview has taken place or the written feedback materials have been sent to you. Your data will be stored for up to 2 years by the primary researcher, Lauren Gating, on the University of Glasgow computer system within a password-protected profile, while the research is being conducted. Your data will then be transferred and stored for ten years on the University of Glasgow's research repository to allow for any necessary quality assurance checks in the future. After this time, the data will be securely deleted.

### What are your rights

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. You may also have the right to object to the processing of data and the right to data portability. If you wish to exercise any of these rights, please submit your request via the [webform](http://www.gla.ac.uk/myglasgow/dpfooffice/gdpr/gdprrequests/) ([www.gla.ac.uk/myglasgow/dpfooffice/gdpr/gdprrequests/](http://www.gla.ac.uk/myglasgow/dpfooffice/gdpr/gdprrequests/)) or contact [dp@gla.ac.uk](mailto:dp@gla.ac.uk).

### Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer at [dataprotectionofficer@glasgow.ac.uk](mailto:dataprotectionofficer@glasgow.ac.uk)

If you are not satisfied with our response, you can complain to the Information Commissioner's Office (ICO) <https://ico.org.uk/>

## Appendix 29: Study 4 - Interview schedule

### 1. Prep before calling

Put phone on silent

### 2. introductions

Hello [name], It's Lauren Gattin the research student calling about our interview

[Pleasantries] How are you?

Did the envelope I sent you arrive yet?

(If no, ask to rearrange the interview)

Are you still able to do the interview now? Are you somewhere quiet and comfortable? And can you hear me ok?

Do you have the four coloured pages with you now?

(if no, 'are you able to get them, before we start the interview?'. If they can't, ask to rearrange the interview)

I'm going to be calling these pages the designs or design pages. Can you put the pages so that they are in a pile in front of you, either in your hands or on a table if there's one in front of you.

### 3. Inform participant about study

The interview that I've asked you to take part in is to find out what changes I should make to the designs, to make them better looking and easier to understand. I will be writing about this study in my student thesis and may also present the work in written reports or presentations to other researchers. I won't use your name in any of my reports. There are some important things to know about taking part in this interview. Firstly, you can pause, stop or leave the interview at any time without giving any reason. This will not affect health services you get. I have a plan in place for how I will keep your information protected, secure and private. This is described in the Privacy Notice, the page with the blue writing that was included in the letter I sent you. The main things to know are, after this interview I will be deleting your name, phone number and address from my records. You can still call my number though. You have the right to see what I record from your interview and you can have it deleted at any time. I won't be able to delete information that has been mixed in to my analysis. The university hold on to data for ten years in case it needs to be inspected, but only myself and an inspector will be able to see the data

Have you got any questions about the study or the interview before we start?

### 4. Turning on the recorder

Are you happy for me to record the interview on an audio recorder?

(if no, "that's ok, we can still continue with the interview, I will take written notes as we go along")

(if yes, turn on recorder then say "Just so you know, after the interview, I will listen back to the recording and delete any section that could identify you, such as names of people and places.")

### 5. Consent

Now that the recorder is on, I need to get you to answer two questions that show you are happy to be recorded

Firstly, can you just confirm for me, by saying yes or no, that you know what is involved in taking part in this study?

And, secondly, by saying yes or no, are you happy to take part in this interview and for it to be audio recorded?

## 6. Interview guidance

For this type of interview, the best answers are often the first things that pop in your head, so please don't hold back.

While you are looking at the designs, you might have questions about screening or lung cancer that come up. If this happens, I won't answer your question straight away, but I will write it down so that I can answer it for you at the end of the interview. This is because the answer to your question might be somewhere further on in the designs and I'd like to find out if the designs are any good at telling you everything you might want to know about lung screening.

The way I'd like to do this interview is to get you to read through each of the pages from top to bottom. The whole time that you are reading through each page, I'd like you to be saying out loud whatever comes to your mind. Say out loud whatever you may be thinking or feeling when you are reading through the page. It will be really good to hear you describe the pictures in your own words. This will help me to understand what the designs look like to you

It can feel a little awkward at first but I've found people quickly get used to it. I'll be listening and not saying anything. If you go quiet for a long time, I will prompt you by asking what you are thinking or looking at. But other than that, I'll be keeping silent.

If you are ready to start, please let me know which page you are starting with by telling me what colour the background is.

## 7. Research question: feedback on the experience of seeing and reading the design prototypes. Whether they are understandable or enjoyable

- What are you looking at now?

Describe to me, in your own words, what is going on in the picture

- o What do you think that picture is trying to do or say?
- o What do you think that picture could be saying about lung screening?

Now looking at all the pages

- Are there any parts you particularly like the look of?
  - o How much do you like this bit?
  - o What about it do you like?
- Any parts you really didn't like the look of?
  - o How much do you dislike this bit?
  - o What about it do you dislike?

- Are there any sections on this page that feel overly complicated?
  - o like it gives too much information or could be said in a simpler way?
- Are there any words on this page that you thought people might find difficult to understand?
  - o Like they were overly complicated
- Are there any pictures on this page that seem unusual or that don't make sense?
  - o Like people would find them difficult to understand

#### 8. Demographic questions

I'm now going to ask you some questions about yourself and your life circumstances. This is to see if I have been able to get feedback from a mix of people who can represent Glasgow. Some of the questions may seem obvious to us both, but I'm going to ask them anyway because I don't want to make any assumptions about you. It's also ok for you to choose to not answer a question.

- How old are you? (if you don't want to say, you could say that you are between two ages like between 55 and 65)
- What is your gender? (so, man or women for example)
- What is your ethnicity? (so, Scottish, or British or for example)
- Do you smoke or have you smoked cigarettes in the past?
  - o How much would you smoke a day?
  - o How many years have you smoked?
- Do you own any cars or vans?
  - o How many?
- Do you own or rent the place where you live?
  - o Own: Do you Own outright or are you Buying on mortgage
  - o Rent: do you Rent from local authority, from a housing association, or from a private landlord
  - o Something else:
- What the highest formal qualification you've completed through school or work?
  - o You might have done Highers/O-Grade/Certificate of Secondary Education/GCSEs; Vocational qualifications/Diploma/NVQ1+2; Advanced Higher/A-level/Certificate of Sixth Year Studies/NVQ3; Bachelor Degree/NVQ4; Masters/PhD; Apprenticeship/Tickets
- Are you currently; employed, unemployed, on leave or retired?
  - o employed: is this Part-time employed/Full-time employed/Self-employed
  - o on leave: is this paid sick leave or unpaid sick leave

## 9. Health literacy questions

now I have some slightly more general questions about health information

- Thinking about the types of leaflets you've been given or sent by the doctors, in the past. Would you say those leaflets are usually easy to understand or are they usually difficult to understand?
- How much did you know about cancer screening tests before this interview (like the mammogram, the smear, or the bowel test?)
- How much did you know about lung cancer before this?

## 10. Go over participant questions

[keep note of questions participant asked during think-aloud activity, here]

## 11. Debrief

Would you like me to send you information about my study once I've finished it? Are you happy for me to keep your phone number to be able to send it to you?

That's the end of the interview, I've now turned off the audio-recorder.

I have £10 to give you as a thank you for taking part. I can either give it to you as a bank transfer, as a chopping voucher or give it to a charity of your choice? Which would you like to do?

Would you like to give any feedback about the interview?

I'm still looking for more people to interview, if you know anyone who is over 50 and have smoked, please share my details with them.

Would you like me to give you any contact details for places to get advice and support about cancer?

Thank you very much for taking this time to help me with my research.

## Appendix 30: Study 4 - Example transcriptions around the designs

"I'd be a bit concerned because nothing seems to be definite you know even getting screening doesn't definitely you know give you the answers that you require that's what that whole page tells me"

So the next one is green it's that one green, I better check my green and my blue

"what risks come along with lung screening" [own words]

**What risks come with doing lung screening?**

"that's not very- that's not a positive"

Like many medical tests, the lung screening test does not always give the correct result.

① The test might find signs of cancer that turn out not to be cancer.

"this page kinda made me a wee bit more concerned"

On second read through: "The diagram down with erm you know the signs of cancer and the footprints and the wee cancer maner not actually cancer. That's self ex- that's fine."

Signs of cancer

Not actually cancer

In these cases, the person would have gone through diagnostic testing which comes with its own risks.

in first read through, didn't read this green section

② The test might not find signs of a cancer that is actually there.

"I suppose even just reading halfway down you know it kind of makes me wonder what's the point then of having screening"

No signs of cancer

Cancer not found

These cases are extremely rare but worth being aware of.

"The diagrams are- the diagrams are actually say er- they kind of probably say more than erm you know there more positive than the words"

③ The test might find a cancer that is the type that grows slowly

"Again, the same, you know, it's quite a negative. Um it doesn't motivate you (laugh)"

Some cancers grow so slowly they would not cause the person problems in their lifetime. People with this type of cancer will still be given treatment because we cannot tell if a cancer is slow growing.

one of these cancers is slow growing

"the two of them look exactly the same"

④ Radiation

In the scanner you will have a small amount of radiation pass through you

amount during scan.

amount needed in a year to cause cancer.

However, the amount of radiation is very low compared to the amount that can cause cancer.

And then it talks about the radiation 'the scanner you will have a small amount of radiation pass through you erm which is fine

"however the amount of radiation"- the diagrams quite good because it visually shows you the amount you would need in a year to have caused cancer and how much radiation you receive is you know, minimum compared to that which is quite good."

⑤ Stress

Different parts of the screening can be stressful for people.

Going to the screening

Waiting for the results

Receiving the results.

Centre

"Going to the screening is probably the most stressful, I'd suggest"

"I like the two bottom diagrams but the first four diagrams are quite- they don't convince me to go for screening, if that makes sense [note: what makes these particularly different from the others, that could give me an indication as to what qualities of the pictures this participant likes]"

## Appendix 31: Study 4 - Example section of completed coding frame for design elements

| Extract and intended message                                                                                   | Participants and final suggestions                                                                                                                                                                                                                                                                                                                    | P1, M, 58, S1<br>Has had a scan                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | P2, F, 53, S1<br>Message                                                                                                                                          | P4, F, 66, S3<br>Depiction                                                                                                                                                                                                                                                                                                                                                                                                                                                                | P5, F, 68, S1<br>Depiction                                                                                                                                                                                                                                                                 | P9, F, 66, S1<br>Has had a scan |
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## Appendix 32: Study 4 - Examples of usability testing findings being applied to the designs

**What's the point of lung screening?**

*Handwritten notes:* easier for doctors to treat, better chance of longer life & less suffering

**Screening can find cancer early**

Searching for signs of lung cancer. and catching lung cancer early. (He's got you)

*Handwritten notes:* Think of alt way to explain treatment as one participant paused on the word 'cancer'. The icons were mostly recognised. The only part not entirely recognisable were the depictions of the cancer, with three participants referring to them as "symbols" (P4), "pink clouds" (P5) and "pink images" (P10). Could write 'cancer' in black on both of the images. Two participants identified the intended message and no participants construed and inappropriate message. So, this section could be kept as is.

**If left alone, cancer can grow bigger and may spread to other parts of the body.**

here, the cancer is still small. left alone, the cancer has kept growing.

*Handwritten notes:* This will mean less suffering if the cancer is found early or we stumbled over. The icons were recognised by nearly everyone. One participant did not recognise the seeing glass and another did not recognise the foot prints. So, could update to make those two elements bigger or clearer. The message of the picture was not forth coming. Either leave as an icon or replace it or discard and put the version with screening compared to diagnosis earlier in the designs. Move 'left alone.' to lower position than 'here the cancer.' because it's in wrong order. Move second sentence because some participants skipped over. Move the 'but' because 2 P read it mid sentence.

**This means the longer cancer is left alone, the more difficult it can become to treat.**

**That is why it is important to find cancer early.**

**People often say that they will go to screening if they think there is something wrong**

*Handwritten notes:* The image was recognised by all but the message was not and, for most participants, distracted from the message by making it look as though a consultation with the doctor is the first step to screening as well as resulted in participants talking about cancer symptoms. Need a picture that instead conveys the symptomlessness of early cancer plus non-obvious symptom-ness plus pain-lessness of lung and perhaps screening 'stepping in' before cancer is at late stage.

**But screening is for people who don't have symptoms because...**

**When the cancer is small, people don't get obvious symptoms.**

*Handwritten notes:* When the cancer is small, I've probably said it's a cold or something. When the cancer is still small, I don't have any of the signs of feeling pain. When the cancer has spread, I've got a cough. Lung is a body part & worse than that doesn't feel pain.

**People usually don't feel it because...**

**So.. What is lung screening?**

It takes place at either a hospital or a clinic and is done using a CT scanner.

You lie down on a plastic bed which slowly moves through the centre of the scanner.

The scanner is a thin hoop.

The scanner creates images of our lungs.

A doctor then looks at these images.

To check for any signs of cancer.

*Handwritten notes:* Image of the scanner was well recognised, much helped by text info around the image saying 'scanner'. I don't think any changes need to be made. Image recognised and participants make the link that this follows on from the previous image even though it's got a different position on the page. I don't think any changes need to be made. Two participants said they didn't think the bed was plastic. Maybe remove that word. The message is relatively well understood from the picture. Participants refer to the depictions of the cells in the same way they had before: 'clouds' (P5), 'pink images' (P10). The icons were mostly recognised. The only part not entirely recognisable were the depictions of the cancer, with three participants referring to them as "symbols" (P4), "pink clouds" (P5) and "pink images" (P10). Could write 'cancer' in black on both of the images. Two participants identified the intended message and no participants construed and inappropriate message. So, this section could be kept as is. Can I think of a way of better integrating the text above and below with the picture. The additional information about the specific time frame for follow-ups is not necessary at this stage in communicating with invitees and it causes participants to worry about the time frame. so, I think it should be removed. I still don't like the working of the title, that it ends with 'found'.

**The doctor will then give you one of these three possible results:**

- 1** We didn't find any signs of cancer. (P10) *Handwritten notes:* We didn't find any signs of cancer. (P10) let your GP know if you don't think you have symptoms. (P10)
- 2** We found something that might be a cancer in the future. (P10) *Handwritten notes:* What does that mean for me? It'll be better from follow-up scan.
- 3** We found signs that might mean you have cancer. (P10) *Handwritten notes:* We found signs that might mean you have cancer. (P10) now we'll get you to do a test to find out if you really have cancer.

**EXTRA**

Signs of other conditions unrelated to cancer. If the doctor sees signs of other health conditions, your GP will be told and will talk to you about it.

*Handwritten notes:* The follow up scan is done to see if anything changes between the first and the second scan. Many signs don't become cancer so it's safer to do scans to spot any changes. Swap the numbers 2 and 3 around because people are naturally read in columns. Change the font and/or text size of the thought and speech bubble as one participant found it difficult to read. P2 and P9 suggested the picture was acceptable. P10 refers to the footprints as 'black images' again. Information about the diagnostic tests caused some participants to stop and wonder what was going on from the main message of the section. Participants felt there wasn't enough information about the tests. I think the information about the diagnostic tests should either be removed or moved to the 'risks' page where risks of additional tests is mentioned. I also feel this picture should maybe be on the 'what's the point in lung screening' page.

## Chapter 8 Appendixes

### Appendix 33: Study 5 - Picture narrative LCS information

What's the point of lung screening?

Finding cancer early will give you the best chance for better treatment options, less suffering and a longer life. ✓✓✓

Screening can find cancer early.

Searching for signs of lung cancer...

Hmm

and catching lung cancers early.

Ha! got you

If left alone, cancer can grow bigger and may spread to other parts of the body.

Here, the cancer is still small.

Cancer

This means the longer cancer is left alone, the more difficult it can become to treat.

Left alone, the cancer has kept growing.

Cancer

That is why it is important to find cancer early.

People often say that they will go to screening if they think there is something wrong, but screening is for people who don't have symptoms because...

People usually don't get symptoms that are easy to recognise.

cough cough

I've probably got a cold or something.

When the cancer is still small.

People usually can't feel if they have cancer in their lungs.

Lungs don't have any way of feeling pain.

When the cancer has spread and grown bigger.

## So... What is lung screening?

It takes place at either a hospital or a clinic and is done using a CT scanner.



You lie down on a bed which slowly moves through the centre of the scanner.

The scanner is a thin hoop.

The scanner creates images of our lungs.

A doctor then looks at these images.



To check for any signs of cancer.

The doctor will then give you one of these three possible results:

1

We didn't find any signs of cancer.

Great!

Remember to let your GP know if you ever think you have symptoms.

I will do.

2

We found something that might become cancer in the future.

What does that mean for me?

It'll be best for you to have a follow-up scan.

3

We found signs that might mean you have cancer.

What now, doc?

Now we'll get you to do a test to find out if you really do have cancer.

The follow-up scan is done to see if anything changes between the first and the second scan. Many signs don't become cancer so it is safer to do follow-up scans to spot any changes.

EXTRA

**Signs of conditions unrelated to cancer.** If the doctor sees signs of other health conditions, your GP (General Practitioner) will be told and will talk to you about it.



## Who is lung screening for and why?

Remember the benefits of lung screening. By doing screening, you improve your chances of:

Simpler treatment



Less suffering

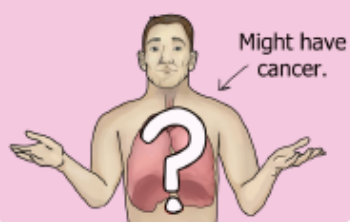


Longer life



The following things increase our chance of benefitting from lung screening.

- 1 Being likely to have lung cancer.



The main things that increase our chances of getting lung cancer are:



Being older



Heavy smoking

Smoking an average of 10 cigarettes a day for 20 years.

- 2 Being likely to benefit from treatment.

Healing after being treated for cancer.



The main things that increase our chances of benefitting from treatment are:



Being under 75 years old

Without being frail or having other serious health conditions.

Those two reasons are why you would be invited to lung screening if you are...

over 50 years old and smoked heavily within the last 15 years.

under 75 years old.



## What risks come with doing lung screening?

**Risk 1:** You might be given treatment for a cancer that would not cause you problems in your lifetime.



### Risk 2: Signs but no cancer

You could be told you have signs that might be cancer...



go for further tests to find out if cancer is there..



and find out you do not have cancer.



In this case, you would go through further tests that also have risks but you would not benefit from the screening.

### Risk 3: Cancer but no signs

You could be told you don't have signs of cancer...



not go for further tests ...



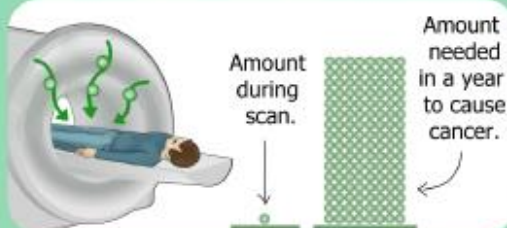
and not find out about a cancer that is actually there.



This is extremely rare but worth knowing.

### Risk 4: Radiation

In the scanner you will have a small amount of radiation pass through you.



The amount is very low compared to the amount that can cause cancer.

### Risk 5: Stress

Different parts of the screening can be stressful for people.



## Appendix 34: Study 5 - Text and pictures LCS information (study condition 1)

What's the point of lung screening?

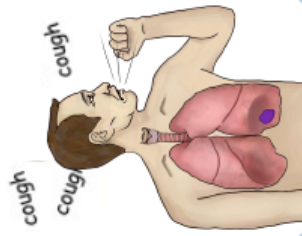
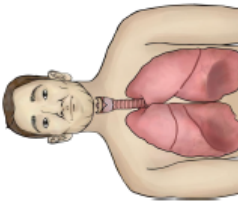
Screening can find cancer early. Screening means searching for signs of lung cancer and catching lung cancer early. Finding cancer early will give you the best chance for better treatment options, less suffering and a longer life.

If left alone, cancer can grow bigger and may spread to other parts of the body. This means the longer cancer is left alone, the more difficult it can become to treat. That is why it is important to find cancer early.

People often say that they will go to screening if they think there is something wrong, but screening is for people who don't have symptoms because...

People usually don't get symptoms that are easy to recognise, when the cancer is still small. For example, coughing more than usual, which people are more likely to think is being caused by a cold or something else.

People usually can't feel if they have cancer in their lungs, even when the cancer has spread and grown bigger. Lungs don't have any way of feeling pain.

So... What is lung screening?

It takes place at either a hospital or a clinic and is done using a CT scanner. You lie down on a bed which slowly moves through the centre of the scanner. The scanner is a thin hoop. The scanner creates images of our lungs. A doctor then looks at these images to check for any signs of cancer.

The doctor will then give you one of these three possible results:

(1) No problems were found  
This result means that the doctor did not find any signs of cancer.

(2) Signs of something that might become lung cancer found  
With this result, it is best to have a follow-up scan to see if anything changes between the first and second scan. Many signs don't become cancer so it is safer to do follow-up scans to spot any changes.

(3) Signs of lung cancer found  
With this result, you will be invited to diagnostic tests to find out if you really have cancer.

(Extra) Signs of conditions unrelated to cancer found  
If the doctor sees signs of other health conditions, your GP (General Practitioner) will be told and will talk to you about it.



What risks come with doing lung screening?



**Risk 1.** You might be given treatment for a cancer that would not cause you problems in your lifetime.

**Risk 2.** Signs but no cancer The test might find signs that might be cancer that turn out not to be cancer. When this is the case, you would go through additional tests that come with their own risks.

**Risk 3.** Cancer but no signs The test might not find signs of a cancer that is actually there. These cases are extremely rare but worth being aware of.

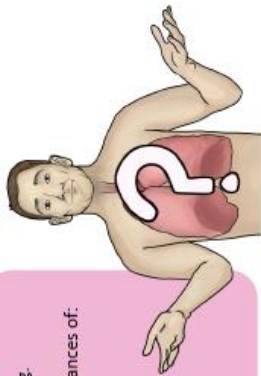
**Risk 4.** Radiation In the scanner you will have a small amount of radiation pass through you. The amount of radiation is very low compared to the amount that can cause cancer.



**Risk 5.** Stress Different parts of the screening can be stressful for people. Such as going to the screening, waiting for the results, and receiving the results.



Who is lung screening for and why?



Remember the benefits of lung screening. By doing screening, you improve your chances of:

- Simpler treatment
- Less suffering
- Longer life

The following things increase our chances of benefitting from lung screening:

Being likely to have lung cancer. The main things that increase our chances of getting lung cancer are being older and heavy smoking. Heavy smoking would be an average of 10 cigarettes a day for 20 years.

Being likely to benefit from treatment. The main things that increase our chances of benefitting from treatment are being under 75 years old, as well as not being frail or having other serious health conditions.



Those two reasons are why you would be invited to lung screening if you are between 50 and 75 years old and have smoked heavily within the last 15 years.

## Appendix 35: Study 5 - Text-only LCS information (study condition 1)

So... What is lung screening?

It takes place at either a hospital or a clinic and is done using a CT scanner.

You lie down on a bed which slowly moves through the centre of the scanner. The scanner is a thin hoop.

The scanner creates images of our lungs. A doctor then looks at these images to check for any signs of cancer.

The doctor will then give you one of these three possible results:

**(1) No problems were found**  
This result means that the doctor did not find any signs of cancer.

**(2) Signs of something that might become lung cancer found**  
With this result, it is best to have a follow-up scan to see if anything changes between the first and second scan. Many signs don't become cancer so it is safer to do follow-up scans to spot any changes.

**(3) Signs of lung cancer found**  
With this result, you will be invited to diagnostic tests to find out if you really have cancer.

**(Extra) Signs of other conditions unrelated to cancer found**  
If the doctor sees signs of other health conditions, your GP (General Practitioner) will be told and will talk to you about it.

What's the point of lung screening?

Screening can find cancer early. Screening means searching for signs of lung cancer and catching lung cancer early. Finding cancer early will give you the best chance for better treatment options, less suffering and a longer life.

If left alone, cancer can grow bigger and may spread to other parts of the body. This means the longer cancer is left alone, the more difficult it can become to treat. That is why it is important to find cancer early.

People often say that they will go to screening if they think there is something wrong, but screening is for people who don't have symptoms because...

People usually don't get symptoms that are easy to recognise, when the cancer is still small. For example, coughing more than usual, which people are more likely to think is being caused by a cold or something else.

People usually can't feel if they have cancer in their lungs, even when the cancer has spread and grown bigger. Lungs don't have any way of feeling pain.

### Who is lung screening for and why?

Remember the benefits of lung screening.

By doing screening, you improve your chances of:

- Simpler treatment
- Less suffering
- Longer life

The following things increase our chances of benefiting from lung screening:

**Being likely to have lung cancer.** The main things that increase our chances of getting lung cancer are being older and heavy smoking. Heavy smoking would be an average of 10 cigarettes a day for 20 years.

**Being likely to benefit from treatment.** The main things that increase our chances of benefiting from treatment are being under 75 years old, as well as not being frail or having other serious health conditions.

Those two reasons are why you would be invited to lung screening if you are between 50 and 75 years old and have smoked heavily within the last 15 years.

### What risks come with doing lung screening?

#### **Risk 1.**

You might be given treatment for a cancer that would not cause you problems in your lifetime.

#### **Risk 2. Signs but no cancer**

The test might find signs that look like cancer that turn out not to be cancer. When this is the case, you would go through additional tests that come with their own risks.

#### **Risk 3. Cancer but no signs**

The test might not find signs of a cancer that is actually there. These cases are extremely rare but worth being aware of.

#### **Risk 4. Radiation**

In the scanner you will have a small amount of radiation pass through you. The amount of radiation is very low compared to the amount that can cause cancer.

#### **Risk 5. Stress**

Different parts of the screening can be stressful for people. Such as going to the screening, waiting for the results, and receiving the results.

## Appendix 36: Study 5 – Invitation flier

«Full\_name\_proper»  
«ADDRESS\_LINE\_1»  
«ADDRESS\_LINE\_2»  
«ADDRESS\_LINE\_3»  
«POSTCODE»

By taking part, you will be helping to improve how lung screening information is communicated. This will support people in your community in deciding to go for lung screening which will hopefully help reduce how many people are negatively affected by lung diseases.

**If you decide to take part...** at the beginning of the questionnaire, you will be shown lung screening information in one of three design types. You will then be asked questions about whether you found the information engaging and supportive. You will then be asked questions about yourself (such as your age and living situation). This will let us know if the designs are more or less helpful for different people and it will let us check if the people taking part in the questionnaire are representative of all people living in Glasgow. The questionnaire takes people around 15 minutes to complete.

All information collected in this study will be kept private and handled securely. The study has been reviewed by an ethics committee at the University of Glasgow.

**For more information**, call the researcher Lauren on 07502 157585 or go to this website:  
[www.sites.google.com/view/picturing-lung-screening/questionnaires](http://www.sites.google.com/view/picturing-lung-screening/questionnaires)

Return address:  
Ms L Gitting, Mental Health & Wellbeing, Admin Building, Gartnavel Royal Hospital, Glasgow G12 0BR

**Appendix 37: Study 5 – Invitation letter, participant information sheet and  
privacy notice**

**The purpose of the study is...** to help improve the information given to people about lung screening. The aim of this study is to test the impact of different types of design on how useful lung screening information is for people who would be invited to lung screening.

A secondary aim of this study is to test whether, and in what ways, the different types of design differ in how helpful they are for different groups of people (for example, a person's age, gender or living situation).

**Why you have been invited to take part.** The questionnaire is for anyone living in Glasgow, aged between 50 and 75 years old. The study is for people living in Glasgow because the designs have been made by and for people living in Glasgow. This study is for people aged between 50 and 75 because lung screening information is most likely to benefit people in this age range. Lauren hopes 600 people can take part in the questionnaire, to be able to draw confident conclusions about the designs.

Your address has been randomly selected from a list obtained from the company, Experian. The company is GDPR compliant and only provided the researcher with a list of names and addresses of people living in Glasgow who are 50 and 75 years old.

**Do you have to take part.** No, it is up to you to decide whether or not to take part. This will not affect the standard of care you may receive now or in the future and will not affect your opportunity to take part in other research in the future.

**What will happen if you decide to take part.** At the beginning of the questionnaire, you will be shown lung screening information. You will then be asked questions about how useful you found the information. You will then be asked questions about yourself (such as your age and living situation). This will let us know if the information is helpful for different people and it will let us check if the people taking part are representative of all people living in Glasgow.

**If you change your mind about taking part.** You can stop completing the questionnaire at any time and we will not have access to your responses. If you are completing the questionnaire online, you can close the webpage window and none of the responses you had previously given will be collected. Once you have submitted or posted your questionnaire to us, we will not be able to access or delete the data for you because it will be anonymous.

**The possible benefits of taking part.** If you complete the questionnaire, you will be included in a prize draw, with the chance to win £250, two chances to win £100 and, three chances to win £50. By taking part, you will also be helping to improve lung screening information for people in your community.

**The possible drawbacks of taking part.** The designs being looked at in this study are about lung screening, with reference to lung cancer. This may be a sensitive or upsetting topic for





**Study title:** Designing lung screening information that is engaging and supportive

## Privacy notice

*The University of Glasgow will be what's known as the 'Data Controller' of your personal data processed in relation to Lauren Gatting's PhD research project. This privacy notice will explain how The University of Glasgow will process your personal data.*

### Why we will be processing your data

We are collecting personal data about your name, age, gender, ethnicity, socioeconomic status, smoking status in order to describe the characteristics of the people who took part in the research. We have also processed your contact details to be able to send you an invitation to the study (name and postal address). We will collect and process this data for these purposes only.

### What is the legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is for research and public interest.

### What we do with it and who we share it with

All the personal data you submit will only be processed by staff at the University of Glasgow in the United Kingdom. Your personal data will be anonymous. Your data will be stored within a secure computer system. Your address has been randomly selected from a list obtained from Experian. Further details are available from <https://www.experian.co.uk/privacy/consumer-information-portal/>. The data was shared with the researchers under contract, and with a data sharing agreement in place, to ensure that your data is protected by both parties.

### How long we keep it for

Your contact information (name and postal address) was securely deleted after the study flier or questionnaire was sent to you. The data that you provide to us in the questionnaire will be stored for up to 2 years by the primary researcher, Lauren Gatting, on the University of Glasgow computer system within a password-protected profile, while the research is being conducted. Your data will then be transferred and stored for ten years on the University of Glasgow's research repository to allow for any necessary quality assurance checks in the future. After this time, the data will be securely deleted.

### What are your rights

Because the data you provide to us in the questionnaire will be anonymous, we will not be able to identify your data once you have submitted it to us.

You can request access to the information Experian process about you at any time. If at any point you believe that the information Experian process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. You may also have the right to object to the processing of data and the right to data portability. If you have any queries about, or wish to exercise, any of these rights, you should contact Experian on 0115 828 6738 or [uk.dpo@experian.com](mailto:uk.dpo@experian.com). If you wish to know more about the information held by Experian, you can find out more at <https://www.experian.co.uk/consumer/data-access>

### Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer at [dataprotectionofficer@glasgow.ac.uk](mailto:dataprotectionofficer@glasgow.ac.uk)

If you are not satisfied with our response, you can make complaints to the Information Commissioner's Office (ICO) <https://ico.org.uk/>

Privacy Notice V2 08/01/2021

## Appendix 38: Study 5 - Questionnaire

### Questionnaire



Thank you for being interested in this study!

**Before filling in the questionnaire, please make sure the following are true:**

- You have read the letter that came with this questionnaire.
- You know your participation is voluntary.
- You understand that all data and information you provide will be kept confidential and will be seen only by the researcher, Lauren, and may be seen by research regulators whose job it is to check the work of researchers.
- You understand that data from this questionnaire will be presented in Lauren's PhD thesis and may be presented in research reports and presentations but that your name or anything else that could tell who you are will not be revealed (or made public).
- You agree for the information you give in this questionnaire to be handled in the ways described in the privacy notice (that is the last sheet in your questionnaire pack).

### What did you think about the lung screening information?

Please tick in the box by your answers. ☒

**Did you think the pages looked good?**

- |                                          |                                   |
|------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Really good     | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Somewhat good   |                                   |
| <input type="checkbox"/> Not good        |                                   |
| <input type="checkbox"/> Really not good |                                   |

**Did you enjoy reading the pages?**

- |                                               |                                   |
|-----------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Really enjoyable     | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Somewhat enjoyable   |                                   |
| <input type="checkbox"/> Not enjoyable        |                                   |
| <input type="checkbox"/> Really not enjoyable |                                   |

**Did you find the pages interesting?**

- |                                                 |                                   |
|-------------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Really interesting     | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Somewhat interesting   |                                   |
| <input type="checkbox"/> Not interesting        |                                   |
| <input type="checkbox"/> Really not interesting |                                   |

**Did you think the pages gave enough information?**

- |                                                     |                                   |
|-----------------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Yes                        | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> No, not enough information |                                   |
| <input type="checkbox"/> No, too much information   |                                   |

**Were the pages easy to understand?**

- |                                                        |                                   |
|--------------------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Very easy to understand       | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Easy to understand            |                                   |
| <input type="checkbox"/> Not easy to understand        |                                   |
| <input type="checkbox"/> Not at all easy to understand |                                   |

**Did you feel like the pages were relevant to you?**

- |                                              |                                   |
|----------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Very relevant       | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Somewhat relevant   |                                   |
| <input type="checkbox"/> Not relevant        |                                   |
| <input type="checkbox"/> Not at all relevant |                                   |

**Did you think the information was trustworthy?**

- |                                                 |                                   |
|-------------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Very trustworthy       | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Somewhat trustworthy   |                                   |
| <input type="checkbox"/> Not trustworthy        |                                   |
| <input type="checkbox"/> Not at all trustworthy |                                   |

**Did you think the pages were appropriate for the topic?**

- |                                                 |                                   |
|-------------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Very appropriate       | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Somewhat appropriate   |                                   |
| <input type="checkbox"/> Not appropriate        |                                   |
| <input type="checkbox"/> Not at all appropriate |                                   |

**Do you think the pages would be helpful for someone deciding about doing lung screening?**

- |                                             |                                   |
|---------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Very helpful       | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Somewhat helpful   |                                   |
| <input type="checkbox"/> Not helpful        |                                   |
| <input type="checkbox"/> Not at all helpful |                                   |

**Do you think the pages were good at explaining lung cancer screening?**

- |                                          |                                   |
|------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Very good       | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Somewhat good   |                                   |
| <input type="checkbox"/> Not good        |                                   |
| <input type="checkbox"/> Not at all good |                                   |

**If lung screening became available in your neighbourhood, would you be one of the people invited?**

- |                              |                             |                                   |
|------------------------------|-----------------------------|-----------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not sure |
|------------------------------|-----------------------------|-----------------------------------|

## What are your thoughts on lung screening?

How much do you agree with each of these four statements? Please tick in the box by your answers ☒

1. I wouldn't want to know if I had lung cancer.

- ☐ Strongly agree  
☐ Agree  
☐ Disagree  
☐ Strongly disagree

☐ Not sure

2. I don't think there is any point going for lung cancer screening because it won't affect the outcome.

- ☐ Strongly agree  
☐ Agree  
☐ Disagree  
☐ Strongly disagree

☐ Not sure

3. If lung cancer is found early, there's a better chance of successful treatment and survival.

- ☐ Strongly agree  
☐ Agree  
☐ Disagree  
☐ Strongly disagree

☐ Not sure

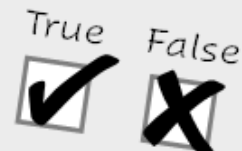
4. I would be so worried about what might be found by the screening that I would prefer not to go.

- ☐ Strongly agree  
☐ Agree  
☐ Disagree  
☐ Strongly disagree

☐ Not sure

For the next questions, in each box, put a tick if you believe the answer is true or a cross if you believe the answer is false.

You can look at the lung information while answering them.



What happens during a lung screening CT scan?

- ☐ you remain standing  
☐ you lie down during  
☐ you have to undress your upper body  
☐ you go into a scanner that is shaped like a hoop

In each box, put a tick if you believe the answer is true or a cross if you believe it is false

**Who would most likely benefit from lung screening?**

- ☐ People of all ages
- ☐ Younger people (under 50 years old)
- ☐ Older people (over 50 years old)
- ☐ People who smoke any amount
- ☐ People who smoke heavily

**What are the reasons for inviting one group of people to screening and not everybody?**

- ☐ If people have more chance of being harmed by the process than benefiting, they are **not** invited
- ☐ If people are unable to have treatment due to other health conditions, they are **not** invited
- ☐ It would be too expensive to screen everyone
- ☐ People are only invited if they are more likely to have lung cancer
- ☐ Not everyone is likely to benefit from lung screening

**What reasons are there for doing lung screening?**

- ☐ It's the best way of finding lung cancer early
- ☐ It can reduce people's chance of dying from lung cancer
- ☐ It can reduce people's chance of dying from causes other than lung cancer
- ☐ It can stop people from getting cancer
- ☐ It can tell you how much you'll benefit from stopping smoking

**What are the harms and potential harms that come with lung screening?**

- ☐ A lot of radiation
- ☐ A small amount of radiation
- ☐ Stress or worry
- ☐ Being sent for diagnostic tests but not actually having cancer
- ☐ Being treated for a cancer that would have not caused any harm in your lifetime

**What are the different results you might get back if you went for lung screening?**

- ☐ You do not have cancer
- ☐ Scan found no problems
- ☐ Scan found signs that might be lung cancer
- ☐ Scan found signs of something that might become lung cancer in the future
- ☐ Scan found signs of a condition that is not lung cancer

## Tell us about yourself and your life situation.

How old are you? \_\_\_\_\_ years

What is your gender? \_\_\_\_\_

(for example, Male, Female)

What is your ethnicity? \_\_\_\_\_

(for example, Scottish, British, Pakistani, African, Chinese)

Do you smoke or have you ever smoked cigarettes?

☐ Yes ☐ No

If yes,

At what age did you become a regular smoker? \_\_\_\_\_

How many cigarettes would you usually smoke a day? \_\_\_\_\_

If you no longer smoke, how many years ago did you stop smoking? \_\_\_\_\_

Do you own or rent the place you live?

- ☐ Own outright
- ☐ Buying on mortgage
- ☐ Rent from local authority
- ☐ Rent from housing association
- ☐ Rent from private landlord
- ☐ Do not own or rent something else \_\_\_\_\_

How many cars or vans do you own?

☐ None ☐ One ☐ More than one

Have you completed any of these types of qualifications?

- ☐ Highers, O-Grade, Certificate of Secondary Education or GCSEs
- ☐ Vocational qualifications, Diploma, NVQ1 or NVQ2
- ☐ Advanced Higher, A level, AS level, Certificate of Sixth Year Studies or NVQ3
- ☐ Bachelor's degree, NVQ4, Masters or PhD
- ☐ Apprenticeship ☐ Have not completed one of these

What type of employment do you have?

- ☐ Retired ☐ On paid sick leave
- ☐ Unemployed ☐ On unpaid sick leave
- ☐ Part-time employed
- ☐ Full-time employed
- ☐ Self-employed
- ☐ Business owner something else \_\_\_\_\_

Do you ever find it difficult to read or understand health and medical information?

- ☐ Yes, often      ☐ Yes, sometimes      ☐ No, never

How much did you know about cancer screening tests before doing this questionnaire?

- ☐ A lot      ☐ A little      ☐ Nothing

How much did you know about lung cancer before doing this questionnaire?

- ☐ A lot      ☐ A little      ☐ Nothing

How much time did you spend looking at the pages with the lung screening information?

- ☐ Did not look at the pages  
☐ Less than 2 minutes  
☐ Between 2 to 10 mins  
☐ More than 10 mins

Thank you! That is the end of the questionnaire questions.

**Any other thoughts.** If you have any other thoughts about the lung screening information that you would like to let us know about, please write it in this text box. (For example, maybe there was other information you wanted to know about or that you did not want to hear about).

**Feedback section.** If you have any feedback for the researchers about the way this study has been conducted, please write your feedback in this text box.

### **Prize draw**

Your prize draw code is 'PRIZE DRAW «prize\_draw\_3385»'

If you would like to be included in the prize draw, simply text or email you're prize draw code to Lauren on 07502 157585 or L.Gatting.1@research.gla.ac.uk. Make sure to include your contact details in the message so that we will be able to contact you if you are a winner of the prize draw.

Or you can call Lauren on 07502 157585 about being included. If you wish to leave a voice message, state your prize draw code and contact details and you will be included in the prize draw.

We will only use the contact details you provide to contact you if you win in the prize draw and will be deleting the information once the prize draw has ended.

### **Where to go to get advice and support if affected by or worried about cancer.**

If you need support for yourself or someone else.

- Macmillan, the cancer charity, have a free support line 0808 808 0000 that you can call any day between 8am and 8pm.
- Cancer research UK, another charity, also have a free support line 0808 800 4040 that you can call from Monday to Friday between 9am and 5pm.

If you think you may have cancer, please contact your GP.

- Either, find out where your nearest general practice is by asking people you know or by searching online, then go in and ask the receptionist for an appointment.
- Or, you can go online, search for 'general practice' and where you live, click on a result for a website in your area and there will be a number for that GP that you can call to book an appointment.

Thank you so much for taking part in this questionnaire. In volunteering your time to do this, you have supported a research student in their training and have contributed towards improving lung screening information.

**How to return the questionnaire**

Please use the free-return envelope to send your questionnaire back to us. You DO NOT need to put a stamp on it. Post back this booklet with the questions only. In case you misplace the free-return envelope, the return address is:

Lauren Gatting  
Mental Health & Wellbeing  
Admin Building, Gartnavel Royal Hospital  
FREEPOST SCO3907  
Glasgow  
G12 0BR



# About the study



## Who

I'm Lauren, a PhD research student looking into ways of 'using picture narrative to make lung screening information engaging, accessible and supportive' (that's my project title)

## What

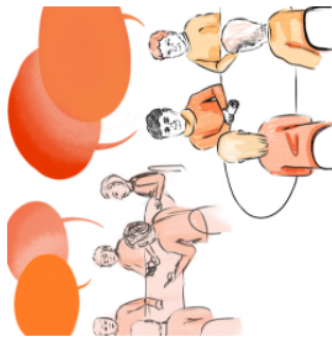
**In the first and second year** I looked into past studies and theories to identify what things are important in the communication of lung screening information to people invited to take part.

**In the third year** I did a [workshop](#) in Glasgow with people predicted to get most benefit from lung screening and from support with deciding whether to go to screening. We looked at the things I identified as being important in year 1 and 2 and discussed design ideas for a lung screening information leaflet. Then, I worked with an artist (who had attended the workshop) to design a prototype of information for lung screening invitees.

**Now in the fourth year** I recently did [interviews](#) with people living in Glasgow to get their feedback on the prototype. I'm using this feedback to figure out what changes I should make to the designs to make them more attractive, easier to understand, acceptable and supportive for people invited to do lung screening. Once I've updated the designs, I'll be asking people to complete a questionnaire to find out if the designs meet these goals and will compare this to lung screening information that is either only writing or writing with pictures that aren't narrative.



# Workshop



## What was it about

We ran a community workshop to design health information about lung cancer screening with people who would most likely benefit from a taking part in lung screening.

We advertised the workshop through community groups at Possilpoint community centre (Glasgow), to people over 50 years old who had been, or were, smokers.

## How was it organised

The workshop was made possible through the existence of the Link Up programme. Programme coordinator, Gillian Halliday, and community development volunteer, Billy Aird, gave significant support with inviting people to the workshop and securing a room in the community centre where the workshop was held. The workshop would not have been possible without this help.

"Operational since 2012, Link Up is an Inspiring Scotland programme investing in 9 urban communities. It aims to tackle disadvantage by using social participation to enable local people (many amongst the most vulnerable) to help themselves, each other, and their community." See more at - [Link Up website](#)

## What happened



# Interviews



## Interviews and updating the designs

Between March and April this year (2021), I interviewed eight people who were in the priority group\* for the lung screening information that I'm designing. The interviews were to find out what parts of the prototype designs worked and which didn't work. I'm currently (as of May 17th) analysing the interviews and will use the findings to refine the designs of the lung screening information - making sure the content and style is suitable for the audience.

Thank you again to each of you who took part.

\*The priority group is people who'd be most likely to benefit from, and be invited to, a lung cancer screening based on their age and smoking history, as well as, living in places in Glasgow with lower access to other cancer screening programmes and worse cancer outcomes.

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