



Bissett, Maria (2025) *Developing a transcultural arts-based participatory approach to exploring the drivers of diabetes and hypertension among African communities in Scotland and Malawi*. PhD thesis.

<https://theses.gla.ac.uk/85507/>

Copyright and moral rights for this work are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This work cannot be reproduced or quoted extensively from without first obtaining permission from the author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

Enlighten: Theses

<https://theses.gla.ac.uk/>

[research-enlighten@glasgow.ac.uk](mailto:research-enlighten@glasgow.ac.uk)

**Developing a Transcultural Arts-Based  
Participatory Approach to Exploring the  
Drivers of Diabetes and Hypertension among  
African Communities in Scotland and Malawi**

**Maria Bissett, MSc, BSc**

**Submitted in fulfilment of the requirements for the degree of  
Doctor of Philosophy in Social and Public Health**

**School of Social and Political Sciences**

**College of Social Sciences**

**University of Glasgow**

## Abstract

**Background:** African communities in Scotland and Malawi are disproportionately affected by noncommunicable diseases (NCDs), including diabetes and hypertension. There is a need to understand the specific socio-cultural drivers of these diseases among different communities to develop health promotion interventions that are effective and sustainable. Arts-based participatory approaches are a collaborative strategy to explore underlying experiences of NCDs using creative activities (e.g. music, drawing). A transcultural model which values multiple perspectives and diverse cultural identities, could support the development of a methodology that can be adapted and applied with diverse communities to generate culturally-situated insights into NCD risk factors and inform culturally compelling health promotion interventions. This research aims to develop a framework for a transcultural arts-based participatory approach (TABPA) to explore the drivers of diabetes and hypertension among African communities in Scotland and Malawi.

**Methods:** This research involved close collaboration with community members, local arts-practitioners, and stakeholders in each setting, and was carried out in three phases to develop a TABPA framework for wider implementation. Phase 1 involved a familiarisation process with communities in Malawi and Scotland. Walkalong interviews (N= 8 Malawi: N=10 Scotland) were used to explore local perspectives on community, NCDs, and local art forms. Three single-gender community workshops (Malawi: N=10 gender and N=12 gender, Scotland: N=11 women) were used to determine what art forms would be compatible with community interests and adaptable to explorations of NCDs, and how participants would respond to arts-based participatory workshops in practice. Finally, two stakeholder workshops (Malawi: N=10 in-person, Scotland: N=4 online) were conducted to learn more about community capacity for arts-based health research from the perspectives of key local stakeholders.

Phases 2 and 3 involved the pilot and refinement of the TABPA in Scotland (Phase 2) and Malawi (Phase 3). Single-gender TABPA workshops were piloted with women in Scotland (N=12) and men Malawi (N=10) before being refined and conducted with women in Malawi (N=10) and men in Scotland (N=3). The TABPA

workshops followed a simple, flexible, scaffolding structure, using arts-based activities to explore community perspectives on the risk factors of diabetes and hypertension. Data from all three Phases were analysed using reflexive thematic analysis.

**Findings:** Phase 1 walkalong interviews in both Malawi and Scotland generated a deeper understanding of the local contexts that would shape community involvement in the TABPA workshops. In Malawi, participants defined community as belonging to “one family” within their local area. In Scotland, definitions of community were more complex, with many participants seeing themselves as belonging to several communities at one time. In both settings, communities were concerned about diabetes and hypertension, were knowledgeable about risk factors, including diet and stress, and several had personal or familial experiences of the diseases. Many participants indicated that they had experience of arts-based activities through community events (Malawi), community organisations (Scotland) and places of worship (both). However, community members in each setting revealed barriers to participation in arts, such as a lack of time or opportunities. These insights informed the design and implementation of the Phase 1 community and stakeholder workshops, which highlighted that a range of art forms including music and dance, drama, drawing, and poetry, could be effectively used to explore hypertension and diabetes, especially if they are culturally engaging (e.g. music) and accessible (e.g. drawing). Offering flexibility and choice over the art-form and the content fostered participant engagement, relationship building and co-learning. Stakeholders in each context also highlighted the importance of supporting workshop accessibility (e.g. by providing reimbursement for travel and childcare).

The Phase 2 and 3 TABPA workshops were initially informed by the Phase 1 findings and refined using learnings from initial pilot implementations in both countries. The workshops used a scaffolding structure consisting of five activities including games, individual visualisations, creative group activities, performance and reflection. Community members used drama, song, drawing and storytelling, and shared culturally-situated understanding of the risk factors of diabetes and hypertension (e.g. social prestige as a driver of unhealthy eating in Malawi and

the impact of the UK immigration on health behaviours in Scotland). Participants also shared personal and emotive narratives about how they and their families had been impacted by diabetes and hypertension and reflected positively on the TABPA workshops as a space where they felt “free” to express their views. However, the workshops also highlighted power dynamics during the co-production of knowledge, such as differing expectations regarding whether the workshops should include health information dissemination and diverging expectations around the quality of the artistic outputs. Overall, the TABPA workshops supported the model and highlighted that community involvement in the development could support a culturally-compelling research design.

**Conclusions:** Although this research was developed and conducted in diverse contexts, the TABPA workshops appeared promising as a means to gain culturally-situated insights into the drivers of diabetes and hypertension in each community. Thus, while the need for Phase 1 will depend on the practitioner’s familiarity with the community, this research presents a TABPA framework consisting of: i) a familiarisation phase to gain in-depth understanding of the target community and local context; and ii) a scaffolding TABPA workshop protocol to explore community perspectives and experiences of NCD risk factors. Recommendations for future implementation of the framework by researchers and practitioners are provided including the importance of flexibility, supportive facilitators and responsiveness to community and practitioner expectations.

# Table of Contents

Abstract .....	ii
Table of Contents .....	v
List of Tables.....	x
List of Figures .....	xi
Acknowledgments .....	xiii
Author’s Declaration .....	xv
Abbreviations .....	xvi
1 Introduction.....	1
1.1 Noncommunicable diseases in Sub-Saharan African and the UK.....	1
1.2 The Rationale for Arts-Based Participatory Health Research .....	4
1.3 The Rationale for a Transcultural Approach.....	5
1.4 Aim and Research Questions .....	6
1.5 Overview of Design .....	6
1.6 Thesis Structure.....	8
2 Defining a Transcultural Arts-based Participatory Approach (TABPA).....	12
2.1 Art as a Research Method .....	12
2.1.1 Arts-Based Methods in Health and Noncommunicable Disease Research.....	12
2.1.2 Sociology of Art.....	14
2.2 A Transcultural Approach.....	17
2.2.1 Defining Transcultural .....	17
2.2.2 Transcultural Health Research .....	20
2.3 Community Based Participatory Research (CBPR) .....	21
2.3.1 Background.....	21
2.3.2 Key Principles.....	23
2.3.3 Navigating Power and Participation in CBPR .....	24
2.4 A Transcultural CBPR Model for the Development of the TABPA .....	26
2.4.1 Transcultural Contexts Domain .....	28
2.4.2 Transcultural Partnership Processes Domain.....	29
2.4.3 Transcultural Intervention and Research Domain .....	30
2.4.4 Transcultural Outcomes Domain .....	32
2.4.5 A Transcultural Community-Based Participatory Research Conceptual Model .....	34
2.5 Contribution of the TABPA Framework .....	36
2.6 Summary .....	37

3	Methodology .....	38
3.1	Positionality .....	38
3.1.1	Shifting Epistemologies.....	38
3.1.2	Experiences in the Arts.....	39
3.1.3	An ‘Outside’ Researcher .....	40
3.2	Epistemologies of Arts-Based Health Research.....	41
3.3	Research Design and Timeline .....	43
3.4	Settings, Partnerships and Recruitment.....	44
3.4.1	Malawi .....	44
3.4.2	Scotland .....	48
3.5	Phase 1 Methods: Walking Interviews, Community and Stakeholder Workshops .....	51
3.5.1	Walkalong Interviews .....	52
3.5.2	Community Arts-Based Participatory Workshops .....	53
3.5.3	Stakeholder Arts-Based Participatory Workshops.....	54
3.6	Phase 2 and 3 Methods: Transcultural Arts-Based Participatory Approach Workshops .....	57
3.6.1	Pilot and Refinement .....	58
3.7	Dataset .....	61
3.8	Reflexive Thematic Analysis .....	63
3.8.1	Walkalongs .....	65
3.8.2	Community and Stakeholder Workshops .....	68
3.8.3	Phase 2 and 3 TABPA workshops .....	73
3.8.4	Developing the TABPA Framework.....	76
3.9	Ethical Considerations .....	76
3.9.1	Malawi: Informed Consent and Cultural Sensitivity .....	77
3.9.2	Scotland: Informed Consent and Cultural Sensitivity .....	79
3.9.3	Ethical Considerations in Walkalong Interviews .....	80
3.9.4	Navigating Sensitive Topics .....	81
3.10	Limitations.....	81
4	Walkalongs in Malawi: Community, Arts and Health.....	83
4.1	Introduction .....	83
4.2	Walking in Malawi .....	84
4.3	Everyday Life in Sector A, Lilongwe, Malawi .....	89
4.3.1	Households and Mobility.....	89
4.3.2	A ‘Peaceful’ Residential Area .....	90
4.3.3	Community as ‘One family’ .....	91

4.3.4	The Marketplace: Food Security and Economic Opportunity .....	93
4.3.5	Social Life, Celebrations and Religion.....	95
4.4	Local Arts and Participation.....	96
4.5	Community Health and Noncommunicable Diseases.....	99
4.5.1	Community Health Concerns .....	100
4.5.2	Community Knowledge and Perspectives of Diabetes and Hypertension.....	102
4.6	Summary .....	108
4.7	Reflections For TABPA Development and Implementation .....	110
5	Walkalongs in Scotland: Community, Arts and Health.....	112
5.1	Introduction .....	112
5.2	Walking in Scotland .....	112
5.3	Everyday Life among African Communities in Glasgow .....	114
5.3.1	Mobility and Migration.....	115
5.3.2	Multiple Definitions of Community .....	116
5.4	Local Arts and Participation.....	120
5.5	Community Health and Noncommunicable Diseases.....	123
5.5.1	Community Health Concerns .....	123
5.5.2	Community Knowledge and Perspectives of Diabetes and Hypertension (BP).....	126
5.6	Summary .....	138
5.7	Reflections for TABPA Development and Implementation.....	140
5.7.1	Walkalong interviews .....	140
5.7.2	Walkalong Interviews as Preparation for TABPA Implementation .	141
6	TABPA Development in Two Contexts.....	142
6.1	Introduction .....	142
6.2	What art forms are compatible with community interests and adaptable to explorations of hypertension and diabetes? .....	144
6.2.1	Music and Dance.....	147
6.2.2	Theatre and Drama .....	153
6.2.3	Drawing .....	156
6.2.4	Poetry.....	161
6.2.5	Alternative Forms of Art .....	164
6.3	Arts-Based Participatory Workshops in Practice: Strengths and Challenges .....	165
6.3.1	Relationship Building, Co-learning, and Challenging Power Hierarchies .....	166
6.3.2	Facilitation: Framing Content and Navigating Stigma .....	171

6.3.3	Practical Considerations: Accessibility .....	176
6.3.4	Practical Considerations: Time management and Consent .....	177
6.4	Summary .....	178
6.5	Reflections for Development.....	179
7	TABPA Method as Findings .....	181
7.1	Introduction .....	181
7.1.1	Developing and Refining the TABPA protocol .....	182
7.2	Fostering a Safe and Supportive Environment: “You made us express ourselves freely” .....	186
7.3	Co-producing Knowledge .....	191
7.3.1	Health Enquiry vs Health Promotion: Navigating Participant Expectations .....	192
7.3.2	The Legitimacy of Arts-Based Methods in Health Research: Navigating Interdisciplinarity.....	198
7.4	Ethical Considerations: Navigating Informed Consent.....	206
7.5	Practical Considerations: A Note on the use of Warm-up games .....	209
7.6	A Brief Reflection on Facilitator Knowledge and Experience .....	212
7.7	Summary .....	212
7.8	Conclusions and Implications for the Transcultural Arts-Based Participatory Approach Framework .....	213
8	Culturally-Situated Understandings of Noncommunicable Disease Risk Factors .....	215
8.1	Introduction .....	215
8.2	Visualisation Activity: Narrative, Imagery and Metaphor .....	215
8.3	Building Knowledge Through Creative Processes .....	224
8.3.1	Diet, Food and Cultural Identities .....	224
8.3.2	Social Prestige .....	233
8.3.3	Physical Activity .....	236
8.3.4	Financial and Family Stress .....	238
8.3.5	Migration, Discrimination and a Hostile System .....	245
8.3.6	Individual Mindset and ‘Ignoring’ Advice .....	249
8.4	Conclusions .....	251
9	The Transcultural Arts-Based Participatory Approach: A Methodological Reflection.....	253
9.1	Introduction .....	253
9.2	A Summary of Research Questions 1-5.....	254
9.2.1	How do the perspectives and experiences of community members and stakeholders inform the development and implementation of the TABPA methodology (RQ1)? .....	254

9.2.2	To what extent can the TABPA minimise researcher-participant hierarchies and encourage inclusivity among participants in practice (RQ2)?	255
9.2.3	What factors influence the feasibility and acceptability of the TABPA for use with African communities in Scotland and Malawi (RQ3)?...	256
9.2.4	Can the TABPA be used to generate culturally-situated understandings of the target communities lived experiences, beliefs, and attitudes towards hypertension and diabetes risk factors (RQ4)? .....	257
9.2.5	What skills, knowledge and resources are necessary to support wider implementation of the TABPA (RQ5)? .....	258
9.3	How does TABPA development compare between African communities in Scotland and Malawi and what does this mean for a transcultural approach in practice? (RQ6).....	259
9.3.1	Transcultural Contexts .....	260
9.3.2	Transcultural Partnership Processes.....	263
9.3.3	Transcultural Research Processes and Outputs .....	273
9.3.4	Transcultural Research Outcomes: A TABPA Framework and Recommendations.....	276
	Postscript .....	282
	A Final Reflection on Positionality, Transculturality and Ethical Dilemmas ..	282
	Transcultural, Ethical and Relational Challenges of Being an Outside Researcher .....	282
	An Outsider: An Opportunity to Learn and Reflect .....	290
	A Final Reflection on Ethics in Practice .....	291
	Going Forward .....	293
	List of References .....	295
	Appendices .....	314
	Appendix 1: TABPA Refined Workshop Protocol.....	314
	Appendix 2: Ethics Approvals .....	319
	Appendix 2A: Phase 1 University of Glasgow Approval .....	319
	Appendix 2B: Phase 2 and 3 University of Glasgow Approval.....	320
	Appendix 2C: Phase 3 NCRSH Malawian Ethics.....	321
	Appendix 3: Example Participant Information Sheets .....	322
	Appendix 3A.....	322
	Appendix 3B.....	328

## List of Tables

Table 1: Summary of Phase 1 Community Workshop Protocol .....	54
Table 2: Summary of Pilot and Refined TABPA Protocols .....	60
Table 3: Summary of data collected organised by each phase, research method and the chapter it is presented in. ....	63
Table 4: Summary of primary, secondary and tertiary themes for Walkalong Interviews in Scotland and Malawi .....	68
Table 5: Themes that directly contributed to the development of the TABPA framework.....	76
Table 6: Malawi Walkalong Interviews: Summary of walks, participants and description of walking and interview conditions.....	85
Table 7: A Summary of Phase 1 Community and Stakeholder Workshops and Relevant Data Codes .....	144
Table 8: Summary of Phase 1 Community Workshops in Malawi and Scotland describing games used and participant's choice of art forms. ....	146
Table 9: Summary of Pilot and Refined TABPA workshops in Malawi and Scotland. ....	185

## List of Figures

Figure 1-1: Overview of TABPA development process Phases 1-3 including the relevant research questions and methods for each phase. ....	7
Figure 2-1: CBPR Conceptual Model by Ortiz, Nash et al. (2020) adapted with permission from Wallerstein, Oetzel et al. (2008) and Wallerstein, Duran et al. (2017). ....	27
Figure 2-2 Transcultural Community-Based Participatory Research Conceptual Model for TABPA development. Adapted from Ortiz, Nash et al. (2020), Wallerstein, Oetzel et al. (2008), Wallerstein, Duran et al. (2017) and Scholte (2014). ....	35
Figure 3-1 TABPA Project Timeline 2021-2024. Yellow bubbles show dates of ethical approval, Green bubbles show data collection and events in Scotland, Blue bubbles show data collection and events in Malawi.....	44
Figure 3-2 Visual Process Summary of Phases 2 and 3 of Data Collection.....	58
Figure 3-3 Image of physical annotation of Phase 1 Malawi Women's Community Workshop Transcript .....	69
Figure 3-4 Photographs of mapping process during RTA of Phase 1 Community and Stakeholder Workshops.....	71
Figure 3-5 Photograph of thematic analysis mapping process for the Phase 1 methodological development: whiteboard showing codes being generated into relevant themes. ....	72
Figure 3-6 Generation of Methodological Themes from Phase 2 and 3 TABPA workshops .....	74
Figure 4-1: Images from Sector A, Area 25 Lilongwe.....	91
Figure 4-2: A secondary school stage in Sector A that served as the site for all workshops in Malawi. ....	98
Figure 6-1: Image from Men's Community Workshop, Malawi. Men dancing while singing a song about diabetes and high blood pressure. ....	148
Figure 6-2: Images from Women's Community Workshop Malawi. The top image shows Group 3 drawing the image. The bottom image shows the final drawing. The description of the drawing by community members is provided on page 138. ....	157
Figure 6-3: Image from Group 1 in Malawi Men's Community Workshop: Man holding two drawings. The participant's description is provided above (p. 139). ....	158
Figure 6-4: Image from Group 2 in Scotland Women's Community Workshop. A drawing depicting factors that impact health according to the traffic light colour system. The image is described by participants above (p.140).....	160
Figure 6-5: Images from Group 2 in Women's Community Workshop Malawi. The image on the left shows the written poem in Chichewa. The image on the right shows a participant reciting the poem. ....	163
Figure 8-1: Image from Malawi women's refined TABPA workshop visualisation activity (Activity 2). The participant's description of the image is described above (p.217). ....	217
Figure 8-2: Image from Malawi women's refined TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.217). ....	218
Figure 8-3: Image from Malawi women's refined TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.218). ....	219

Figure 8-4: Image from Malawi women's refined TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.220). .....	221
Figure 8-5: Image from Scotland men's refined TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.221). .....	222
Figure 8-6: Image from Malawi Men's TABPA Visualisation Activity (Activity 2): The participant's description of the image is described above (p.222). .....	222
Figure 8-7: Image from Malawi men's pilot TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.223). .....	223
Figure 8-8: Image from Scotland women's pilot TABPA workshop. Group 1's drawing of 'unhealthy' (above) and 'healthy' foods (below) and behaviours from Activity 3 and 4 respectively. ....	225
Figure 8-9: Image from Scotland women's pilot TABPA workshop. Close up of Group 1's Drawing of 'unhealthy' foods and behaviours from Activity 3. ....	225
Figure 8-10: Image from Scotland women's pilot TABPA workshop. Close up of Group 1's Drawing of 'healthier' foods or behaviours from Activity 4. ....	226

## Acknowledgments

I want to thank my supervisors, Professor Chris Bunn and Professor Cindy Gray for your mentorship and generosity. I am immensely privileged to have been part of a such a positive team that has supported and challenged me to become a better researcher. Thank you for believing in me, advocating for me, sharing your knowledge and expertise, and for providing me the opportunity to undertake this work.

A huge thank you to everyone in Malawi who made this research possible. To Miguel Jafuli, Luke Manja, Rhoda Malowa and Trust Kalima Banda for your facilitation in Malawi and ongoing support. I knew my research was in safe hands with each of you and I am grateful for your hard work, expertise and guidance. Thank you to the Sector A Chiefs for welcoming me into your community and all your help throughout this research. I would also like to thank everyone at the Malawi Epidemiology and Intervention Research Unit for looking after me and letting me draw from your knowledge and resources, and my friend Professor Mia Crampin, for letting me stay in your home and cuddle your dogs.

A special thanks to all the people that supported the Scottish component of this project. To Angie Mwafulirwa for your guidance and kindness. This research would not have been possible without you. I look forward to continuing our partnership beyond my PhD. I also want to thank Dr Josephine Adekola, Adekemi Giwa and Segun Ibigbemi for your support with recruitment and trust to conduct this research. To my sister, Christiana, I wrote in the acknowledgments of my MSc dissertation that I look forward to future Bissett sister collaborations. I am grateful that I was able to make this happen so quickly. Thank you for your unwavering support, expertise, and love. To Dr Anna Clover, thank you for your friendship, words of wisdom and for stepping in to facilitate the workshops.

To Adrian, Mhairi and Benny, thank you for the work you do and for helping me meaningfully give back to the communities. To Mo and the Common Ground, thank you for creating such an important creative space in Glasgow, it was a privilege to be able to use your venue.

Thank you to the Culture and Bodies Team who inspired this research, laid the groundwork and gave me an opportunity to find my niche.

To Dr Sharifa Abdulla, Elita Chamdimba, and Dr Penelope Siebert, I am thankful to you all for your knowledge, encouragement and kindness. Our discussions and your work on arts-based, community and decolonising methods inspired and challenged me.

Thank you to my Happy Mondays: Molly Gilmour, Lewis Forsyth and Martha O'Carroll. I am grateful to you for our writing days, for being there on long days in the ARC, reading my work, reassuring me and for kindly telling me when to get a grip. I look forward to Friday pints with you all soon.

I would like to thank my partner, David Pyper, for championing me, making me laugh and taking care of me in the tough moments. I appreciate you.

Thank you to my parents and friends for all your love, support and patience throughout this PhD. A special thank you to my dad, Briana and Stan for proofreading my work and to my godmother Professor Marie T Hosey, for reviewing my thesis and being my academic inspiration.

Finally, and most importantly, a big thank you to all those who participated in this research in Scotland and Malawi for your generosity and trust. This thesis is dedicated to you.

## **Author's Declaration**

I declare that, except where explicit reference is made to the contribution of others, that this dissertation 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.

Printed Name: Maria Bissett

Signature:

## Abbreviations

Abbreviation	Definition
CBPR	Community Based Participatory Research
GP	General Practitioner
HIV/AIDs	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
MEIRU	Malawi Epidemiology and Intervention Research Unit
NHS	National Health Service
NCD	Noncommunicable Disease
SSA	sub-Saharan Africa
TABPA	Transcultural Arts-Based Participatory Approach
UK	United Kingdom

# 1 Introduction

This thesis presents research on the development of a framework for a transcultural arts-based participatory approach (TABPA) to explore the drivers of diabetes and hypertension among African communities in Scotland and Malawi.

The following chapter will provide a brief introduction to describe the context, rationale and research questions that shaped this research. The chapter will begin by outlining the prevalence of diabetes and hypertension globally, in the UK and in sub-Saharan Africa, and among African communities in the UK and Malawi. It will then describe the complex drivers of these diseases and the history of biomedical impositions that means there is need for alternative research approaches that centre community knowledge and interests. The aim, research questions and research design will be introduced before culminating in an overview of the thesis structure.

## 1.1 Noncommunicable diseases in Sub-Saharan African and the UK

Noncommunicable diseases (NCDs) account for 74% of global mortality (World Health Organization 2022). Cardiovascular diseases, cancer, diabetes, and chronic respiratory conditions are responsible for the majority of this burden (World Health Organization 2022). In 2021, it was estimated that 529 million people were living with diabetes and that this is projected to rise to 1.31 billion by 2050 (Ong, Stafford et al. 2023). Type 2 diabetes formed the majority of this burden, accounting for 96% of cases worldwide (Ong, Stafford et al. 2023). In addition, hypertension is one of the most important risk factors for noncommunicable diseases, especially cardiovascular diseases (Mills, Stefanescu et al. 2020, Zhou, Perel et al. 2021). In 2019, the condition was estimated to affect 1.28 billion people (Zhou, Carrillo-Larco et al. 2021).

The global impact of NCDs is strongly related to health inequalities both within and between countries (Di Cesare, Khang et al. 2013, Miranda, Barrientos-Gutiérrez et al. 2019, Zhou, Perel et al. 2021, Hayanga, Stafford et al. 2023). In the United Kingdom, it is estimated that 7% of the population have diabetes (Whicher, O'Neill et al. 2020) and approximately 30% of adults have

hypertension (The Scottish Government 2020, NHS England 2023). This burden disproportionately impacts Black and Minority Ethnic communities due to a complex interaction between social, structural, behavioural, environmental, and biological factors (Modesti, Agyemang et al. 2018, Agyemang and van den Born 2019, Goff 2019, Higgins, Nazroo et al. 2019, Henry Osokpo, James et al. 2021). Minoritised ethnic groups including Black African and Caribbean populations in the UK have up to a five times higher risk of diabetes than the general population (Goff 2019). Research from the UK suggests that by age 80, 40-50% of African Caribbean men and women will have diabetes, at least double that of the White European UK population of the same age (Tillin, Hughes et al. 2013). The prevalence of hypertension is also higher among Black African men (30.8%) and women (34.4%) in comparison to Caucasian men (19.4%) and women (13%) (Lane, Beevers et al. 2002). More recent evidence has indicated that men and women of African descent in the UK have higher blood pressure at 30 and 40 years of age than Caucasian men and women (Agyemang, Humphry et al. 2012). There is limited data on the prevalence of hypertension among African communities in the UK in the last decade, although there is some evidence among specific migrant groups. The Research on Obesity and Diabetes among African Migrants study highlighted that the prevalence of hypertension among Ghanaian African migrants in Europe is higher than non-migrants in Ghana (Agyemang, Nyaaba et al. 2018). Therefore, migration could influence the risk of African communities in the UK through complex pathways. This will be discussed more below.

Low-middle income countries are similarly experiencing an unequal share of the NCD burden (Miranda, Barrientos-Gutiérrez et al. 2019). In sub-Saharan Africa (SSA), between 1990-2017, chronic NCDs accounted for a 67% increase in disability adjusted life years and by 2030, are estimated to overtake premature mortality from communicable, maternal, and perinatal diseases (Mathers and Loncar 2006, Gouda, Charlson et al. 2019). In Malawi, cardiovascular disease, cancer, diabetes, and chronic respiratory conditions are estimated to account for 23% of premature mortality (World Health Organization 2022). Both hypertension (32.9%) and diabetes (5.6%) are highly prevalent and underdiagnosed (Price, Crampin et al. 2018, Amberbir, Lin et al. 2019).

The extent of health inequalities and chronic disease among Black African and other minoritised ethnic populations in the UK was starkly highlighted by the COVID-19 pandemic (Greenaway, Hargreaves et al. 2020, Agyemang and van den Born 2022). However, the specific drivers of chronic disease among Black communities are still poorly understood. Studies have indicated that the interaction between factors including migration, socioeconomic position, environment, cultural values and racism/discrimination, likely play a role although these will vary among different communities (Higgins, Nazroo et al. 2019, Henry Osokpo, James et al. 2021, Agyemang and van den Born 2022). Qualitative research with West African migrants living with type 2 diabetes in England demonstrated how migration-related lifestyle change brought cultural, financial, and social barriers to disease management (Alloh, Hemingway et al. 2019). For example, participants noted that moving to the UK had reduced their physical activity as they no longer had to travel long distances for necessities and that the gym was not accessible for reasons such as finances, comorbidities, and cultural beliefs (Alloh, Hemingway et al. 2019). Chronic NCD management among African migrants in the UK and other high-income countries has also been linked to cultural dietary preferences, trust/mistrust of Western healthcare, preferences for herbal treatments and the support of family and friends (Brown, Avis et al. 2007, Alloh, Hemingway et al. 2019, Goff 2019, Henry Osokpo, James et al. 2021), although, as emphasised Ige-Elegbede, Pilkington et al. (2019), in the UK, the specific barriers and facilitators of healthy behaviours like physical activity among African and Caribbean populations are notably under researched. Further, health promotion initiatives often do not bring cultural influences into consideration, culminating in interventions that fail to engage communities, and are ineffective and unsustainable (Brown, Avis et al. 2007, Ochieng 2013, Moore, Rivas et al. 2022).

In Malawi and wider sub-Saharan Africa, the causes of NCDs are also complex. Both historically and currently, undernutrition in the region has been linked to a predisposition for poor metabolic health, while the prevalence and treatment of infectious diseases may further exacerbate NCD risk factors (Gowshall and Taylor-Robinson 2018, Miranda, Barrientos-Gutiérrez et al. 2019). The commercial influx of calorific and low nutrient foods, alcohol and tobacco, and an increase in air pollution in urban areas have contributed to an environment

that heightens chronic disease risks (Miranda, Barrientos-Gutiérrez et al. 2019). In addition, communities face several structural barriers to healthy behaviours including insufficient access to exercise spaces and healthy food choices associated with increasing urbanisation and economic development (Gowshall and Taylor-Robinson 2018, Miranda, Barrientos-Gutiérrez et al. 2019). Cultural drivers such as food preferences and an appreciation of larger body types as a marker of prosperity and good health (Nyirenda 2016, Gowshall and Taylor-Robinson 2018, Zimmermann, Bunn et al. 2018, Thakwalakwa, Flax et al. 2020) also influence the extent to which communities engage in healthy behaviours. Therefore, NCD health promotion interventions designed in high income countries are unlikely to be translatable to the Malawian context.

Thus, African communities both in the UK and in Malawi are experiencing a disproportionate share of the NCD burden, especially that of diabetes and hypertension. Due to the complexity of different risk factors and diverse cultural beliefs, there is a need to understand diabetes and hypertension more fully from the perspectives of these communities.

## **1.2 The Rationale for Arts-Based Participatory Health Research**

Health research has historically been interwoven with colonial power dynamics (Vaughan 1991, Amster 2022). In sub-Saharan Africa, disease management practices have been linked to the maintenance of colonial control, and the justification of biomedical understandings and ‘scientific validity’ over local knowledges (Vaughan 1991, Amster 2022). In the UK, racism, inequalities and biomedical impositions also persist, with health promotion interventions failing to recognise the lived experiences, cultural beliefs and practices of minority ethnic communities (Liu, Davidson et al. 2012, Creamer, Attridge et al. 2016, Moore, Rivas et al. 2022, Powell, Njoku et al. 2022). By failing to account for socio-cultural specificity, disease prevention strategies can be ineffective, reinforce colonial power dynamics and generate a mistrust of researchers (Leininger 1991, Vaughan 1991, Liu, Davidson et al. 2012, Smith 2021, Moore, Rivas et al. 2022). Therefore, new approaches that centre community understandings of health are necessary.

Arts-based participatory research is one strategy that seeks to promote more equitable engagement with community members while encouraging the communication of rich narratives and experiences (Coemans and Hannes 2017, Van der Vaart, van Hoven et al. 2018). Prior to this research I was involved in the Culture and Bodies Project which sought to develop a culturally situated arts-based participatory method to explore experiences of NCDs in Malawi and Tanzania (Bissett, Gray et al. 2022). Arts-based participatory workshops were compared to focus group discussions for the depth of content generated and the presence of research-participant hierarchies. The arts-based participatory workshops generated more personal and emotive understandings about NCD experiences and successfully reduced researcher-participant hierarchies. However, there were still challenges with the emergence of stigmatising content (e.g. that diabetic wounds smell bad) and the need for more reflective activities to build on the narratives (Bissett, Gray et al. 2022). The current research does not form part of the Culture and Bodies project, but it does seek to build on the findings to develop an approach that is applicable both in sub-Saharan Africa and with African communities in the UK. The Culture and Bodies Project provided community members with a choice of what NCD they focussed on. In Malawi, communities chose diabetes and hypertension. Thus, building on these findings and given the high prevalence of both diseases in Malawi and among African communities in Scotland (Section 1.1), I decided to focus this research on diabetes and hypertension.

### **1.3 The Rationale for a Transcultural Approach**

As highlighted in Section 1.2, hypertension and diabetes are common globally, and diverse communities face barriers to their prevention and control. However, the causes and prevention of these diseases are shaped by a range of unique socio-cultural factors in each community. I, therefore, aimed to develop the TABPA as a framework that could be flexible enough to account for cultural and community specificity yet follow a broad structure that could be used and adapted to different cultural contexts. This led me to develop an approach that sought to embrace the diversity and complexity of different cultures and cultural identities as a means to understand the culturally-situated drivers of diabetes and hypertension among two distinct communities (See Chapter 2.2). Building on prior connections in each setting, the Culture and Bodies Project,

and the impact of diabetes and hypertension in each community, I chose to develop the TABPA with African communities in Scotland and Malawi.

## **1.4 Aim and Research Questions**

This research aims to develop a framework for a transcultural arts-based participatory approach (TABPA) to exploring the drivers of diabetes and hypertension among African communities in Scotland and in Malawi. It will address the following six research questions:

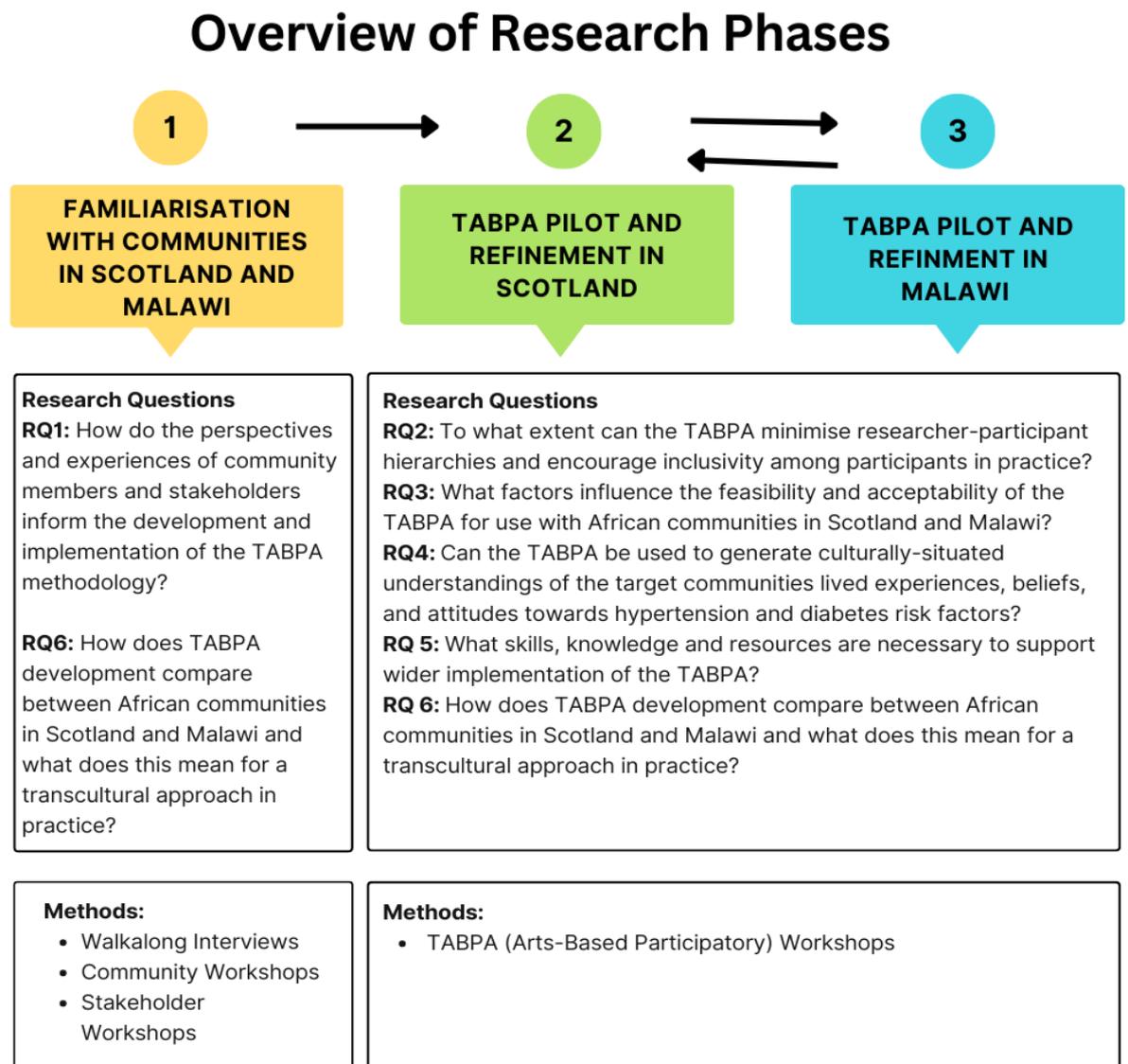
1. How do the perspectives and experiences of community members and stakeholders inform the development and implementation of the TABPA methodology?
2. To what extent can the TABPA minimise researcher-participant hierarchies and encourage inclusivity among participants in practice?
3. What factors influence the feasibility and acceptability of the TABPA for use with African communities in Scotland and Malawi?
4. Can the TABPA be used to generate culturally-situated understandings of the target communities lived experiences, beliefs, and attitudes towards hypertension and diabetes risk factors?
5. What skills, knowledge and resources are necessary to support wider implementation of the TABPA?
6. How does TABPA development compare between African communities in Scotland and Malawi and what does this mean for a transcultural approach in practice?

## **1.5 Overview of Design**

In order to develop the TABPA framework, this research involved close collaboration with community members and stakeholders in Scotland and Malawi. It was conducted in three broad phases:

- Phase 1: familiarisation with local communities, health and art forms in Glasgow, Scotland and Lilongwe, Malawi.
- Phase 2: pilot and refinement of the TABPA workshops with the target community in Glasgow.
- Phase 3: pilot and refinement of the TABPA workshops with the target community in Lilongwe (facilitated by a local Malawian arts-practitioner identified in Phase 1).

The relevant research questions and methods used for each phase are described in Figure 1-1 below.



**Figure 1-1: Overview of TABPA development process Phases 1-3 including the relevant research questions and methods for each phase.**

## 1.6 Thesis Structure

This thesis is presented in nine chapters. This first chapter has provided a brief introduction highlighting the context of noncommunicable diseases among African communities in Scotland and Malawi. I introduced the rationale for an arts-based participatory and a transcultural approach to gain culturally-situated insights into the drivers of diabetes and hypertension among these two distinct communities. I have also stated the aim and introduced six research questions that will be addressed throughout this thesis and provided brief overview of the phased research process used to develop the transcultural arts-based participatory approach framework.

In Chapter 2, I break down the theoretical underpinnings of the transcultural arts-based participatory approach through an exploration of the literature. I do so by exploring the origins and practices of arts-based, transcultural and community-based participatory research in turn before highlighting how these approaches can complement one another towards an integrated methodological approach. The chapter concludes by introducing the transcultural community-based participatory research conceptual model for TABPA development and highlighting the contribution of the TABPA.

In Chapter 3, I present the phased research design I used to develop the TABPA methodology. The chapter begins by providing a detailed exploration of my positionality as an interdisciplinary researcher with reflection on my shifting epistemologies across disciplines and my colonial complicities as a white researcher working with African communities. I go on to explore the epistemologies of arts-based health research and how they led me to the methods used. I outline the research design, settings, partnerships and recruitment strategies in Malawi and Scotland, and describe my methods for Phase 1 (walkalong interviews, community and stakeholder arts-based participatory workshops) and Phases 2 and 3 (TABPA workshops). Finally, I describe my process of analysis before concluding with some of the ethical considerations of the research.

In Chapter 4, I explore the findings of Phase 1 walkalong interviews in Malawi. I provide a detailed exploration of the contexts of community, local arts and

health in Sector A (pseudonym) within Area 25, Lilongwe, Malawi as described by community members themselves and begin to address RQ1. I start the chapter with a reflection on the use of walkalong interviews in Malawi and consider some of the strengths and weaknesses of the approach. I go on to explore definitions of community and everyday life among community members in Sector A, before examining the facilitators and barriers to participation in arts-based activities. I then describe community perspectives and experiences of health with focus on diabetes and hypertension. I conclude by summarising the understanding gained on these diverse contexts and the significance for TABPA development and implementation.

In Chapter 5, I continue to address RQ1 and develop my contextual understandings with focus on the findings of walkalong interviews with African community members in Glasgow, Scotland. As in Chapter 4, I explore definitions and experiences of community, local arts and health as described by community members. The chapter structure mirrors that of Chapter 4.

In Chapter 6, I explore how community and stakeholder perspectives from Phase 1 workshops inform the development of the TABPA methodology (RQ1). Following an introduction to the Phase 1 workshops, I begin by examining what art forms are compatible with community interests and adaptable to explorations of hypertension and diabetes. This is done through reflection on the art forms (music and dance, theatre and drama, drawing and poetry) community members chose to use in the Phase 1 community workshops and why, stakeholder perspectives on the use of art in health research and wider literature. I then go on to consider the strengths and weaknesses of arts-based participatory workshops in practice highlighting issues including relationship building, co-learning and power hierarchies, notes of facilitation and practical considerations. I conclude by reflecting on five key findings that informed methodological development of the TABPA for Phases 2 and 3.

Chapter 7 presents the first of two chapters exploring the pilot and refinement of the TABPA workshops with communities in Scotland (Phase 2) and Malawi (Phase 3). I aim to address RQs 2, 3 and 5 by exploring four methodological themes in turn: i) fostering a safe and supportive environment, ii) co-producing knowledge, iii) ethical considerations and iv) practical considerations. I first

consider how the processes and facilitators of the TABPA workshops supported the generation of personal narratives and contributed to a safe and supportive environment. I then explore the complexities of co-producing knowledge by reflecting on community expectations of the TABPA as an educative process and diverging perceptions academic and artistic legitimacy when creating artistic outputs. I reflect on the processes of obtaining informed consent and the ethics around structured institutional procedures when conducting arts-based research and propose the need for alternative strategies. I then reflect on practical considerations, particularly the use of warm-up activities and how they can contribute to relaxed atmosphere. I conclude by reflecting on the implications for a final TABPA framework.

In Chapter 8, I continue to explore the findings from Phases 2 and 3 with focus on the utility of the TABPA as a means to generate culturally-situated understandings of the target communities lived experiences, beliefs, and attitudes towards hypertension and diabetes risk factors (RQ4). The chapter is structured to reflect on how the different TABPA processes contributed to the generation of in-depth health knowledge in both Scotland and Malawi. It begins by exploring how the TABPA visualisation activity supported community members to conceptualise their perspectives on diabetes and hypertension through the use of narrative, imagery and metaphor. In the following section I consider how knowledge on the risk factors for diabetes and hypertension was built through processes of discussion, artistic development and reflection throughout the workshop. I conclude by summarising the findings and reflecting on the utility of the TABPA workshop as a means to generate culturally-situated knowledge in each setting.

In the final chapter (Chapter 9), I present a critical reflection on the transcultural development of the TABPA methodology. I begin the chapter by summarising the findings in relation to RQs 1-5. I then address the final research question, RQ6, and provide a critical reflection on the strengths and weaknesses of the TABPA in relation to the transcultural community-based participatory research conceptual model presented in Chapter 2. Using the four domains of the model (contexts, partnerships, research processes and outputs, and outcomes) I compare methodological development between Scotland and Malawi, highlighting strengths, missteps and opportunities for future work. The

chapter concludes with my recommendations for a transcultural arts-based participatory approach framework and a reflection on long term outcomes.

## **2 Defining a Transcultural Arts-based Participatory Approach (TABPA)**

This chapter presents the theoretical underpinnings of the transcultural arts-based participatory approach where I will discuss each of the TABPA components in turn. The chapter will begin with an overview of art as a health research method and sociological approaches to art with a focus on how art is defined and understood to function in society. I will then discuss what I mean by the term ‘transcultural’ before outlining community based participatory research, and its key principles, strengths, and challenges. Finally, I will introduce a transcultural community based participatory model which will act as a guide for the development of the TABPA framework.

### **2.1 Art as a Research Method**

#### **2.1.1 Arts-Based Methods in Health and Noncommunicable Disease Research**

Arts-based methods have grown in popularity in health research in recent years as researchers have sought to explore new ways of generating knowledge (Boydell, Gladstone et al. 2012, Coemans and Hannes 2017). Arts-based methods encompass a broad range of art forms and practices, including visual arts, photography, performance, and written narratives, which may be used either on their own or in combination towards the research goals (Coemans and Hannes 2017, Gerber, Biffi et al. 2020). Further, they can be used throughout the research process, although are most frequently applied as a tool for data collection and dissemination (Coemans and Hannes 2017).

There are several advantages to using arts-based approaches in health research, particularly in health enquiry. They can provide better understandings of illness experiences through the exploration of underlying meanings (Boydell, Gladstone et al. 2012) and by fostering the communication of personal, emotive narratives (Boydell, Gladstone et al. 2012, Van der Vaart, van Hoven et al. 2018, Gerber, Biffi et al. 2020). Indeed, the arts can support new embodied and emotional forms of knowing, facilitating the communication of experiences that are often difficult to express through words alone (Boydell, Gladstone et al. 2012, Van der Vaart, van Hoven et al. 2018, Gerber, Biffi et al. 2020). These narratives may

contribute to new knowledge on treatment and disease (Boydell, Gladstone et al. 2012) and greater insight into the subtleties and nuances of participants' experiences (Coemans and Hannes 2017). In the United States, Stuckey and Tisdell (2009) used narrative interviews and creative expression (imagery, photography and written reflections) as methods to explore experiences of type 1 diabetes, and found that participants were able to draw on their emotions to express deeper meaning about the disease. Research using body-mapping and storytelling as a method to explore HIV-narratives among Black women in South Africa similarly encouraged the expression of personal narratives and supported participants to take control of their own stories (Horne 2011).

Evidence has also indicated that arts-based approaches are complimentary to participatory methods and help to reduce hierarchies between researchers and participants (Daniels 2003, Coemans and Hannes 2017, Gerber, Biffi et al. 2020, Gerber and Siegesmund 2022). By rebalancing power and promoting creativity, participants are given a safer space to explore their perspectives and experiences, develop confidence and find empowerment in the research (Boneh and Jaganath 2011, Boydell, Gladstone et al. 2012, Coemans and Hannes 2017). Abdulla (2024) recently explored the use of folk media (traditional and local arts-practices e.g. storytelling and proverbs) as a creative participatory method for knowledge generation in HIV/AIDs research in rural Malawi. The integration of 'play' and imagination contributed to safe spaces situated between reality and the imaginary, where participants could speak openly about their perspectives and experiences of the disease without fear of real-life consequences (Abdulla 2021, Abdulla 2024). However, it should not be assumed that arts-based methods are always participatory, especially when imposing topics and art forms on communities that do not reflect their interests (Kamlongera 2005, Chinyowa 2015, Abdulla 2020, Bunn, Kalinga et al. 2020, Gerber, Biffi et al. 2020). The benefits of arts-based methods in health research are best realised when appropriate time and care are dedicated to community engagement (Abdulla 2020, Bunn, Kalinga et al. 2020, Gerber, Biffi et al. 2020). This will be discussed further in the context of community-based participatory research in later sections.

Creative methods have commonly been used to explore NCDs in high income countries (Boydell, Gladstone et al. 2012). However, in sub-Saharan Africa, they

have been primarily applied in infectious disease research, particularly HIV/AIDs (Bunn, Kalinga et al. 2020). Where arts have been used to explore NCDs in sub-Saharan Africa, they have generally been applied in the context of health promotion rather than generating knowledge on experiences (Bunn, Kalinga et al. 2020). For example, in South Africa, drumming was used as an effective intervention for improving mental and cardiovascular health and reducing hypertension (Smith, Viljoen et al. 2014), while radio-drama and photo-comics have been explored to promote cervical cancer screening (Risi, Bindman et al. 2004). As described in the previous chapter, the Culture and Bodies Project sought to explore the use of arts-based participatory workshops as means to explore perspectives on NCDs, including diabetes, hypertension and cancer among communities in Malawi and Tanzania. The approach showed several strengths but required further development to promote more reflexivity and prevent the reinforcement of stigmatising views (Bissett, Gray et al. 2022), findings that have directly guided the development of the current study.

Overall, there is substantial evidence demonstrating the benefits of arts as a method in health research. The development of an approach using creative methods to explore experiences of NCDs among African communities both in Scotland and Malawi, appears highly appropriate to gain rich understanding of local knowledge and promote community engagement in combination with participatory approaches.

### **2.1.2 Sociology of Art**

Building on the use of art in health promotion, it is useful to reflect on how art is defined and how it functions in society. Until relatively recently, art and sociology have been conflicting disciplines (Bourdieu and Johnson 1993, Alexander and Bowler 2014). Art and its study have been established as an elite sphere, requiring “*creative genius*” (Bourdieu 1991: p.146) and exclusive specialised knowledge on its forms to appreciate it as such (Alexander and Bowler 2014). However, the importance of co-creation and community in the production of art forms has since been recognised by several sociological theorists. I will go on to discuss these reasonings further in the following sections and in doing so reflect on my own work.

To understand what we mean by art, symbolism presents a good starting point. Emile Durkheim (2016) writes of symbolism and meaning through analysis of totems of Aboriginal Australians. It is argued that symbols are created from an inability to communicate the depth of emotion or sentiment that a person may feel towards an “*abstract*” concept or object, whereby such feelings are redirected to a “*concrete object*” that they better understand (Durkheim 2016: p.210). This “*concrete object*” acts as a sign which “*we sacrifice ourselves to*” (p.210). Thus, this powerful link between human emotion and symbolism may translate into what we know of as art. Indeed, Talcott Parsons (1991) notes that expressive symbolism is directly related to how art becomes “*cathected*” (p.388) (emotionally charged). The transformation from symbolism to art, however, is often reliant on the dynamics between a group, formed through mutual communication and understanding, as Durkheim (2016: p.204) writes:

“Since a collective sentiment cannot express itself collectively, except on the condition of observing a certain order permitting co-operation and movements in unison, these gestures naturally tend to become rhythmic and regular; hence come songs and dances”

Signs and symbols therefore, become a type of mutual communication through which art forms are created. It is important to note that a distinct symbol may have one meaning for one community and a completely different meaning in another, yet this does not undermine the importance of collective expression (Durkheim 2016). This understanding of the production of art arguably resonates with folk art forms where the community create art for each other rather than for a specific external (and often commercial) audience, as often observed in the formal production of art (Alexander and Bowler 2014). Chosen symbolism and art forms are valuable to consider in my own transcultural work whereby, art created by communities in Malawi and by African communities in Scotland will likely convey specific meanings and emotional complexities in each context.

Beyond symbolism, sociologists have also reasoned that art is co-created and inextricably linked to community and tradition. Howard Becker (1974: p.769) notes that art in all its forms is created by a “*large network of cooperating people*” who contribute in some way to the final product even if simply providing the materials for a painter to paint or the costumes for a play. To achieve this cooperation, artistic conventions that both the artist and the

audience have a mutual understanding of are usually followed, including both what materials are used and what abstractions are applied (e.g. the use of colour and shade to demonstrate dimensions in a painting) (Becker 1974). As with symbolism, it is the collective knowledge of artistic conventions that denotes emotional meaning, and arguably through this cooperation and agreement, a creative product becomes art. Karl Mannheim (1933) follows a similar logic, arguing that any artistic production is informed not only by a person's new creative ideas but also their upbringing, life experience and importantly, pre-existing traditions and processes in society, specifically the *life-community*:

“This ongoing existence, does not take place in a vacuum devoid of tradition, but rather rests on the given state of the life-community, which manifests itself in tendencies of will and structure of objects” (Mannheim 1922 quoted in Tanner 2003: p.219)

Mannheim (1922) goes on to write that the “*life-community* exists” when there is immediate contact within society, while the “*cultural-community*” goes further to encompass those who share the same traditions in artistic forms and techniques as their only commonality (Mannheim 1922 quoted in Tanner 2003: p.220). However, he emphasises that there must have been in some past time and place, a shared society which has since diverged e.g. European-American cultural community (Tanner 2003). This could be true of African communities in Scotland and Malawi. Although community members may have heterogeneous and dynamic cultural identities and experiences, they may still share some common traditions (e.g. storytelling) that may have been influenced and dispersed across sub-Saharan Africa before, during and after colonial times (Kamlongera 1986, Abdi 2009). Nonetheless, these commonalities do not mean that the cultural meaning is the same in every community, therefore, it is still important to be cautious when integrating traditional art forms into research (Abdulla 2020).

Furthermore, Bourdieu and Johnson (1993) argue strongly that art is social and is created through the interaction between a person's habitus, and the field of production. The concept of *habitus* is defined as the product of a person's social conditioning, a set of acquired characteristics which can both be shaped by the field and shape the social positioning of an individual (Bourdieu and Johnson

1993, Bourdieu 2017). The field of artistic production can be understood as a structure of objective social relations in which people take positions and struggle to attain their share of resources or prestige in the form of symbolic capital (Bourdieu 1991, Bourdieu 1996). However, Bourdieu (1996) argues that this field can be divided into two sub-fields: large-scale production and restricted production. Large-scale production is shaped by heteronomous principles where art is made for large audiences for economic profit i.e. popular culture (e.g. a Hollywood film) (van Maanen 2009). Restricted, small-scale production generally functions outside of the economic field, autonomous to the field of power, where artisanal goods are made for a smaller audience (van Maanen 2009). Success in the restricted field of production requires higher levels of symbolic capital. Therefore, artwork is shaped by the artist's social positioning, the constraints of the field of artistic production, its established social histories, and its autonomy in relation to the environment, rather than the "*miracle of [the artist's] creative genius*" (Bourdieu 1991: p.146).

My research is firmly aligned with theories that art is social. Art is formed through shared meanings and co-created both directly through shared emotional sentiments and indirectly through the external social and structural influences we are exposed to. To understand what this means across the two cultural contexts of my research, it is next important to discuss what I mean by the term transcultural and how it is related.

## **2.2 A Transcultural Approach**

### **2.2.1 Defining Transcultural**

The term transcultural was first attributed to scholar Fernando Ortiz's 1940 work on *transculturation* in Cuba (König and Rakow 2017). Ortiz sought to deviate from the term, 'acculturation', as describing a unidirectional transfer of values from one culture to another, towards a vocabulary that recognises the mutual and potentially transformative influence that different cultures may have on each other (König and Rakow 2017). However, definitions of transcultural have since shifted and diverged across research disciplines (König and Rakow 2017). General definitions that transcultural means to 'bridge cultural divides' are

often observed in applied research such as nursing and counselling when trying to establish intercultural communication (König and Rakow 2017).

In academic disciplines such definitions have been criticised for their simplicity in assuming that cultures are fixed. Instead, transcultural is often understood: “to describe a particular method of approach that, from a thematic point of view, deconstructs concepts such as “society,” “class,” “nation,” “culture,” or “civilization.” (König and Rakow 2017: p.95). In applying this definition, a multiplicity of truths, experiences and perspectives across cultures are considered. Epstein (2009) also emphasises that transculture is concerned with recognising the importance of differences in cultural groups, noting:

“Transculture is a new sphere of cultural development that transcends the borders of traditional cultures (ethnic, national, racial, religious, gender, sexual, and professional) ...

We acquire transculture at the boundaries of our own culture and at the crossroads with other cultures through the risky experience of our own cultural wanderings and transgressions” (Epstein 2009: p.4)

Therefore, transcultural is understood in a more dynamic and transformative sense, moving away from ideas of fixed cultural concepts. Wyse, Nikolajeva et al. (2012) similarly consider transcultural meanings as phenomena associated with place-related identity, formed from individual experiences and interactions (social and physical). According to these understandings, when transcultural approaches are applied, the diversity of experience and collaboration across different groups are valued (Winschiers-Theophilus, Zaman et al. 2019, Soong, Kerkham et al. 2021). Drawing on Epstein’s definition of transculture, Winschiers-Theophilus, Zaman et al. (2019) argued for a transcultural approach to Indigenous knowledge preservation in community technology design using case studies of their projects in Malaysian Borneo and Namibia. They found that extended collaboration across cultures in joint design activities allowed for dynamic co-creation of meanings and the formation of “*joint reflected narratives*” (p.5).

Such definitions of transcultural align with my own work, where I seek to co-develop an approach that is truly reflective of local understandings of noncommunicable diseases. In doing so as a white Scottish researcher, my own

understandings will interact with the identities and cultures of both participants and stakeholders in the Scottish context and Malawian contexts. As noted by Abdulla (2021), in Malawi, culture and art forms are unquestionably intertwined with the country's history of colonialism. In the Scottish context, it is likely that the cultures of participants will be dynamic and diverse depending on their own histories and geographies. Therefore, I recognise the need to be reflexive of how all perspectives may be valued while balancing the efficacy of the workshop when situated in each specific context.

Scholte (2014) argued for seven pillars of a transculturalist path in the context of global cooperation. These include reflexivity; acknowledgement of culture/power relations; recognition of complexity; celebration of diversity; cultivation of humility; promotion of deep listening; and reciprocal learning for positive change. While Scholte (2014) expressed that he developed these pillars separately from previous definitions of transcultural, they reflect the same values of recognising multiple truths and perspectives as other definitions of transcultural. I will return to this idea at the end of the section.

Firstly, *reflexivity* is crucially important to be able to recognise one's own biases and contexts, and value alternative perspectives, both culturally and more generally. *Acknowledgment of culture and power relations* further allows for the parties to consider steps to promote open communication and more equitable relationships across and among groups. The *recognition of complexity* counters definitions that fail to account for the fluidity of culture and its elements, again promoting better communication and deeper understandings of diverse narratives. *Celebration of diversity* reinforces the previous point and promotes actively welcoming alternate truths and ways of understanding. According to Scholte (2014) the *cultivation of humility* is crucial amidst multiple perspectives, arguing that being humble in conflicting understandings mitigates potential for impositions of knowledge, particularly those impositions that may reinforce established power dynamics. Similarly, the *promotion of deep listening* strengthens relationships and promotes a dialogue of trust and solidarity. Finally, *reciprocal learning* for positive change brings together a shared diversity of cultural knowledge to promote positive social action.

This transcultural theory was recently applied in cross-national study exploring counsellor burnout in the United States (US) and South Korea (West-Olatunji, Yang et al. 2017). The researchers noted that applying a transcultural lens illuminated the complexities of comparing the two cultural groups and, as US based researchers, aided in providing a more nuanced consideration of the South Korean context. Scholte's (2014) work, therefore, provides a set of guidelines to consider, alongside those of arts-based participatory research, to continually reflect on to ensure that the development of the workshop is reflective of the interests of parties in each context and potentially beyond.

In summary, definitions of transcultural vary. Nonetheless, the value of multiple perspectives and cultural identities and the importance of reflexivity were common features of a transcultural discourse that inspire my own work. The interaction between cultures is undoubtedly complex in both Scotland and Malawi, where a variety of nuanced understandings will inform the development of the approach. Scholte's work is particularly relevant to navigating this and will be returned to later in this chapter in the context of community based participatory research (see Section 2.3).

### **2.2.2 Transcultural Health Research**

As described in the previous section, the term *transcultural* has many definitions and its use in practice diverges across disciplines. From a health perspective, the use of the term is most often used in nursing and counselling frameworks to provide culturally competent care. For example, Leininger's Cultural Care Diversity and Universality Theory was developed as a means to understand culturally-relevant factors that could influence care among individuals and groups, specifically as a means to provide "*culturally congruent, safe and meaningful care to clients of diverse or similar cultures*" (Leininger 2002, p.190). It has since informed and shaped a discipline of Transcultural Nursing in its own right (McFarland, Wehbe-Alamah et al. 2018). However, although transcultural frameworks are used in health research and practice to understand and inform culturally competent care, there is limited evidence of their application as a means to guide research practice or intervention development.

The development of health interventions is a costly, time-demanding and resource-heavy process, that requires several steps of development, feasibility testing, pilot and refinement. The adaptation of successful interventions to new contexts, may therefore prove more cost and time-effective than developing new interventions outright (Movsisyan, Arnold et al. 2021). Yet, the context matters, and it is important to consider why and how interventions are being adapted. The most common reasons for adaptation include improving the cultural appropriateness or introducing the intervention to a new population group or setting, and the most common adaptations are often in the content and delivery methods (Escoffery, Lebow-Skelley et al. 2018, Movsisyan, Arnold et al. 2021). To be able to adapt interventions to the local culture and context, it is important to first understand the needs of the target population (Movsisyan, Arnold et al. 2021). This is something the TABPA framework contributes to.

The use of a transcultural approach in this work therefore offers a unique opportunity to embrace the complexity and diversity of culture as described in the previous section while also offering a pragmatic approach to the cost and resource challenges of culturally-situated intervention development. The TABPA framework is designed as a means to provide enough structure that the approach can be used and easily adapted in diverse contexts and offers the flexibility to embrace the complexity of culture, wherever it is applied.

## **2.3 Community Based Participatory Research (CBPR)**

### **2.3.1 Background**

Community-based participatory research (CBPR) is an approach that has gained momentum in recent years to mitigate power imbalances in the health research process and promote more equitable partnerships between researchers and participants (Ortiz, Nash et al. 2020). The paradigm has emerged independently from several research traditions, most notably Kurt Lewin's Northern action research and Southern participatory practices, including Paolo Freire's (1972) *Pedagogy of the Oppressed* (Wallerstein and Duran 2008).

Kurt Lewin was a social psychologist who developed the concept of action research in the 1930s and early 1940s (Adelman 1993). Action research was a

collaborative approach that sought to bring people together to discuss social problems, and collectively decide on the next steps towards solving them (Lewin 1946, Adelman 1993). Importantly, Lewin argued that those affected by the problems should be included as active participants in this practice (Adelman 1993). The process of action research involves a cycle of planning, action, and evaluation (Lewin 1946). Each stage should involve careful planning around how to achieve social change, followed by the execution of the identified actions (Lewin 1946). These actions should then be evaluated to determine the extent to which they were successful, identify any strengths and weaknesses and inform the next stage of the research (Lewin 1946). Thus, the process is an iterative collaboration between researchers and communities.

The Southern tradition emerged across Africa, Asia, and Latin America in the 1970s (Fals-Borda 1987, Minkler 2004, Wallerstein and Duran 2008). Many academics, particularly social scientists, anthropologists, theologians, and educators, were becoming increasingly aware of the social challenges in their communities, and how they were being produced by growing capitalism and global development (Fals-Borda 1987). Unable to resolve conflicts between empiricism within academic institutions and the need for social justice in their communities, many researchers set about creating alternative research practices (Fals-Borda 1987). Paulo Freire was a Brazilian scholar who among others in the Southern tradition, argued for an emancipatory research shift, promoting dialogical learning, collaboration, and social action (Minkler 2004, Wallerstein and Duran 2006). In *Pedagogy of the Oppressed*, Freire (1972) argues for a radical approach to education, where educators should foster inclusion and participation with those being educated. In doing so community structures are transformed and its members control over their future is strengthened (Abdulla 2020). The aims have since been expanded to promote more equitable research and harm reduction with minoritised communities in the Global North (Wallerstein and Duran 2006, Wallerstein and Duran 2008, Ortiz, Nash et al. 2020).

Research in sub-Saharan African and in high income countries has demonstrated the utility of community based participatory research in culturally-situated noncommunicable disease prevention and control. For example, Chimberengwa and Naidoo (2019) used CBPR to promote hypertension awareness, prevention

and treatment in Zimbabwe and found that collaboration with village health workers supported community empowerment and improved hypertension-related health delivery. In the United States, researchers used CBPR to develop a socio-culturally responsible physical activity and nutrition programme with migrant and refugee women (Wieland, Weis et al. 2012). The study recruited 29 women to participate in a half-day fitness retreat to inform the intervention and ran focus group discussions to explore participant's responses to possible exercise and nutrition education strategies. The resulting programme was highly acceptable to the community and improved both healthy behaviours and quality of life (Wieland, Weis et al. 2012).

Thus, my own research follows a community-based participatory research approach to explore the risk factors of diabetes and hypertension. My philosophy closely aligns with the Southern tradition valuing subjective knowledge and emancipatory values (Israel, Schulz et al. 1998, Wallerstein and Duran 2006, Wallerstein and Duran 2008). I will describe the guiding principles of CBPR in more detail in the next section.

### **2.3.2 Key Principles**

Numerous participatory approaches have emerged, including, but not limited to, community-based participatory research, participatory action research, community engaged research and youth participatory action research (Minkler 2004, Ortiz, Nash et al. 2020). While the approaches may differ in and across disciplines, they are often modelled on two main pillars: addressing community exploitation in research and promoting community empowerment (Blumenthal 2011). CBPR can be defined as:

“a collaborative process that equitably involves all partners in the research process and recognises the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change” (Minkler 2004: p.686).

Israel, Schulz et al. (1998) outlined eight main principles of CBPR. Firstly, CBPR recognises the community as a unity of identity, and seeks to engage groups that are already established. The community does not have to be formed from geographical proximity, rather, a shared set of common values, norms,

knowledge, or interests between a connected group (Israel, Schulz et al. 1998). Secondly, the approach builds on the strengths and resources that already exist within the community. This means supporting the community by drawing on the diversity of individual skills, community networks and relationships as well as local organisational structures. This sets up for the third principle, facilitation of collaborative partnerships throughout the research. Community members should be involved in each phase of the process from design to dissemination, and strong equitable partnerships should be developed to explore the issues identified by the community. The fourth principle is the integration of knowledge and action for the mutual benefit of all partners. In the context of CBPR, this means finding a way to bring together the local knowledge of community members and the knowledge of researchers and other project partners, culminating in an output that promotes community change and, in some form, benefits everyone involved. Fifth, CBPR should be a process that promotes co-learning and empowerment. Each partner should learn from each other's diverse skills and knowledge while also acknowledging and sharing power and capacity. Sixth, CBPR should be both a cyclical and iterative process of collaboration. The seventh principle involves the promotion of positive health and wellbeing and addressing the social determinants of health including cultural, political, and biomedical factors. Finally, the findings of CBPR should be disseminated to all partners in a format that is clear, respectful and acknowledges the contribution of each (Israel, Schulz et al. 1998).

### **2.3.3 Navigating Power and Participation in CBPR**

CBPR appears highly promising to counter problematic research practices and promote more equitable and sustainable health research. However, it should be noted that it is not sufficient to simply say you are 'doing CBPR' research without thoroughly reflecting on various challenges throughout. Power hierarchies and the extent of participation within the CBPR process need to be considered (Wallerstein and Duran 2006, Wallerstein and Duran 2010).

Power dynamics and tensions in health research often emerge due to complex historical traumas which manifest in distrust of researchers (Wallerstein and Duran 2006, Wallerstein and Duran 2008, Ortiz, Nash et al. 2020, Smith 2021). Medicine has an entrenched history of racism and colonial harm (Amster 2022,

Hussain, Sadigh et al. 2023). For example, Marion Sims, is credited as the ‘father of gynaecology’, yet conducted medical experimentation on enslaved black women without anaesthesia between 1845 and 1849 (Amster 2022, Hussain, Sadigh et al. 2023). Similarly, the Tuskegee syphilis study in the United States, between 1932 and 1972, led to poor African American men being secretly denied treatment for syphilis for four decades (Reverby 2012). Racism persists throughout health and medical research today (Powell, Njoku et al. 2022, Hussain, Sadigh et al. 2023). For example, racialised minority populations are still underrepresented in health research which can result in the development of health interventions that do not reflect community needs or interests and reinforce harms (Powell, Njoku et al. 2022). Furthermore, those in academic and medical leadership positions are predominantly white, reinforcing structural and racial inequalities in health research and practice (Hussain, Sadigh et al. 2023). The legacies of these medical harms and ongoing racism and inequalities have led to a long-standing distrust of medical power among diverse black communities (Scharff, Mathews et al. 2010, Jaiswal 2019, Bécares, Shaw et al. 2022, Ojo-Aromokudu, Suffel et al. 2023).

In CBPR, the Western scientific expertise of ‘outside’ researchers from the Global North and imposition of biomedical language that does not represent community knowledge can still occur and diminish community experiences (Minkler 2004, Wallerstein and Duran 2006, Wallerstein and Duran 2010). There is a need for ongoing communication and relationship building to fully align with the equitable principles of CBPR, minimise power dynamics and promote more trusting relationships (Minkler 2004, Wallerstein and Duran 2006, Wallerstein and Duran 2010). My positionality also brings further reflexivity of cultural diversity and tensions that may emerge around power and race (Minkler 2004). Through my work with Black African communities, it is crucially important to continually reflect on possible instances of racism and where they might occur whether institutionally, through interpersonal interaction or internalised prejudices (Minkler 2004). Thus, it is important to employ ‘cultural humility’ through ongoing self-reflection, critique, and education, work to identify inherent biases and correct them when they emerge (Wallerstein and Duran 2006). I will discuss this further in Chapter 3.1.

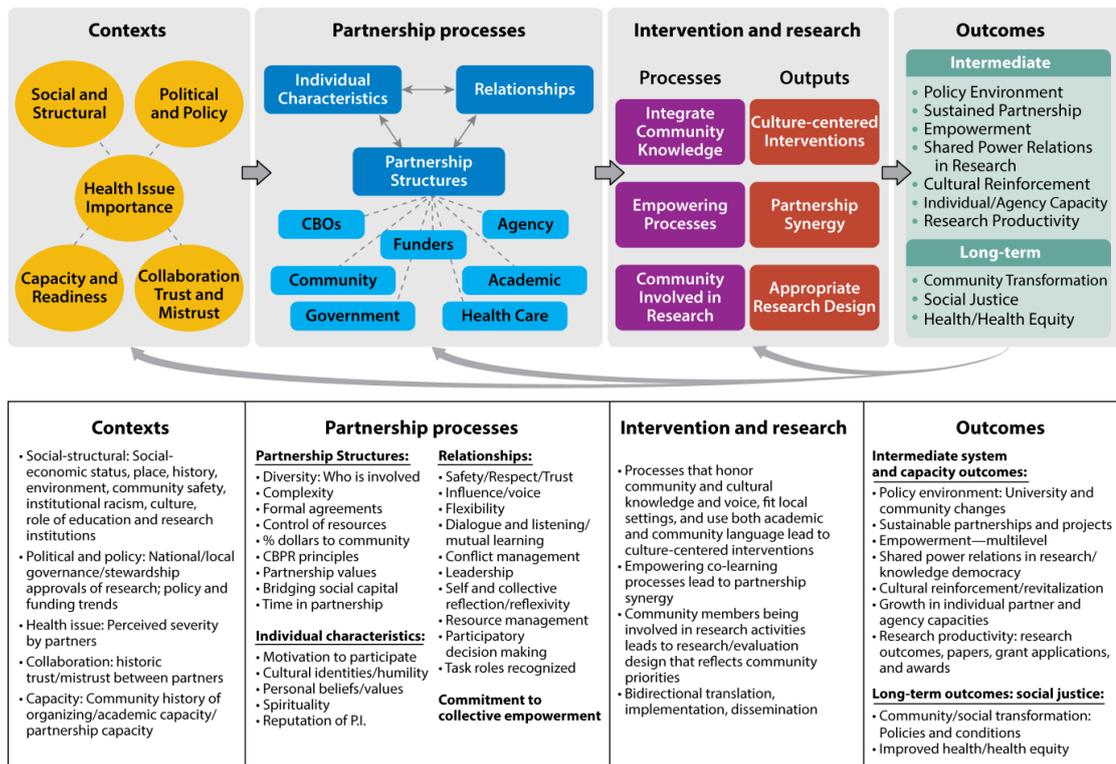
Challenges with power can also be observed when determining who consents on behalf of the community (Wallerstein and Duran 2006). The heterogeneity of community structures makes it difficult to establish whose interests are reflected. This is especially challenging when institutions and funders make the decision on who should provide consent (Wallerstein and Duran 2006). The recognition, and value, of community knowledge is a fundamental component of CBPR, therefore it is important to employ strategies that prioritise community voices; for example creating Community Advisory Boards to guide practice and define culturally situated principles (Wallerstein and Duran 2006, Wallerstein and Duran 2010).

Finally, it is important to consider how to promote active participation throughout the research. In some cases, research has used participation to satisfy funding requirements rather than promote genuine partnerships (Israel, Schulz et al. 1998, Wallerstein and Duran 2010). Participation is an ongoing process and will face further barriers, including to what extent the research becomes a burden on the community amongst time and financial constraints and to what extent the community claims ownership of the project (Wallerstein and Duran 2010). Some community members may also be more concerned with tangible outcomes and services than participating in knowledge generation (Blumenthal 2011). Where CBPR focuses on involving the community in data analysis, dissemination and further capacity training for lasting social change, participants may find greater empowerment in the process than traditional research methods (Israel, Schulz et al. 1998, Wallerstein and Duran 2010).

## **2.4 A Transcultural CBPR Model for the Development of the TABPA**

Ortiz, Nash et al. (2020) developed a conceptual CBPR model as a valuable guiding tool for the planning and evaluation of CBPR (adapted from Wallerstein, Oetzel et al. (2008) and Wallerstein, Duran et al. (2017)). There are four domains: *Contexts; Partnership Processes, Intervention and Research, and Outcomes* (Figure 2-1) which interact to guide the CBPR process in a way that reflects its principles and helps to navigate potential challenges in power and participation.

## CBPR conceptual model



Ortiz K, et al. 2020. *Annu. Rev. Public Health*. 41:177–99

**Figure 2-1: CBPR Conceptual Model by Ortiz, Nash et al. (2020) adapted with permission from Wallerstein, Oetzel et al. (2008) and Wallerstein, Duran et al. (2017).**

CBPR falls under the domain of Community Engaged Research (CEnR) a term adopted by the National Institutes for Health to incorporate different forms of participatory research (e.g. participatory action research, citizen science and CBPR) (Ortiz, Nash et al 2020). These approaches were adopted with the aim of confronting historical distrust in research with marginalised communities caused by academics imposing power dynamics, and failures to return findings to the communities being researched. The CEnR terms used across different research disciplines often overlap with CBPR which can pose challenges when evaluating the effectiveness of community-driven solutions (Ortiz, Nash et al 2020). Therefore, through a scoping meta-review, Ortiz, Nash et al (2020) used their CBPR conceptual model to map the CEnR literature according to each of the four domains. They found that 100 studies largely supported their model, and that CEnR and CBPR align with many of the same concepts and are underlined by contact, trust, empowerment and reciprocity. Thus, the CBPR model appears to be a highly appropriate as an encompassing framework to guide the development of a TABPA framework that centres equitable health practices.

The CBPR conceptual model (Ortiz, Nash et al. 2020) directly and indirectly aligns with Scholte's (2014) seven transcultural pillars (Section 2.2) which reflect an important guiding philosophy for my research. The complementary nature of these two models supports their integration towards the development of a transcultural community based participatory research approach that reflects my own aims.

In the following sections I will outline how these the transcultural pillars align within each CBPR domain and can be integrated into an adapted transcultural CBPR model to guide my research.

### **2.4.1 Transcultural Contexts Domain**

When conducting CBPR, understanding the *contexts* in which the research is situated is fundamental to successful collaborations. There may be several different contextual factors that can either facilitate or act as barriers to partnerships (Ortiz, Nash et al. 2020). Within the model, five themes are identified as possible contexts that should be considered including: Social and Structural (e.g. culture), Political and Policy (e.g. funding trends), Health Issue Importance (e.g. perceived severity of health issues by community), Capacity and Readiness (e.g. does each partner have time/resources for the proposed project?) and Collaboration, Trust and Mistrust (e.g. have historic collaborations been successful?). In this section I describe how the transcultural philosophy can guide the researcher within the Contexts domain (Scholte 2014, Ortiz, Nash et al. 2020).

**Reflexivity:** The researcher should consider how their own knowledge, beliefs and values may conflict with those situated in the specific contexts in which they are working. This is especially important when navigating the Social-Structural, Health Issue importance and Collaboration contexts.

**Acknowledgment of Culture and Power relations:** The researcher should identify, highlight, and interrogate the presence of power and privilege across each of the contexts in which they work, including their own contribution (whether explicit or implicit).

**Recognition of Complexity:** It should be recognised that cultures are neither homogenous nor static and instead researchers should value how cultures will shift and change within and across the Social and Structural context.

**Celebration of Diversity:** The diversity of different contexts should not only be acknowledged but actively celebrated as resource that provides multiple perspectives.

**Cultivation of Humility:** Cultivating humility involves introspection and humbleness when faced with irresolvable cultural differences. By respecting alternative and diverse contexts, the potential for impositions of knowledge and reinforced power dynamics are minimised.

**Promotion of Deep Listening:** Deep listening enables further recognition and cooperation amidst contextual differences to avoid imposing knowledge and power dynamics (e.g. hearing and respecting the expertise of community members).

**Reciprocal Learning for Positive Change:** By learning from different contexts, each partner can apply the knowledge they have gained in future projects and contribute to positive change in future.

## 2.4.2 Transcultural Partnership Processes Domain

The Partnership Processes domain calls for recognition of the important interaction between individual characteristics (e.g. beliefs), partnership structures (e.g. complex stakeholder interests) and relationships between partners (group dynamics e.g. dialogue) (Ortiz, Nash et al. 2020). Each of these themes should be explored and designed with the primary goal of collective empowerment (Ortiz, Nash et al. 2020). As with the Contexts Domain, the transcultural pillars provide guiding principles to successful partnership processes across diverse cultures. These are described below:

**Reflexivity:** By reflecting on their own biases and valuing cultural differences, researchers may be more aware of potential partnership barriers and begin to work more openly towards dialogue and positive solutions. This can contribute to

strengthened relationships between partners (e.g. by increasing trust and resolving conflicts) and guide the creation of partnership structures.

**Acknowledgment of culture and power:** Those with power and privilege hold a responsibility to openly acknowledge their position, act to educate themselves and work to mitigate their contribution to inequalities. This includes examining the presence of power in partnership structures, relationships and individual characteristics and recognising where partnerships have been exploited in the past.

**Recognition of Complexity:** Recognising and valuing the complex dynamics between different stakeholders sets a strong foundation for developing more nuanced dialogues and partnership structures that reflect each parties' interests and concerns.

**Cultivation of Humility:** The cultivation of humility can strengthen partner relationships by promoting respect, deeper listening, and conflict management.

**Celebration of Diversity:** Celebrating cultural diversity will guide the creation of partnership structures that draw on diverse partners and their resources and build partner relationships where each can mutually benefit.

**Promotion of Deep Listening:** By actively employing deep listening, partners are better situated to understand, empathise with, and respond to different partners and their individual characteristics (e.g. cultural identities) and to promote relationships built on trust and solidarity. This may also lead to the necessary adjustments within partnership structures to reflect alternative partner perspectives.

**Reciprocal Learning for Positive Change:** Sharing knowledge and collaborating with project partners contribute to new strategies for positive change in the future.

### **2.4.3 Transcultural Intervention and Research Domain**

The successful development of strong partnerships contributes to intervention and research processes that prioritise community involvement throughout. This

is achieved by integrating community knowledge into research methods, empowering each partner to collaborate and promote more equitable power dynamics and involving the community directly in the development of research activities. When community involvement is integrated at each stage of the research process, there are several positive research outcomes, including culturally centred research, partnership synergy and appropriate research designs that reflect the priorities of the community (Ortiz, Nash et al. 2020).

The transcultural pillars align strongly within the Intervention and Research domain of the CBPR model, seeking to prioritise community involvement, equitable partnerships and celebrate diverse cultural knowledge:

**Reflexivity:** Awareness and respect of cultural differences, supported by reflexivity contributes to processes that integrate community knowledge towards culturally centred research. Reflexivity also facilitates an openness to co-learning processes resulting in partnership synergy.

**Acknowledgment of culture and power:** Acknowledging and challenging culture and power relations in health research can lead to processes that more equitably involve the community in the research and research outputs that actively reflect the priorities of the community.

**Recognition of Complexity:** Recognition and appreciation of cultural complexity will contribute to processes that integrate community knowledge and involve the community in research, culminating in culturally centred research outputs that reflect the priorities of the community.

**Celebration of Diversity:** Celebrating cultural diversity will further support research that draws on the diverse expertise of the community and partners to generate culturally centred research outputs that reflect the priorities of the community and promote partnership synergy.

**Cultivation of Humility:** Cultivating humility will contribute to empowering co-learning research processes and improving partnership synergy.

**Promotion of Deep Listening:** Deep listening will further contribute to empowering co-learning research processes that improve partnership synergy.

**Reciprocal Learning for Positive Change:** Reciprocal learning for positive change may lead to research outputs that actively reflect the priorities of the community and the research team.

#### **2.4.4 Transcultural Outcomes Domain**

The Outcomes domain describes the intermediate and long-term goals of the CBPR process. These outcomes are directly and indirectly influenced by the context of the research, the collective empowerment achieved by research partnerships, the nature of community involvement throughout the process and achievement of culturally centred outputs that reflect the priorities of the community. Intermediate goals are centred around the principles of CBPR. These include influencing the policy environment, promoting sustained partnerships and the empowerment of all partners, shared power relations in research, cultural reinforcement, and revitalisation, promoting individual agency and capacity and research productivity. Long-term goals focus on community transformation through policy and conditions, improving health, health equity and promoting lasting social justice.

Each of the transcultural pillars could influence any of the CBPR outcomes to some extent; however, areas where they most align are described below.

**Reflexivity:** Awareness of and reflection on one's own positionality is fundamental to promoting equitable collaboration and working towards intermediate outcomes including sustained partnership and shared power relations in research.

**Acknowledgment of culture and power:** Recognising culture and power dynamics throughout the CBPR process is likely to contribute to intermediate outcomes including shared power relations, sustained partnership and cultural reinforcement.

**Recognition of Complexity:** Acknowledgment of cultural complexity throughout the CBPR process will contribute to intermediate outcomes, including shared power relations, cultural reinforcement and long-term community transformation and social justice.

**Celebration of Diversity:** Celebrating cultural diversity will most contribute to intermediate outcomes including empowerment, cultural reinforcement, individual and agency capacity and long-term community transformation, social justice and health equity.

**Cultivation of Humility:** The cultivation of humility throughout the research process will influence intermediate outcomes including the extent of shared power relations in research and the opportunity for sustained partnership.

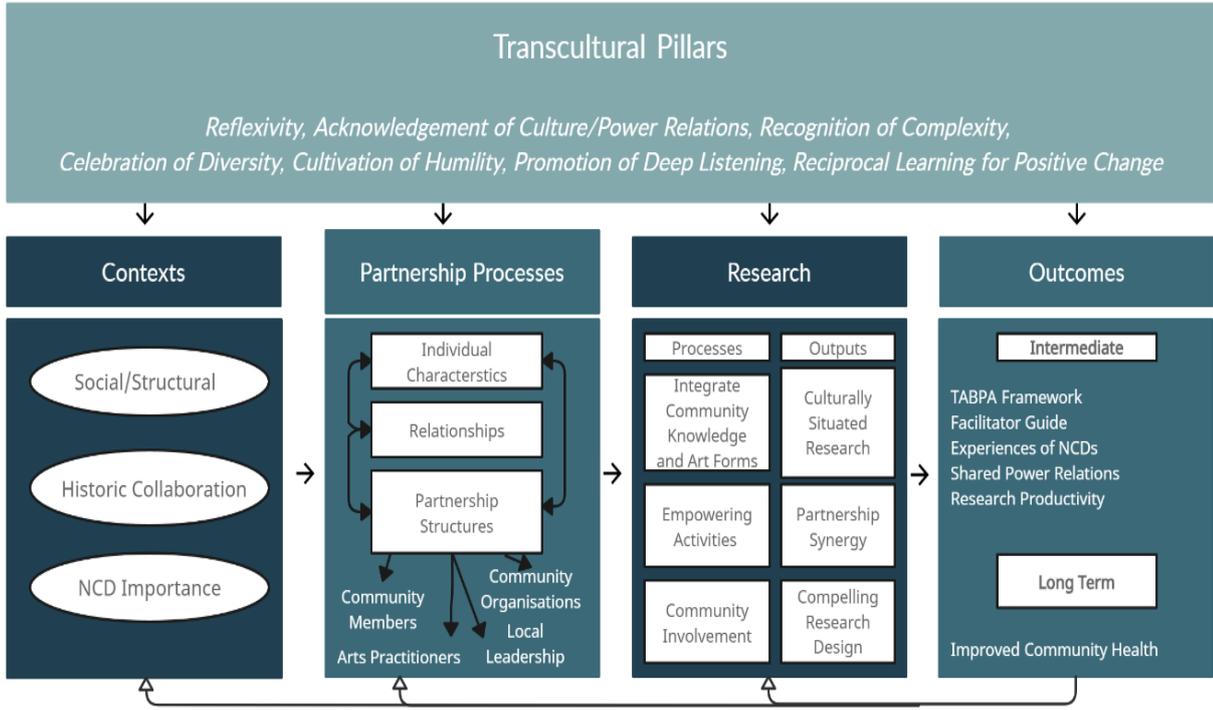
**Promotion of Deep Listening:** Deep listening will contribute to shared empowerment, sustained partnerships, shared power relations and cultural reinforcement. It may also contribute to long term outcomes including community transformation, social justice, and health equity.

**Reciprocal Learning for Positive Change:** Reciprocal learning for positive change will contribute to intermediate outcomes including influencing the policy environment, research productivity, empowerment, and cultural reinforcement. This pillar is also the most important to the achievement of long-term research outcomes that benefit all partners including community transformation, social justice, and health equity.

In summary, Scholte's (2014) transcultural pillars provided a set of fundamental principles that guide the development of the CBPR model from context through to the research process. By integrating these pillars into the CBPR domains, outcomes may better reflect the strengths of collaboration across diverse cultural contexts. In the following section, I will demonstrate how these pillars map onto my own transcultural community-based participatory research conceptual model to guide the development of the transcultural arts-based participatory approach (TABPA) framework with African communities in Scotland and Malawi.

### **2.4.5 A Transcultural Community-Based Participatory Research Conceptual Model**

In Figure 2-2, I have attempted to visually integrate the transcultural pillars into a CBPR conceptual model adapted for the development of an arts-based participatory approach to explore experiences of diabetes and hypertension among African communities in two diverse cultural contexts (Scotland and Malawi) (See Chapters 1.2 and 1.3). The model was adapted using the Visioning with the Community Based Participatory Research (CBPR) Model: Facilitator Guide and Workbook for Using CBPR Model for Planning Community-Engaged Research Partnerships (available at: [https://engageforequity.org/tool\\_kit/visioning\\_cbpr\\_model/](https://engageforequity.org/tool_kit/visioning_cbpr_model/) ). It describes how the transcultural pillars influence each of the CBPR domains and how each domain is linked to the next in a dynamic, fluid process.



Contexts	Partnership Processes	Research	Outcomes
<p><i>Social and Structural:</i> Cultural Racism and Colonial History Environment</p>	<p><i>Individual Characteristics:</i> Motivation to Participate Cultural Identities/Humility</p>	<p>Processes that integrate community knowledge and perspectives on NCDs and use local arts forms and language to do so, reflect cultural contexts and contribute to culturally-situated/centred research</p>	<p><i>Intermediate:</i> TABPA Framework Evidence of local communities experiences, perspectives and beliefs about NCDs Shared power relations in research and knowledge democracy Research Productivity: Thesis, research papers and conference presentations</p>
<p><i>Historic Collaboration, Trust and Mistrust:</i> Impositions in Health and Academic Research from Global North and White Researchers. Successful Collaborations using ABPR</p>	<p><i>Relationships:</i> Trust and Respect Flexibility Dialogue and Mutual Co-Learning Reflexivity Community Voice Participant Decision-Making</p>	<p>Processes that use participatory arts-based activities to empower community members and promote co-learning contribute to partnership synergy</p>	<p><i>Long Term:</i> Improved Community Health: through knowledge generation, community engagement and policy.</p>
<p><i>NCD Importance:</i> Community perception of NCD severity, specifically diabetes and hypertension</p>	<p><i>Partnership Structures:</i> Diversity: Community Members, Local Arts Practitioners, Local Chiefs, Community Organisations Complexity CBPR principles Benefits/Compensation Time</p>	<p>Processes that prioritise community involvement in the research contributes to the design of a transcultural arts-based participatory approach that is not only culturally-situated but culturally-compelling.</p>	

**Figure 2-2 Transcultural Community-Based Participatory Research Conceptual Model for TABPA development. Adapted from Ortiz, Nash et al. (2020), Wallerstein, Oetzel et al. (2008), Wallerstein, Duran et al. (2017) and Scholte (2014).**

## 2.5 Contribution of the TABPA Framework

This research brings together arts-based methods, CBPR and a transcultural philosophy towards the development of the Transcultural Arts-Based Participatory Framework. It is important to note that the application of Arts-Based Participatory strategies in health research and intervention design is not new, and many researchers are exploring the redistribution of power in health research in creative ways. For example, Abdulla (2021) conducted workshops to explore community perspectives of HIV/AIDS over nine days, generating deep understanding through the use of traditional folk media. This approach allowed for rich and culturally-situated collaboration; however, the time-intensive nature of the collaboration will be out of reach for many health researchers, particularly amidst competing funding pressures. This is something that the TABPA framework aims to address, by creating a flexible approach that can be implemented in a condensed time-frame. Furthermore, although Abdulla's work took place over several days, arts, folk and creative practices are still able to provide rich, in-depth understanding of community perspectives and alternative ways of knowing compared to many traditional research methods like focus groups (Bissett, Gray et al. 2022) and often in a more time-efficient way than methods like ethnography. The current research aims to find a balance between the richness of arts-based methods and the time demands of authentic participatory engagement, while also working across cultural contexts.

Thus, the Transcultural Arts-Based Participatory Framework offers four key intersecting contributions to health research practice and intervention design that each build on existing practices. 1) It seeks to use arts-based methods to generate rich narratives about health behaviours, specifically NCD risk factors. 2) It draws on community-based participatory research to redistribute power in the research process and contribute to more equitable health and research practices. 3) It seeks to acknowledge and embrace the diversity and complexity of culture in the co-production of knowledge in different contexts. 4) The most important contribution of this research is that it seeks to do this in all in a time-efficient and pragmatic way, necessary for the time, resource and funding limitations of current practices in health research and intervention design.

## 2.6 Summary

To summarise, arts-based methods have been applied both in the UK and in sub-Saharan Africa and offer one approach to gain new understandings of local perspectives and experiences of these diseases. Through the creation of safe spaces, community members can use their imagination to communicate their underlying emotions and personal beliefs and inform health outcomes that will be culturally-compelling to the community. Indeed, as argued by sociological theorists the creation of art is a social activity shaped by emotional meanings and structural influences and therefore is highly compatible with emancipatory social research like CBPR.

Arts-based methods could be integrated with community-based participatory research to ensure that the research centres community interests and does not impose Western biomedical knowledge and reinforce power relations. CBPR is a collaborative approach that requires careful planning and constant negotiation with community members and other project partners to ensure that the process is equitable for all parties and promotes active participation towards social change. The CBPR conceptual model acts as a toolkit with which to navigate this process and challenges that may emerge (Ortiz, Nash et al. 2020) while Scholte's (2014) transcultural pillars provide a philosophy for the development of a method that reflects different cultural contexts. Upon integration they act as a new transcultural CBPR model that acts as a guide for my methodological development.

Arts-based, transcultural, and participatory research practices all place emphasis on collaboration and celebrate multiple perspectives while recognising the importance of reflexivity and open communication. By bringing these together, each of these components compliments the other towards the development of a new approach in collaboration with local communities to understand the lived realities of diabetes and hypertension and inform approaches to health promotion that can lead to lasting change in Scotland and in Malawi.

## 3 Methodology

In this chapter, I detail the methodological processes I used to develop, pilot and refine the TABPA methodology with African communities in Malawi and Scotland. The chapter will begin by exploring my own positionality and epistemologies with a focused exploration of the epistemologies of arts-based health research. I will then introduce the research design, describe the settings, partnerships and recruitment strategies in Malawi and Scotland and provide a detailed description of the methods used in each phase of the research. Finally, I will describe my processes of analysis, and the chapter will end with a discussion of relevant ethical considerations.

### 3.1 Positionality

According to Merriam, Johnson-Bailey et al. (2001), positionality is determined by “*where one stands in relation to the ‘other’*” (p.411) and that this is shaped dynamically according to factors including race, class, gender and sexuality, at times irrespective of our own cultural identity. I consider myself to be an interdisciplinary researcher where my knowledges, practices and values have been developed, challenged and shaped through a range of activities, education and collaborations. I hold a BSc in Pharmacology, an MSc in Global Health and have had a long-standing interest and participation in the arts. I am also a white Scottish woman, studying (for the third time) at the University of Glasgow, a Global North Institution which has important, complex and at times confronting, implications for researching with Black African communities in the Global South and minoritised communities in the Global North. The following section will reflect on my own positionality, including my shifting epistemologies as I have moved across and within disciplines and the power dynamics when working as an outside researcher in two settings.

#### 3.1.1 Shifting Epistemologies

Prior to my MSc, my training and thinking had largely been framed by a post-positivist ontology common to the life sciences. I valued validity and reliability in experimental research, and testing hypotheses through lab-based methods (Moon and Blackman 2014, Moon, Cvitanovic et al. 2021). My undergraduate

dissertation was a laboratory project examining the biological association between hypertension and stroke. Following this degree, I was becoming more politically aware of health and social inequalities, both socially and through my studies. Around this time, there was a shift in my epistemology, and I moved towards social constructionism paradigms, using alternative methodologies that prioritise subjectivity, and value social, cultural and historical perspectives (Moon and Blackman 2014). However, this divergence does not mean that my positivist thinking has disappeared, particularly while still working in a discipline that remains situated within biomedical modes of thinking. Interdisciplinary research which can often bring conflicts due diverging research priorities and perceptions of academic legitimacy (Boydell, Hodgins et al. 2016, Renwick 2016). Indeed, dominant perceptions of what research is ‘valuable’ has contributed to a growth in government funding for STEM research and a decline in social science research funding (Holmwood 2014, Renwick 2016). In my role as researcher, I experienced my own conflicts with how to balance my ethical position and value community knowledge without contributing to possible harms through the spread of health misinformation (see Chapter 7.3.1). However, interdisciplinary researchers argue that consideration of diverse epistemologies may promote reflexivity of our own knowledge, as well as more productive and more genuine collaboration (Renwick 2016, Moon, Cvitanovic et al. 2021). Therefore, I do not mark my interdisciplinarity or diverging epistemologies as a weakness, instead, I argue they have supported me to reflect on and challenge my own knowledge and decision-making towards a more authentic engagement with the communities I worked with.

### **3.1.2 Experiences in the Arts**

My motivations for pursuing arts-based research were shaped by my personal experiences in the arts and an opportunity to explore this in my masters. Although I do not claim to be formally trained as an artist or practitioner, I recognise that I have benefitted from my involvement in the arts since my teenage years. I was a member of young person’s performance company *Junction 25* from the ages of 12 to 18. *Junction 25* was formed by theatre-makers Jess Thorpe and Tashi Gore, as a space where young people could come together to create performance informed by our own experiences and perspectives on the world. Central to the philosophy was collaboration, shared

ownership, and co-authorship (Thorpe and Gore 2019), values that have readily translated into my own research today. *Junction 25* was also formed as way to demonstrate that young people's perspectives should be valued alongside 'professional' artists in contemporary performance. We toured performances across the UK and earned critical success to a level often only afforded to professional companies. I write this to say, that *Junction 25* was a pivotal experience in my personal development and shaped my beliefs that all knowledge and perspectives should be valued.

As previously noted in Chapter 1.2, this research was also directly informed by the Culture and Bodies Project, which aimed to develop a culturally-situated arts-based participatory method to explore experiences of NCDs in Tanzania and Malawi (Bissett, Gray et al. 2022). I joined this project during my Masters, where I was drawn to it as a dissertation topic that brought together my experiences and knowledge in the arts and health. During this research I gained a fundamental understanding and experience of arts-based health research which I have continued to build on since.

### **3.1.3 An 'Outside' Researcher**

I am a white, Scottish, Western-educated woman working with Black African communities. This aspect of my positionality has been an ongoing point of reflection and conflict throughout my engagement with this research. Prior to this research I had never visited Malawi, and although I have lived in Glasgow my whole life, I am still an outsider to the African communities here. While there is growing recognition that "*insider*" and "*outsider*" positionalities are dynamic and situational (Milligan 2016, Abdulla 2021, Smith 2021), there are still important implications for my whiteness within these academic contexts. Through this research, I have undertaken a continual process of education with both contexts, seeking out local and colonial histories, reading local scholars, listening deeply to community members and research partners and dedicating myself to authentic and reciprocal relationship building. I have sat with uncomfortable questions over whether I am the 'right' person to be undertaking this research, recognising that my role in this project is not only a benefit of my privilege but makes me complicit in enduring systems of oppression (Coultras 2022). According to Coultras (2022: p.416) "*there is no redemptive white*

*identity, we can never proclaim ourselves to be anti-racist, anti-colonial, an ally, or an intersectional feminist because to do so reflects a “move towards innocence”, an attempt to rid ourselves of the ethical responsibility of recognising our complicity in ongoing injustices”*. However, this is not to say that we disengage, rather as white researchers we need to hold ourselves accountable and navigate the complexities of recognising when we can and should act, as well as when we should take a step back and create space for ‘marginalised Others’ (Coultas 2022). Coultas (2022) draws on Tuck and Yang (2014) to frame their own dilemmas between action and inaction as “*refusals*” presented as reflections on their “*experiences of unlearning*” and their attempts to challenge “*dominant and oppressive ways of thinking and acting in research*” (p.414). I have endeavoured to reflect on my own complicities throughout this research. However, I argue that a key refusal within this inquiry is to develop an approach that can celebrate diverse knowledges and challenge dominant epistemologies and perceptions of academic legitimacy. This will be explored in detail in the following section.

### **3.2 Epistemologies of Arts-Based Health Research**

As discussed in Chapter 2.1, arts-based research is a broad and encompassing term for a range of methods, practices and approaches. Arts-based research has been embraced by qualitative methods within the social sciences, however its definitions are far broader and represent interdisciplinary and transdisciplinary enquiries and ways of knowing (McNiff 2018, Gerber and Siegesmund 2022). Many scholars argue that this diversity is an inherent strength of arts-based research, which holds an “*inherent[ly] pluralistic and eclectic*” ontology and epistemology that represents and embraces both complementary and contradictory ways of knowing (Bird 2022, Gerber, Biffi et al. 2020: p.2).

According to Bird (2022) “*the epistemology that underpins arts-based research is one that favours intuition and imagination as much as it values analysis and rationality, and that gives space for the ambiguous and the awkward*” (p.3). McNiff (2018) emphasises that arts-based research does not rest on one discipline nor artistic skill or expertise, instead artistic knowledge utilises this diversity to create a universal form of communication. The process of artistic (co-) creation can generate personal, sensory, imaginal, embodied and

emotional ways of knowing that are often not captured in traditional research approaches (Chilton, Gerber et al. 2015, Gerber, Biffi et al. 2020, Gerber and Siegesmund 2022). In the context of health research, arts-based research has been shown to create representations of underlying experiences of health and illness through the generation of emotional and empathetic perspectives and understanding (Boydell, Gladstone et al. 2012, Moss and O'Neill 2019). Thus, as argued by McNiff (2018), the “*artistic process of enquiry*” can not only be used to explore art but also the “*totality of human experience*” (p. 24).

As arts-based research scholarship grows, researchers have recognised conflicts between the inherent philosophy of the methodology and dominant research paradigms that centre rigid, ‘scientific’ and objective concepts, methods and outcomes (Boydell, Hodgins et al. 2016, McNiff 2018, Gerber and Siegesmund 2022). This is especially true within health and medical research, where the legitimacy of arts-based health research is often questioned (Boydell, Hodgins et al. 2016). However, it can be problematic to force arts-based research to fit into positivist parameters. Researchers have argued that it is instead about recognising the value of artistic ways of knowing in their own right, reshaping our understanding of what knowledge is ‘valuable’ and broadening our definitions of academic legitimacy rather than disregarding scientific modes of thought (Boydell, Hodgins et al. 2016, Coemans and Hannes 2017, McNiff 2018, Bird 2022, Gerber and Siegesmund 2022). This perspective is what makes arts-based research so compatible with participatory and to some extent, decolonising, paradigms. By valuing multiple forms of knowing, arts-based enquiry can challenge hegemonic Western and biomedical modes of enquiry and support the redistribution of power (Daniels 2003, Coemans and Hannes 2017, Van der Vaart, van Hoven et al. 2018).

Gerber, Biffi et al. (2020) argue that it is within the contradictions of the epistemology of arts-based research that creativity and ideas evolve to generate individual and social change. Coemans and Hannes (2017) highlighted that arts-based research can also contribute to participants personal transformation by improving confidence, pride and promoting skill development. Nonetheless, the inherent qualities of arts-based research should not be taken for granted. Arts-based research methods can still impose Western and biomedical forms of knowledge onto communities (Abdulla 2020, Bunn, Kalinga et al. 2020).

Therefore, artistic and research methods need to be carefully considered and readily adaptable to reflect the cultural knowledges and contexts of participants (Bunn, Kalinga et al. 2020, Gerber, Biffi et al. 2020, Gerber and Siegesmund 2022).

Finally, the methods in arts-based research should “*respond to problems in unique and pragmatic ways and are not to be constrained by fixed and sanctioned protocols*” (McNiff 2018: p.24). The methodological choices in the current research were shaped in several ways. Firstly, I sought to embrace the generation of multiple and dynamic ways of knowing in line with social constructionist, and arts-based research and participatory epistemologies. Secondly, I sought to explore and integrate art forms culturally-situated within each of the communities I was working with. Thirdly, the methods were shaped by an active intention to promote the co-creation of knowledge and centre community experiences and perspectives. Finally, the methods were inherently informed by my own experiences and expertise in participatory theatre (Gerber, Biffi et al. 2020) (see Section 3.1.2). Each of the methods used will be described in more detail in the following section, however, consistent with the four motivations described above, every method was designed to be open, adaptable and flexible, and to prioritise community choice where possible.

### **3.3 Research Design and Timeline**

As described in Chapter 1.5, this research was conducted in three broad phases. Phase 1 involved familiarisation with local communities, health and art forms with African community members in Glasgow, Scotland and Lilongwe, Malawi. This included walkalong interviews, and community and stakeholder workshops in each setting to inform the development and implementation of the TABPA workshops in Phases 2 and 3. Phase 2 involved piloting and refining the TABPA workshops with African communities in Glasgow. Phase 3 involved piloting and refining the TABPA workshops with the target community in Lilongwe (facilitated by a local Malawian arts-practitioner identified in Phase 1). Phases 2 and 3 involved two arts-based participatory TABPA workshops in each setting.

The project timeline is summarised in Figure 3-1.

# TABPA Project Timeline

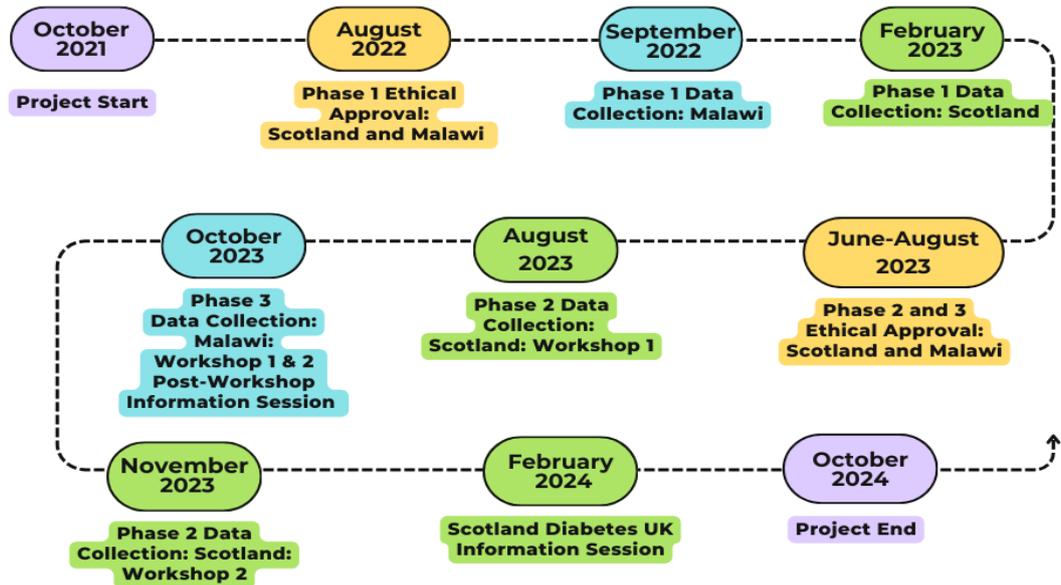


Figure 3-1 TABPA Project Timeline 2021-2024. Yellow bubbles show dates of ethical approval, Green bubbles show data collection and events in Scotland, Blue bubbles show data collection and events in Malawi.

## 3.4 Settings, Partnerships and Recruitment

This research involved diverse partnerships and recruitment strategies that were readily adapted to each setting. These are briefly described below but will be explored throughout the thesis.

### 3.4.1 Malawi

#### 3.4.1.1 Setting: Area 25, Lilongwe

In Malawi, the research was conducted within the high-density area of Area 25, Lilongwe, the capital city. Area 25 has a population of 107,316 (Government of Malawi 2019) with a broad sociodemographic profile (Crampin, Kayuni et al. 2016). The Malawi Epidemiology and Intervention Research Unit (MEIRU) has a long-standing research relationship with Area 25 and has recently been working to establish the area as a health and demographic surveillance site (HDSS) which includes the categorisation of the Area into several distinct sectors. Therefore, the site of the current research was chosen in collaboration with researchers at

MEIRU. Sector A (pseudonym) was chosen for two reasons. Firstly, data collection for the MEIRU demographic survey had not yet extended into the area, meaning that there would be no research overlap to complicate either MEIRU's projects or my own. Secondly, the community had previously participated in research on chronic disease and thus, there was already an established research relationship with the local leadership structures.

#### **3.4.1.2 Partnerships: Community Gatekeepers**

In Malawi, the modern state is a hybrid of formal government and district/area chieftaincies. Traditional leadership structures are formed by a hierarchy, beginning with Traditional Authorities, followed by Senior Group Village Heads then Group Village Heads and finally Village Heads or Town Chiefs in peri urban/urban areas (Eggen 2011, Abdulla 2021). Town Chiefs were a product of complex political and economic developments during the colonial era and redefined amidst later urbanisation under the government of Hasting Kamuzu Banda in the 1970s and 1980s (Cammack, Kanyongolo et al. 2009). Today, Town Chiefs hold unofficial powers, especially relative to rural chieftaincies, although they are still important in filling leadership roles amidst growing urbanisation in Malawi (Cammack, Kanyongolo et al. 2009, Eggen 2011).

The extent of autonomy held by the Town Chief differs between districts and sectors. In Sector A, Area 25, the Chiefs still fulfil very important roles, including as gatekeepers who are responsible for providing access to the community and leading community development activities which will be described in more detail in the following chapter. Therefore, before Phase 1 data collection began, the research was presented to the Chiefs for their approval and support with recruitment. Approval was sought twice more over the project, once following an election during Phase 1 data collection and again before Phase 3 data collection. On each of these occasions, the three chiefs were provided with a gift of 3,000 Malawian kwacha each (~£3), the equivalent of a chicken. Note that all currency conversions in this chapter between GBP and Malawian Kwacha are correct at the time of data collection. Please refer to Section 3.4.1.4 for more detail on their support with recruitment.

### 3.4.1.3 Partnerships: Facilitators

The research was conducted in collaboration with arts-based facilitators who supported data collection, research reflections, protocol refinement, translation, transcription, and presentation of findings. In Malawi, it was fundamental to partner with facilitators i) who were Malawian and whose knowledges were rooted in the local context and ii) had the skills required to facilitate arts-based health research. Due to the duration of the research and unforeseen circumstances, I partnered with four different facilitators: Miguel, Luke, Rhoda, and Trust. Each of the facilitators were experienced in arts-based and participatory work in research and/or development. Miguel, Luke and Rhoda were known to and recommended by my first supervisor (CB) to support data collection. Rhoda recommended Trust as one of her colleagues on past projects. All facilitators chose to be identified by name.

Phase 1 methods were conducted by Miguel and Luke, respectively. Both translated all documents relevant to the research (e.g. consent forms). Miguel was initially involved as the primary facilitator and directly supported walkalong interviews by helping to recruit participants and live translating the interviews between Chichewa and English. Unfortunately, due to other work commitments Miguel had to leave the project and Luke stepped in for the Phase 1 workshops. All workshops in Malawi were conducted in Chichewa, therefore Luke was the primary facilitator of Phase 1 community and stakeholder workshops, while I was available for support. As Luke was unavailable when I returned to Malawi for Phase 3 data collection, Rhoda (primary facilitator) and Trust (secondary facilitator) led workshop facilitation in Chichewa. Again, I was nearby to observe and offer support where needed. Before and after data collection, I would work with each facilitator to reflect on and refine the protocol or topic guides. This will be discussed further in Section 3.6. Phase 1 and Phase 3 workshop audio was transcribed and translated by Luke and Rhoda respectively. It was an ethical and moral imperative that each facilitator was paid for their time and contributions, thus rates and days of work were negotiated at the beginning of each partnership and adapted as appropriate.

#### 3.4.1.4 Participants and Recruitment

All recruitment in Malawi was done through convenience and snowball sampling with the support of the Chiefs and Malawian facilitators. The specificities of recruitment for each method are described below.

**Phase 1 Walkalong Interviews:** The Chiefs informed the community of the research and our presence in Sector A, Area 25. Over five days we went for walks in the sector and invited community members to participate in a walkalong interview. The only inclusion criteria were that participants were over 18 years old and lived in Area 25, preferably Sector A. Recruitment was kept open to try to include a range of demographics, however, we tried to be responsive to those who directly approached us to participate in the research. Eight walkalong interviews were conducted with 11 participants in total (5 male, 6 female). Community members could choose to be interviewed alone (N=5) or with a friend or family member (N=3). Participants were also given a choice over the route and duration of the walk (see Section 3.5.1). Participants chose their own pseudonym for reporting their words.

**Phase 1 Community Workshops:** Two single-gender workshops (N=12 [women], N=10 [men]) were conducted to minimise the impact of gender norms on the discussions, activities and outputs. All participants were over 18. As the workshops were designed to be exploratory, Luke advised we should invite individuals with some experience of arts-based research. Therefore, Luke invited five young people (18-25) from a previous project and the Chiefs selected another five individuals from the community. In both workshops, additional participants turned up as they had heard about the research in the community. We were responsive to this and invited them to take part.

**Phase 1 Stakeholder Workshops:** One stakeholder workshop was conducted with local Chiefs (N=4), health surveillance assistants (community-level health workers employed by the Malawian government) (N=2) and local artists (N=4) (total N=10). The health surveillance assistants were invited by the local Chiefs while the artists were recruited through Luke's own network.

Phase 3 TABPA workshops: Two single-gender TABPA workshops (N=10) were conducted. Recruitment was conducted at the Chief's discretion; the only criteria were that they invited participants from a range of age groups and from within Sector A.

#### **3.4.1.5 Payment and Incentives**

As arts-based participatory research requires community members to invest a considerable amount of their time, it was essential to compensate participants for their involvement in the research (Bunn, Kalinga et al. 2020). In Malawi, payment needs to be carefully negotiated within the requirements of the Malawi National Committee on Research in the Social Sciences which only permits compensation in the form of reimbursement (e.g. for travel) rather than participation itself. This meant that compensation could be provided for workshops but not walkalong interviews. Workshop participants were provided with what was agreed with researchers at MEIRU to be a generous rate, within the range set by the ethics committee. Participants within Phase 1 (2 hour) workshops received 6000 Malawian kwacha (£5), which was increased to 9000 Malawian kwacha (£8) for Phase 3 TABPA workshops (3 hours). Participants were also provided with water, juice and snacks during the workshops.

### **3.4.2 Scotland**

#### **3.4.2.1 Setting: Glasgow**

Glasgow is the largest city in Scotland with a population of 622,820 (National Records of Scotland 2024). According to Scotland's 2022 Census, 17.3% of Glasgow's population identified as an ethnic minority, with 2.1% identifying as African, the third largest ethnic group (Scotland's Census 2023). Between 2001 and 2011, the African ethnic group accounted for the greatest proportionate increase in size compared to other ethnic minority groups in Glasgow (Walsh, Buchanan et al. 2019). The size of the African population has also been projected to rise to 3.4% of the city's population by 2031 (Walsh, Buchanan et al. 2019).

The definition of the 'African community' in Glasgow was deliberately kept open to account for the diversity of the African diaspora in the city. Therefore, the

definition was determined in collaboration with stakeholders and with community members themselves. This will be discussed in more detail in Chapter 5.3.

#### **3.4.2.2 Partnerships: Gatekeepers**

In Scotland, this research was supported by partnerships with community organisations working with African communities in Glasgow. Although I had secured a community partnership in Scotland at the time of the project proposal, due to unforeseen circumstances, the representative of the community organisations was unavailable at the time of data collection. I then reached out to several organisations in the city to little success. This was unsurprising as community organisations, particularly those working with minoritised ethnic communities, are often facing complex funding pressures, may have a limited capacity to support research and little motivation, due to inconsistent or negative research relationships in the past (Frerichs, Kim et al. 2017, Dinnie and Holstead 2018, Koekkoek, Van Ham et al. 2021). Through the support of my second supervisor (CG) and their networks, I was introduced to a researcher at the University of Glasgow (Dr Josephine Adekola) who had previous partnerships with African community organisations in Glasgow. With their support I formed partnerships with two community organisations who agreed to work together to support recruitment and provide guidance on Phase 1 of the research. At the beginning of Phase 2, I reached out to both organisations, however, only community organisation 1 was available to continue their support. Community organisation 1 supported Phase 2 recruitment and provided guidance and feedback on the protocol and findings.

#### **3.4.2.3 Partnerships: Facilitators**

Facilitators were also recruited to support data collection in Scotland. As all data collection was in English, they were only required to support workshop facilitation. I recruited my sister Christiana, an artist experienced in community-based projects, to support the practical elements of the Phase 1 community workshops and co-lead Phase 2 workshops. Christiana supported the refinement of the Phase 2 protocol and provided detailed reflections after each workshop. Due to additional practical considerations in the Phase 2 workshops, I also

recruited my colleague Anna as a third support for data collection. Both Christiana and Anna were paid at an agreed daily rate. Both Christiana and Anna chose to be identified by name in this thesis.

#### **3.4.2.4 Participants and Recruitment**

All participants in Scotland were recruited through convenience, snowball sampling with support from the community organisations. The only inclusion criteria were that participants were aged at least 18 years old, could speak English and identified as a member of the African community in Glasgow.

Phase 1 Walkalong Interviews: There were two main recruitment strategies conducted with the support of community organisation 1 (N=6) and community organisation 2 (N=4). Firstly, I visited the headquarters for community organisation 2 where I was introduced to one interested participant and put in touch with the pastor of the local African church. I later attended a church service where the pastor shared the details with the congregation and introduced me to three interested participants. Secondly, I developed a research poster which community organisation 1 shared with their members over WhatsApp. This resulted in the recruitment of two people who, following their participation in a walkalong interview, shared the research within their wider networks resulting in another five walkalong participants. I conducted 10 walkalongs in total, only two of which were with men (see Section 3.10 for discussion of this limitation). Unlike in Malawi, all interviews were conducted individually. Participants chose their own pseudonym for use of their words when reporting the findings.

Phase 1 Community Workshops: One community workshop (N=11 women) was conducted. Recruitment built on the strategies described for walkalong interviews where a poster was circulated by community organisations 1 and 2 and among walkalong participants to share via their networks. Walkalong participants were also invited to participate in the community workshop if they were interested, and four did so. Unfortunately, due to a lack of engagement from male participants and building time pressure it was decided to not hold a men's community workshop in Scotland.

Phase 1 Stakeholder Workshop: One online workshop was conducted (N=4) with representatives from community organisations working with minoritised communities and experienced in community arts (N=3) and the leader of the local African church (N=1). Stakeholders were recruited via my own networks and those of the community partners.

Phase 2 TABPA Workshops: Two single-gender workshops were conducted (N=12 [women], N=3 [men]). Phase 2 recruitment was done through the networks built in Phase 1. A new poster was shared by community organisation 1 and among Phase 1 participants. Several Phase 1 participants were invited to participate in the Phase 2 workshop. 12 women participated in the Phase 2 women's workshop on diabetes, 6 had attended a Phase 1 workshop, 2 had attended a walkalong interview and 4 had not participated in any prior methods. Unfortunately, there were once again challenges recruiting men. Of the 3 participants who attended the men's workshop on hypertension, 1 man had participated in a walkalong interview, and 2 men were recruited through women who had participated in the Phase 2 workshop.

#### **3.4.2.5 Payment and Incentives**

Partners within community organisations 1 and 2 emphasised early on in the research that it would be unethical to invite members of the African community to participate in research without some form of financial compensation, particularly amidst the Cost-of-Living Crisis. Thus, participants in Scotland were provided with supermarket vouchers for £20 for each method in Phase 1 which was increased to £30 for the longer Phase 2 workshops, in addition to transport reimbursement in cash. Tea, coffee, water and snacks were also provided.

### **3.5 Phase 1 Methods: Walking Interviews, Community and Stakeholder Workshops**

Phase 1 integrated the following four methods: 1) NCD-focused walkalong interviews, 2) Arts-focused walkalong interviews; 3) Community arts-based participatory workshops and 4) Stakeholder workshops. The following section will outline the research, the objectives, and the implementation of each of these methods in turn.

### 3.5.1 Walkalong Interviews

Walkalong interviews are situated in-between participant observation and traditional interviews and involve the researcher joining the participant(s) for their ordinary tasks/activities (e.g. visiting the market) where they can observe, listen, and ask questions about participant perceptions and experiences of the chosen environment. In their participatory work with migrant women in North-East England, O'Neill (2018) argues that walking, *“offers a powerful route to understanding the lived experiences...as well as the development of processes and practices of inclusion, towards a radical democratic imaginary”* (p.74-75). Walking is framed as an embodied, almost transformative, practice that not only builds knowledge, but also reshapes the relationship between researchers and participants. A number of researchers have supported this idea and argue that, in comparison to sit-down interviews, walkalong or walking interviews can create more natural, and ‘everyday’ encounters (Kusenbach 2003, Carpiano 2009, O'Neill 2018).

The multi-layered strengths of walkalong/walking interviews, including their compatibility with a participatory research approach, meant they were a clear starting point from which to become familiarised with community members and the contexts of Sector A, Malawi and Glasgow, Scotland. Walking with community members allowed for the exploration of both individual and community perceptions and biographies of ‘place’ with specific focus on NCDs (diabetes and hypertension) and local art forms. Two types of walkalong interviews were conducted (NCD-focused and Arts-focused) using topic guides developed to address the following closely aligned objectives:

- **NCD-focused:** Develop an understanding of day-to-day life in the chosen community, including NCDs of most concern and begin to build relationships with community members.
- **Arts-focused:** Develop an understanding of day-to-day life in the chosen community, including familiarity with local art forms (as well as those related to NCDs) and begin to build relationships with community members.

In keeping with participatory practices and the aim to promote a more natural dialogue, participants were given full control over the route, including the speed and duration of the walk and the extent to which the walk formed part of their daily activities. In Malawi, the walks were conducted in Chichewa, supported by Miguel who live-translated the interview to English.

Data were collected by audio-recording on an encrypted mobile phone and using detailed fieldnotes. In Malawi, observations and reflections were discussed and agreed with the Miguel post-interview.

### **3.5.2 Community Arts-Based Participatory Workshops**

Community arts-based participatory workshops were developed to explore what kind of arts-based activities are compatible with community interests and perspectives on hypertension and diabetes. Specifically, the workshops were designed to achieve the following objectives:

- Develop a practical understanding of what art forms are compatible with community interests and adaptable to explorations of NCDs.
- Develop an understanding of community responses to arts-based workshops in practice to inform the structure of the Phase 2 and Phase 3 TABPA workshops.

The workshop activities and structure were informed by previous Culture and Bodies work (Bissett, Gray et al. 2022) and prior membership of participatory theatre group, *Junction 25* (Thorpe and Gore 2019) (see Section 3.1.2). The workshops followed a simple, open and fluid format of games and arts-based activities where participants were able to choose from a range of materials (paper [A4 and A1], pens [markers and biros], paints, tape [masking and cello tape], coloured pencils and crayons) and practices (e.g. song, dance, visual arts, theatre, poetry) to provide insight on their initial thoughts about hypertension, diabetes, and local art forms. Participants were assured there were no right or wrong answers. Further details are provided in Table 1.

Data were audio-recorded on an encrypted mobile phone. Post-workshop, the facilitators would debrief and reflect on the workshop using an observation proforma. In Malawi, the workshops were conducted in Chichewa by Luke, an experienced Malawian facilitator.

**Table 1: Summary of Phase 1 Community Workshop Protocol**

<b>Summary of Phase 1 Community Workshops Protocol</b>	
<b>Activity 0</b>	<b>Welcome and Consent Process</b>
<b>Activity 1</b>	<b>Getting to know each other with a game</b>
Duration	15 mins
<b>Activity 2</b>	<b>Visualisation Task</b>
Duration	25 mins
Part A	On the A4 paper, write down or draw the first thing that comes into your mind when they hear the terms high blood pressure and diabetes. You can write something about either or both. (5 minutes)
Part B	Sharing Responses Back to the Group
Part C	Group Reflection on Responses and the Task
<b>Activity 3</b>	<b>Creative Response to Activity 2</b>
Duration	50 mins
Part A	Ask participants to get into pairs or groups of three. In their groups they can use any art form of their choice to create an artistic response to what we had discussed in Activity 2. For example: if someone in activity 2 mentioned that salt is a risk factor for hypertension, they could draw a picture of someone salting their meal or write a poem about alternatives to salt.
Part B	Sharing Responses Back to the Whole Workshop
<b>Activity 4</b>	<b>Discussion and Reflections on Responses and Workshop</b>
Duration	15 mins

### 3.5.3 Stakeholder Arts-Based Participatory Workshops

Stakeholder arts-based participatory workshops were developed to learn more about past, present and future capacity for arts-based health research in each setting from the perspectives of local stakeholders. The workshops also aimed to work with these stakeholders to explore solutions to possible NCD-related stigma that might be prompted by arts-based methods. However, due to practical and time constraints in Scotland, the stakeholder workshop took place online,

therefore the session became more of a consultation, and the practical elements were removed. The workshops aimed to address the following objective:

- Develop an understanding of stakeholder perspectives on community capacity for arts-based health research and experiences of working with local communities to inform the development of an initial framework for the transcultural arts-based participatory approach that mitigates the potential for stigma.

In Malawi, stakeholders included local leaders (Chiefs), local artists and health surveillance assistants. In Scotland, stakeholders included a pastor from a local African church and representatives of local organisations with experience of community arts and working with minoritised ethnic communities. While the groups differed in size and specific responsibilities, they both represented community gatekeepers and leadership (cultural or faith) and had a perspective on community art. Furthermore, although the stakeholder group in Malawi also included community health workers, each of the stakeholders in Scotland also had experience of projects focussed on health and wellbeing.

The stakeholder workshops consisted of four main activities.

*Activity 1: Getting to know each other.*

Malawi: Participants were asked if they knew any games to begin the workshop.

Scotland: Participants were asked to introduce themselves and explain their relevant background.

*Activity 2: Learning about local arts*

Participants were asked to explore their knowledge of arts and health by answering the following questions.

- What local art forms are there?
- What arts are associated with health and noncommunicable diseases?

- What art forms are engaging to community members?
- What are some of the challenges with using different art forms in a health context?

Malawi: The questions were each displayed on an A1 sheet pinned to the wall. A nominated participant wrote the group's responses to each question on the corresponding A1 sheet. At the end of the activity, participants were asked to discuss what they had written and if they had any reflections.

Scotland: The questions were written on the Zoom whiteboard function. This was intended to be interactive so that stakeholders could contribute answers themselves, however due to technical issues, I wrote participant answers on the sheet for all to see.

### *Activity 3: Addressing Stigma*

The next activity aimed to explore how to address the idea of addressing stigma directly. Participants were asked to reflect on any experiences where they have even taken part in an activity where they have encountered stigma, especially about health.

Malawi: In small groups, participants were asked to create a performance, using any art form, about what they would do if they were running a meeting or a workshop and somebody said something that promoted stigma. Following the activity, there was a group discussion with emphasis on what could be done to prevent or reduce stigma in these scenarios.

Scotland: Participants were asked to share their own reflections on how the opportunity for stigma could be minimised.

### *Activity 4: Final Reflective Discussion (Malawi only)*

Malawi: The workshop ended with a reflective discussion on the workshop as a whole including asking questions about what participants liked, what they disliked and whether they would change anything.

### **3.6 Phase 2 and 3 Methods: Transcultural Arts-Based Participatory Approach Workshops**

The TABPA workshop protocol used in Phases 2 and 3 was developed iteratively from the findings from Phase 1 (see Chapters 4-6). The approach was designed and refined to meet the following objectives:

- Explore the feasibility and acceptability of using the TABPA in practice with the chosen African community in Scotland and Malawi
- Explore the extent to which the TABPA can minimise researcher-participant hierarchy and encourage inclusivity in Scotland.
- Gain critical experience of how to facilitate the TABPA.
- Explore participants' lived experiences, attitudes, and beliefs about hypertension and diabetes risk factors in Scotland and Malawi

There were two single-gender TABPA workshops in both Scotland (Phase 2) and Malawi (Phase 3). The TABPA followed a similar structure to the Phase 1 community workshops, however, to develop an in-depth understanding of the risk factors for diabetes and hypertension, the workshops were reframed to focus on a single health issue (diabetes or hypertension) and focus in on the risk factors and prevention of the disease.

Due to time and financial constraints of the project, it was recognised that it would not be possible to pilot separate workshops on both diabetes and hypertension with both men and women. Research in Malawi, with Black ethnicities in the UK and globally, has suggested that there is a higher prevalence of diabetes and hypertension among men compared to women (Msyamboza, Kathyola et al. 2012, Msyamboza, Mvula et al. 2014, Ferguson, Ntuk et al. 2018, Zhou, Carrillo-Larco et al. 2021, Zhou, Perel et al. 2021). However, the evidence from the UK is limited and evidence from Malawi suggests that the difference between genders is small (Price, Crampin et al. 2018, Amberbir, Lin et al. 2019). Furthermore, the global prevalence of diabetes and hypertension becomes more similar for men and women in later life

(Huebschmann, Huxley et al. 2019, Zhou, Perel et al. 2021). Thus, understanding the variation between genders in both contexts was complex and it was ultimately decided to focus men’s workshops on hypertension (high blood pressure) and women’s workshops on diabetes.

The TABPA workshop was first piloted with women in Scotland (N=12) in August 2023. In October 2023, the approach was piloted with men in Malawi (N=10) before being refined and conducted with women in Malawi (N=10). The refined TABPA workshop was then conducted with men in Scotland (N=3) in November (2023). This is summarised visually in Figure 3-2.

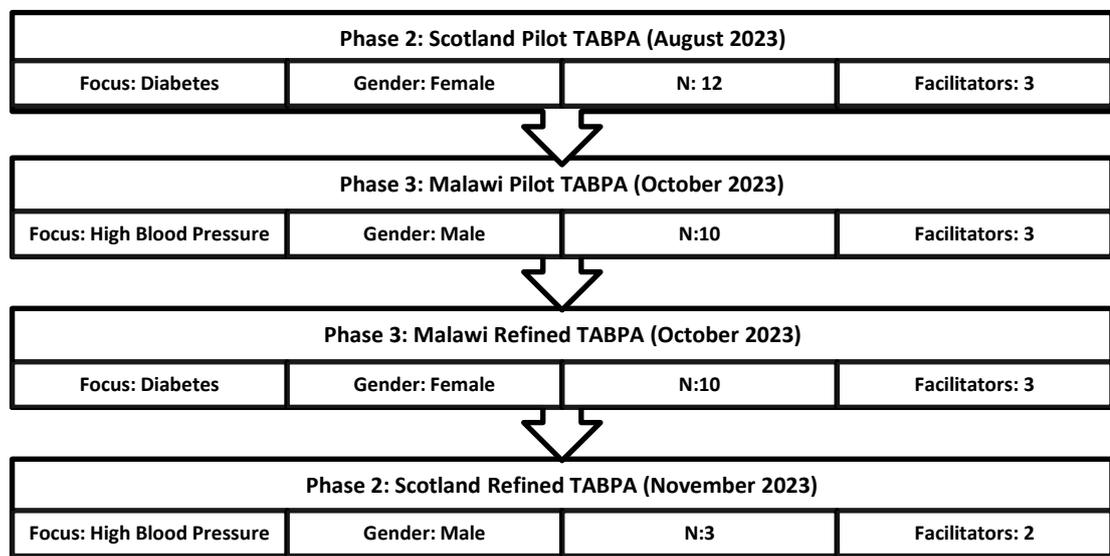


Figure 3-2 Visual Process Summary of Phases 2 and 3 of Data Collection

### 3.6.1 Pilot and Refinement

The pilot and refined TABPA workshop protocols are summarised in Table 2.

Ahead of the pilot in Scotland, I developed an initial TABPA workshop protocol, informed by the findings of Phase 1. I then met with Christiana, where we adapted some of the language to promote more creativity in the workshop. Christiana suggested the most notable change: to make the prompt for the Visualisation Activity (Activity 2) more abstract to encourage more underlying perspectives on diabetes and hypertension. Before piloting the TABPA in Malawi, I met with Rhoda, and we discussed the protocol together. There were no major changes between the Phase 2 Scotland and Phase 3 Malawi pilot workshops

protocols. The key differences between the Phase 1 Community Workshop and the Pilot TABPA workshop protocols are described further in Chapter 7.1

After piloting the TABPA in Malawi, Rhoda, Trust and I met to refine the TABPA protocol ahead of the next workshops. The most notable change was that in the Refined protocol, Activities 3 and 4 were combined to prioritise more time for the creation of the artwork and the time for the Visualisation Activity (Activity 2) was reduced (Table 2). Rhoda also added some suggested prompts for Activity 4 to delve deeper into participants' decision making, including: How did the group choose the character with diabetes? How old is the character? Why did you choose to make the character a man/woman/child?. I discuss the refinements and the experiences that informed them further in Chapter 7. The final refined TABPA protocol is available in Appendix 1: TABPA Refined Workshop Protocol.

Each workshop lasted approximately three hours including the consent process and a break. Detailed fieldnotes and audio-recordings were taken. The latter were transcribed (and translated in Malawi). Photographs and videos were taken of TABPA activities and outputs to support the interpretation of visual data (e.g. drawings and dramas).

Table 2: Summary of Pilot and Refined TABPA Protocols

Summary of TABPA Workshop Protocols		
Pilot or Refined	Pilot	Refined
<b>Activity 0</b>	<b>Welcome and Consent Process</b>	
<b>Activity 1</b>	<b>Getting to know each other with a game</b>	
Duration	15 mins	
<b>Activity 2</b>	<b>Visualisation Task</b>	
Duration	20 mins	15 mins
Part A	<p>Direction: Everybody close your eyes. I'm going to say a word. I want you to think about what comes to mind. The word is diabetes OR hypertension. What comes to your mind? Is it a picture? Is it a feeling? Is it a colour? Is it a thing? Are there any details, is it well defined, is it more blurry? How would you put that on paper? How can you put that feeling or that image on to a piece of paper.</p> <p>There is absolutely no wrong answer, anything you do here is correct. Trust your instincts. What comes to mind when you hear the words high blood pressure (Men's TABPA) or diabetes (Women's TABPA)? Open your eyes.</p>	
	[participants can draw or write this, give <b>4 minutes max</b> ]	[participants can draw or write this, give <b>2 minutes max</b> ]
Part B	Sharing Responses Back to the Group	
Part C	Group Reflection on Responses	
<b>Activity 3</b>	<b>Causes of NCD</b>	<b>Causes of NCD and Possible Solutions</b>
Duration	45 mins	1 hour
Part A	<p>This activity aims to get participants thinking about the <b>causes of the NCD</b> (hypertension or diabetes) and beginning to work together. The workshop is split into two groups. Each group can use any art form they want to explore the causes and create something to share back.</p>	
	<p>This activity aims to get participants thinking about the <b>causes of and solutions to the causes (prevention) of the NCD</b> (hypertension or diabetes) and beginning to work together. The workshop is split into two groups. Each group can use any art form they want to explore the causes and create something to share back.</p>	
	One facilitator will sit with each group to probe for more detail and help them develop their ideas	
Part B (optional)	Sharing Responses Back to the Group. (This was not included in pilot TABPA workshops due to time)	<b>Removed from Refined TABPA</b>
<b>Activity 4</b>	<b>Solutions to NCD Causes and Performance</b>	<b>Performance</b>
Duration	45 mins	40 mins
Part A	This activity will ask participants to develop their ideas/artwork from Activity 3 and with <b>focus on the solutions</b> to the causes/prevention of the NCD	Performance of the art form to the whole workshop only
Part B	Performance of the art form to the whole workshop	
<b>Activity 5</b>	<b>Discussion and Reflections</b>	
Duration	15 mins	10 mins

### 3.7 Dataset

In this section and in Table 3, I provide a summary of the data collected for each Phase and Method used in this research.

**Phase 1 Walkalongs:** Walkalong data from Malawi and Scotland were audio-recorded on an encrypted mobile phone and uploaded to a secure Microsoft OneDrive server. After each walk, observations were noted in an observation proforma and detailed fieldnotes were written. In Malawi, observations were also discussed and agreed with the Malawian practitioner, Miguel, post-interview. A trusted friend and I transcribed the audio-recordings to Microsoft Word. I ensured that my friend signed a document agreeing to uphold the confidentiality of the data. As previously mentioned, interviews in Malawi were live translated from Chichewa to English during the walks, thus while the audio contains both Chichewa and English, only the English translations were transcribed. In Chapter 4, I present extracts depicting Miguel's description of participant responses in English.

**Phase 1 Community Workshops:** In Scotland and Malawi, community arts-based participatory workshops were audio-recorded on an encrypted mobile phone. Paper copies of visual outputs (e.g. drawings and handwritten responses to the visualisation activity) were collected, digitised and uploaded to OneDrive. Photographs and videos of the process and performances were taken using a mobile phone. Finally, observations and post-workshop reflections were discussed with co-facilitators and detailed on an observation proforma. For Scottish data, I transcribed all audio and video-audio to Microsoft Word documents, which were collated to form complete workshop transcripts with photographs of the creative outputs and links to videos. In Malawi, as all data was collected in Chichewa, Luke translated and transcribed the audio and video-audio from each workshop. I then collated the translations into complete workshop transcripts including visual data as above.

**Phase 1 Stakeholder Workshops:** In Malawi, all data from the stakeholder workshop was collected and transcribed in the same way as Phase 1 Community Workshops above. However, due to time-constraints, the Malawian stakeholder workshop transcription was restricted to the main discussions. Furthermore, as a

result of the translation process, some of the individual participant I.D numbers are missing from some of the Malawian Phase 1 workshop transcripts. As the stakeholder workshop in Scotland took place online, the workshop was audio-video recorded on Zoom and downloaded and saved to the secure server. I then downloaded and edited the Zoom transcript while listening to the audio and took screenshots of relevant interactive whiteboard activities and embedded these into the transcript.

Phase 2 and 3 TABPA Arts-Based Participatory Workshops: Data for the TABPA workshops in Phases 2 and 3 were collected in the same way as Phase 1 community workshops. Audio was recorded, photographs and videos were taken on two encrypted mobile phones, and fieldnotes were co-written with co-facilitators following the workshop. In Malawi, both workshops were transcribed and translated by Rhoda. I forgot to remind Rhoda ahead of transcription to provide individual participant IDs for the group work. Therefore, some participant I.D.s were not included in the Phase 3 TABPA transcripts. In Scotland, I transcribed the women's workshop, however, the men's workshop audio was outsourced to an approved provider to alleviate time pressures. Again, I collated all visual data to form complete transcripts.

**Table 3: Summary of data collected organised by each phase, research method and the chapter it is presented in.**

<b>Data Collected</b>	<b>Chapter(s) Data are Presented In</b>
<b>Phase 1</b>	<b>Chapters 4-6</b>
<b><i>Walkalongs (N=9 in Malawi, N=10 in Scotland)</i></b>	Chapter 4: Walkalongs in Malawi Chapter 5: Walkalongs in Scotland
Audio recording/transcripts	
Walkalong observation proforma/fieldnotes	
<b><i>Community Arts-Based Participatory Workshops (N=2 in Malawi, N=1 in Scotland)</i></b>	Chapter 6: TABPA Development in Two Contexts
Audio Recording/Transcripts	
Photographs of Process and Creative Outputs (e.g. visualisations and drawings)	
Videos of Performances (not included in thesis)	
Fieldnotes/Researcher Reflections Proforma	
<b><i>Stakeholder Arts-Based Participatory Workshops (N=1 Malawi)</i></b>	
Audio recording/transcripts	
Fieldnotes/Researcher Reflections Proforma	
Photographs of Creative Outputs (e.g. drawings and flip charts)	
<b><i>Stakeholder Online Participatory Workshops (N=1 Scotland)</i></b>	
Audio-video recording/transcripts	
Fieldnotes/Researcher Reflections Proforma	
<b>Phase 2 and Phase 3</b>	<b>Chapters 7-8</b>
<b>Phase 2</b>	Chapter 7: TABPA Method as Findings Chapter 8: Culturally-Situated Findings of NCD Risk Factors
<b><i>TABPA Arts-Based Participatory Workshops (N=2 Scotland)</i></b>	
Audio Recording/Transcripts	
Fieldnotes/Researcher Reflections Proforma	
Photographs of Process and Creative Outputs (e.g. visualisations and drawings)	
Videos of Performances (not included in thesis)	
<b>Phase 3</b>	
<b><i>TABPA Arts-Based Participatory Workshops (N=2 Malawi)</i></b>	
Audio Recording/Transcripts	
Fieldnotes/Researcher Reflections Proforma	
Photographs of Process and Creative Outputs (e.g. visualisations and drawings)	
Videos of Performances (not included in thesis)	
Rhoda's Reflections on Analysis	

### **3.8 Reflexive Thematic Analysis**

The data from each Phase were analysed using a reflexive thematic approach (Braun, Clarke et al. 2018). Reflexive thematic analysis was developed by Braun

and Clarke as an approach that not just recognises, but embraces, analysis as a subjective and interpretative process (Braun and Clarke 2006, Braun and Clarke 2021, Braun and Clarke 2023). It is a distinctly qualitative approach that centres the researcher's reflexivity and their active role in the construction of codes and, then later, themes as patterns of shared meaning within the data. The values embedded in reflexive thematic analysis sit counter to more positivist-aligned analytic approaches, such as coding-reliability which prioritise the generalisation of findings, seeking accuracy and the absence of bias in coding (Braun and Clarke 2021)

The values and principles of reflexive thematic analysis appeared highly compatible with my own epistemology, the epistemologies of arts-based participatory research and the principles of my transcultural community-based participatory model (Sections 3.1.1, 3.2 and Chapter 2.4.5). Throughout this research I have sought to recognise and reflect on my own positionality and my role in the co-creation of knowledge, acknowledging that the development of the methods used and the analysis of the findings are inherently shaped by my own experiences, knowledge and biases, as well as those of participants and project partners. Reflexivity is one of the key pillars of my transcultural approach and necessary to celebrate the diverse sociocultural perspectives that have shaped this research; therefore, it seemed only appropriate that I embedded this into my analysis.

Braun and Clarke (2006) suggest six phases of reflexive thematic analysis: i) familiarisation, ii) coding, iii) generating initial themes, iv) reviewing and developing themes, v) refining defining and naming themes, and vi) writing the report. However, these phases are not linear, rather the researcher will move iteratively between different phases as they become more familiar with the data and work to generate meaning. In the following sections I describe the process of analysis I followed for each of the methods used in this research seeking to highlight how and why I made analytic decisions. As described by Braun and Clarke (2023), there are any number of ways to 'do reflexive thematic analysis' and setting strict rules is generally counter to the philosophy of the approach. Thus, my approach to analysis would often change slightly for each method, and many of my workings are inherently messy as I worked to make sense of and rework my codes and themes.

### 3.8.1 Walkalongs

Firstly, it is important to note that I conducted analysis independently for walkalongs in Malawi and in Scotland. This was both a pragmatic and analytical choice. I was due to submit a piece of writing for my annual review and due to recruitment delays in Scotland, I had made more progress with my analysis of the Malawian dataset. I, therefore, chose to prioritise my analysis of the Malawi walkalongs, intending to integrate the Scottish walkalong analysis at a later date. However, while I did cross-check my coding and thematic development with my Malawian analysis when conducting my Scottish analysis, when I came to integrate my interpretations of both settings as one Chapter or 'written report', I struggled to pick apart the 'story' I had crafted for each setting. I therefore decided to produce separate, yet parallel, findings chapters for each walkalong in Scotland and Malawi. This analytical choice was linked to my positionality. The process of analysing and writing about each dataset had built my familiarity with each context, helping me to tell the story of each community, and was a useful exercise that supported me to navigate the similarities and differences in methodological development in each context in later phases. I was cautious that trying to reintegrate the data would lose some of the nuances that I had grown to understand, and if not done well, could accidentally create a narrative that oversimplified the heterogeneity between and within each community. Thus, the sections below describe the independent processes of analysis for Scotland and Malawi.

I began my analysis of each set of walkalong interviews by familiarising myself with the data. I had started this process when I transcribed the English translations of the Malawian walkalong interviews, and four of the Scottish walkalongs. I also reviewed the Scottish walkalong transcriptions that were done by a third party, listening to and transcribing extracts that they had struggled to interpret (e.g. due to poor audio quality). I then printed off each interview transcript and the corresponding fieldnotes, and began to read and reread the data, making handwritten notes of initial comments, questions and possible meanings.

Following my initial familiarisation process, I started reading through the transcripts and fieldnotes, guided by the research objectives. This meant

reading through each interview multiple times thinking about and coding for anything related to community, local arts and health. I then reread each interview and accompanying fieldnotes in parallel, thinking about and coding for walkalongs as a method, what had worked well and what were the challenges. Following my initial coding on the physical copies of transcripts, I then transferred the data into NVivo 14 and started to develop subcodes under the general headings of 1) Community, 2) Local Art Forms and Practices, 3) Health and Noncommunicable Diseases, and 4) Walking as a Method.

Next, I extracted each secondary code to Microsoft Word where I summarised the extracts within each code. Through this process, I continued to familiarise myself with the data and started to develop and name themes, breaking down and rebuilding or combining codes to reflect on what was needed to tell the story of each context. For example, when exploring what community meant to participants in Malawi, the codes '*social structures*', '*community activities and development*' and '*challenges in the community*' were broken down and reconstructed into the overarching theme of '*Community as one family*'. Similarly, in Scotland, the codes '*community support*', '*friends, family and social life*' and '*religion*' were integrated into one overarching theme '*Multiple definitions of community*' that allowed for the complexity and diversity of community experiences in Glasgow.

The process of constructing and refining themes continued through the writing up process where I gained initial feedback from my supervisors and set my interpretation of the data in the context of the wider literature. I found this was an important step to make sense of my understanding of each context, identify the gaps in my knowledge and build my findings into a richer interpretation of each setting. However, this could also make it challenging to know when to stop writing and when to reorientate myself back to the focus of the research. Therefore, I returned to my walkalong findings once I had analysed and written a first draft of the findings from all phases of the research, recognising that what I interpreted as important would change and evolve as I learned more about each setting and got to know each participant and their experiences. For example, when initially writing my Scotland Walkalong Chapter, it was unclear whether '*Migration and Mobility*' was relevant enough to the research aims to be a standalone theme or should be collapsed into '*Multiple definitions of*

Community'. However, as the research evolved it became clear through later methods and the literature that experiences of migration were entangled with participants' autonomy to engage in health behaviours and that the initial theme should be centred as important context (See Chapter 8.3.5).

In Table 4, I present the final themes as reported in this thesis. The five primary themes related to the original four codes as means to orientate the findings towards the research objectives: 1) Walking as Method; 2) Everyday Life (Malawi); 3) Everyday Life (Scotland); 4) Local Arts and Participation; 5) Community Health and Noncommunicable Diseases. However, these are broken down further into sub-themes to provide a richer interpretation of the meaning.

Finally, the data within each theme also evolved following feedback from my community partners. For example, the data within the theme 'Prevention, Education and Health Seeking Behaviours' suggested that many Scottish participants found access to health care relatively straightforward in the UK. However, this was counter to my understanding and Community organisation 1's experiences that many Black and minoritised ethnic communities face several intersecting barriers to health care. We agreed it was important that I wrote this nuance into my analysis while not disregarding the experiences of participants (see Chapter 5.5.2.5).

Table 4: Summary of primary, secondary and tertiary themes for Walkalong Interviews in Scotland and Malawi

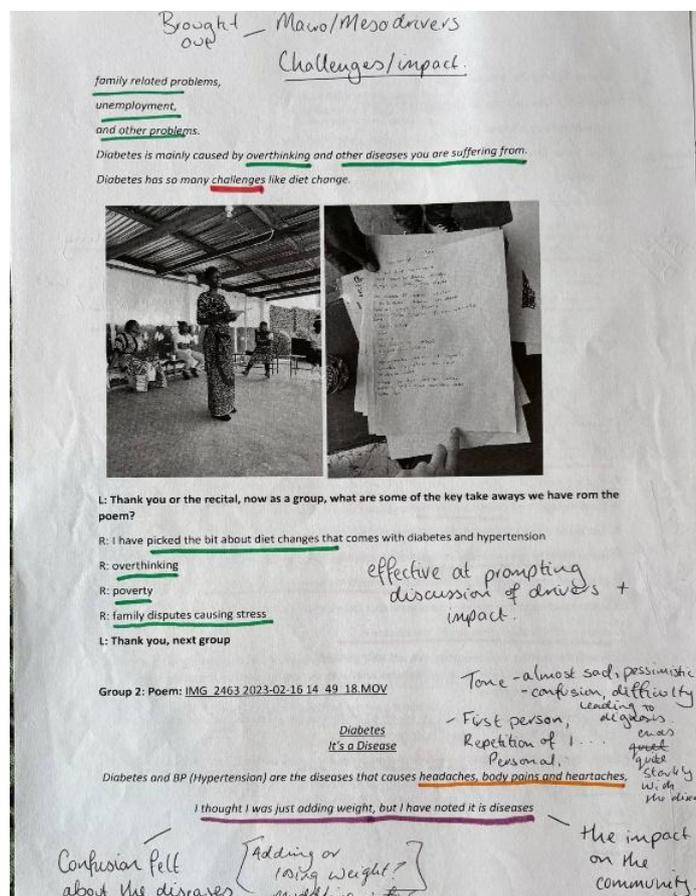
Primary Theme	Secondary Themes	Tertiary Themes
Walking as Method		
Everyday Life: Malawi	Households and Mobility	
	A 'Peaceful' Residential Area	
	Community as 'one family'	
	The Marketplace: Food Security and Economic Opportunity	
	Social Life, Celebrations and Religion	
Everyday Life: Scotland	Mobility and Migration	
	Multiple Definitions of Community	
Local Arts and Participation		
Community Health and Noncommunicable Diseases	Community Health Concerns	
	Community Knowledge and Perspectives on Diabetes and Hypertension	NCDs, Diet and Local Food Preferences (Malawi)
		Stress, Overthinking and Comorbidities (Malawi)
		Symptoms and the Impact on Productivity (Malawi and Scotland)
		Prevention, Education and Health Seeking Behaviours (Malawi and Scotland)
		Migration, Culture and Food (Scotland)
		Facilitators of and Barriers to Physical Activity (Scotland)
	Additional Drivers of Hypertension (Scotland)	
Arts and Health		

### 3.8.2 Community and Stakeholder Workshops

Unlike for the walkalong interviews, I decided to integrate the analysis for Phase 1 (Community and Stakeholder) workshops in Malawi and Scotland. To develop a methodological framework that could be applied and adapted to different cultural and geographic settings, I wanted to ensure that my analysis captured

the integrated perspectives of both communities to reveal the overarching transcultural strengths and challenges of the methodology, in addition to more culturally-situated insights.

As with the walkalongs, I began my analysis of the Phase 1 Community and Stakeholder Workshops by familiarising myself with the data. This involved a combination of transcriptions, adding photographs and links to the videos into the transcripts and watching workshop videos. As all workshop data from Malawi was collected in Chichewa, and Luke conducted the transcription, I found the process of integrating the visual outputs into the transcript and rereading fieldnotes in parallel, particularly important to contextualise my memories of the workshops and build my understanding (see Figure 3-3 for an example).



**Figure 3-3** Image of physical annotation of Phase 1 Malawi Women's Community Workshop Transcript

I printed each transcript and the accompanying proforma. I then read the printed copies of all Community Workshops (Malawi and Scotland) data, colour coding similar ideas, making initial notes and comments on interesting points (Figure 3-3). I then read and reread the data, familiarising myself with community perspectives on diabetes and hypertension and reflecting on the

methodological process. Next, I repeated these steps for the Stakeholder workshops from both Malawi and Scotland focusing on methodological development only.

After making initial notes on paper, I uploaded each transcript and accompanying observation proforma to NVivo 14 where I continued to generate and refine codes. I read through the Community Workshop data, creating inductive codes related to health (e.g. Drivers of NCDs) and the methodology I had used (e.g. Workshop Strengths and Challenges). I then read through each stakeholder transcript and coded for anything that could inform methodological development. Through an iterative process, I reflected on, merged and removed codes resulting in eight primary codes that characterised data from both community and stakeholder workshops in both contexts: i) Art forms, ii) Participant Autonomy and Active Participation, iii) Workshop Atmosphere, iv) Workshop Structure, v) Workshop Facilitation, vi) Perspectives on Diabetes and Hypertension, vii) General Workshop Strengths and viii) General Workshop Challenges.

Due to the methodological focus of this research, the content of the eight codes was then re-examined and mapped according to the research objectives to inform the methodological development of the TABPA. To address the first objective: *develop a practical understanding of what art forms are compatible with community interests and adaptable to explorations of NCDs*, I used my initial analysis to explore how community members used different art forms (e.g. drama, drawing etc.) to share perspectives on diabetes and hypertension. To do this, I examined the overlap between the subcodes of 'Art Forms' and the subcodes of 'Perspectives on Diabetes and Hypertension' and visually mapped out the connections between each. I then continued the mapping process to explore how 'Art Forms' linked to the strengths and challenges of the community workshops and to: *develop an understanding of community responses to arts-based workshops in practice to inform the structure of the Phase 2 and Phase 3 TABPA workshops* (Objective 2). The mapping process is shown in Figure 3-4.

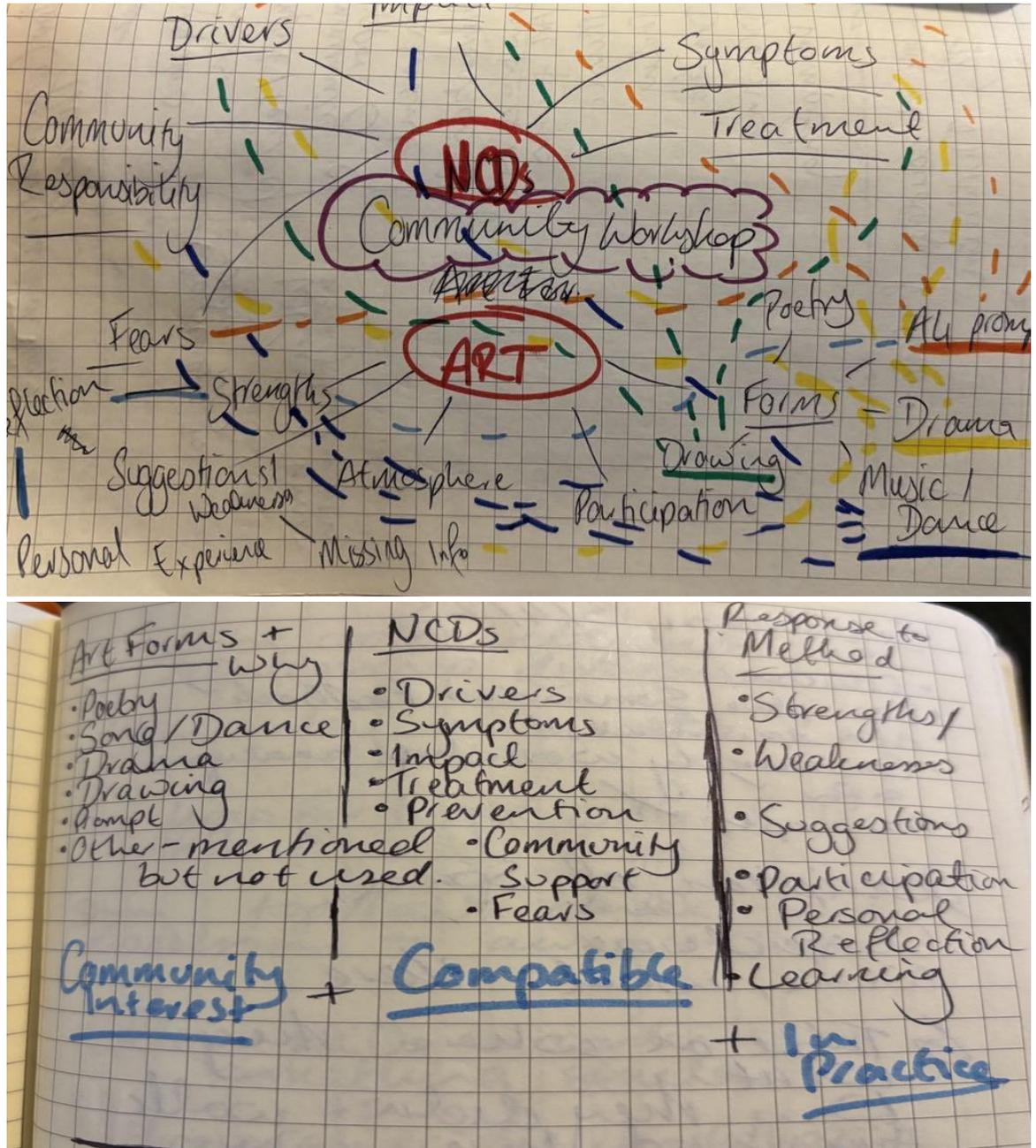


Figure 3-4 Photographs of mapping process during RTA of Phase 1 Community and Stakeholder Workshops

Finally, to construct my themes, I mapped out each of the codes again to identify meaning, reflecting on what I thought were most important learning points from Phase 1 workshops that I would use to inform the development of the pilot TABPA workshop in Phases 2 and 3 (see Figure 3-5).



**Figure 3-5 Photograph of thematic analysis mapping process for the Phase 1 methodological development: whiteboard showing codes being generated into relevant themes.**

As with the walkalongs, the generation of themes continued beyond this initial mapping into the writing process where I set the data in context within the wider literature to tell the story of the workshops, explore why certain art forms may have been more or less culturally appropriate for each setting, reflect on why some elements of the workshops may have worked or not worked and consider what I should do differently in future. I also embedded examples of creative outputs not just to show the methodological implications, but also as a way to centre community perspectives on diabetes and hypertension. I was conscious that participants had shared generous narratives on their experiences of health and illness, and I wanted to ensure that these were not sidelined in pursuit of my own methodological aims.

When producing the written report of my findings in Chapter 6, I sought to include data extracts from each setting (Malawi or Scotland), method (Community or Stakeholder Workshop) and gender (Men or Women's Workshop). When describing a narrative or perspective from one setting or method, I would often return to my earlier coding in the other setting to cross-compare, looking for similarities, differences or contradictions in the data. In some cases, this meant going back to the original transcripts or fieldnotes. This iterative process allowed for a richer interpretation of both contexts, drawing out deeper

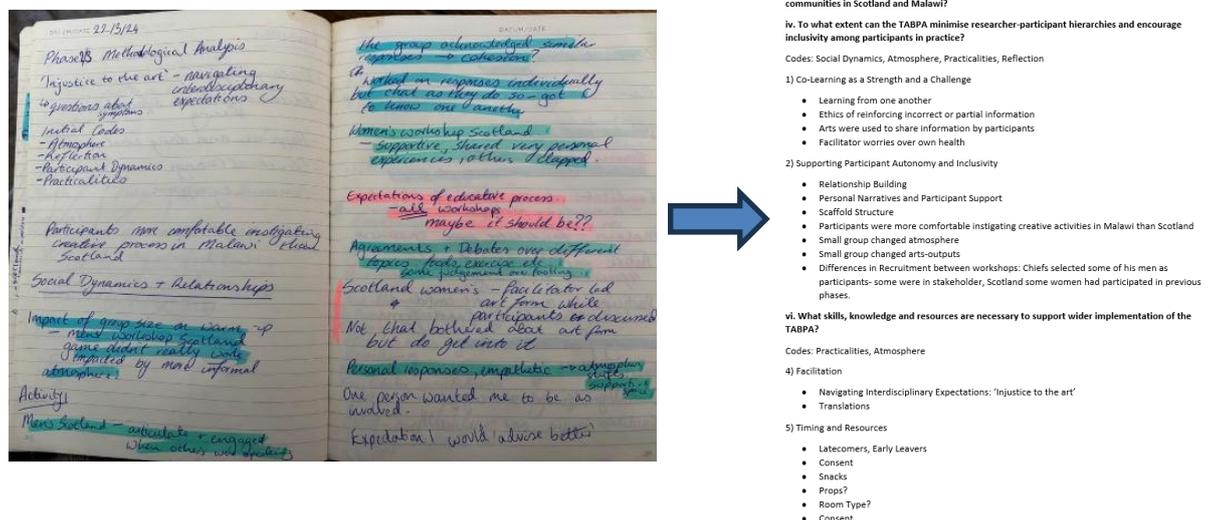
meanings. For example, the popularity of music and dance in Malawi led me to question why it had been a less successful method in Scotland and unpack the wider socio-cultural factors that could influence engagement with the art form. Similarly, when refining the theme '*Framing Content and Navigating Stigma*', insights from the stakeholder workshop influenced me to return to the community workshop data to reassess whether there had been any instances of stigma that I had missed.

The final themes presented in Chapter 6 were: 1) Art forms and Facilitators and Barriers to Participation; 2) Relationship Building, Co-learning, and Challenging Power Hierarchies; 3) Facilitation, Framing Content and Navigating Stigma; 4) Workshop Accessibility; and 5) Time-Management and Consent. I shared my written interpretations in Chapter 6 with Luke (Malawi), Christiana and Community Organisation 1 (Scotland) to ensure that I had not generated findings that misrepresented either the cultural context or the process of data collection, nor missed anything that they thought was important. However, each advised that they had nothing to add and that I had captured their experiences well.

### **3.8.3 Phase 2 and 3 TABPA workshops**

I began reflexive thematic analysis of Phase 2 and 3 workshops by familiarising myself with the data. I completed each step in parallel for data from Scotland (Phase 2) and Malawi (Phase 3). I printed out and read through each transcript and accompanying observation proforma several times. As I was doing this, I reviewed the creative outputs (images and videos) to contextualise the written data. This was particularly key for the Malawian workshops, where I went back and forth between each type of data building my understanding of the events and nuances of the workshops that were often hidden due to language barriers. For example, when participants presented their visualisations in the Phase 3 workshops, I would be able to interpret the images, and Rhoda or Trust would briefly summarise what the participant had said. However, it was only by reviewing the English transcript and looking again at the image that I could comprehend the depth of the participant's perspective.

Once I had made my preliminary notes on the physical transcripts and observation proformas, I uploaded each to NVivo 14 and started to generate initial codes. I began by rereading the data with focus on the TABPA workshops as a method, reflecting on any data that provided insight into practical or relational components of the TABPA workshops that could inform the development of the TABPA framework. Four initial codes were identified: i) Workshop Atmosphere, ii) Workshop Practicalities, iii) Reflections and iv) Social Dynamics and Relationships. I then produced handwritten summaries of each code and used colour coding to map each summary data point back to the research questions. I used this as a starting point to generate themes in Microsoft Word (See Figure 3-6).



**Figure 3-6 Generation of Methodological Themes from Phase 2 and 3 TABPA workshops**

As with the previous methods, my reflexive thematic analysis continued beyond the construction of themes into the writing up process, where insight continued to be developed as themes were tested against the research questions ((Braun, Clarke et al. 2018). As I wrote, read the literature and received feedback from my supervisors, I constructed four primary themes: 1) Fostering a Safe and Supportive Environment; 2) Co-producing knowledge; 3) Practical Considerations and 4) Ethical Considerations.

Similarly to the Phase 1 workshops, I reviewed and modified the content of each theme as I wrote, using the findings from one setting to inform the other. This meant drawing out similarities, parallels and contradictions between data from Scotland and Malawi, returning to earlier coding and transcripts looking for data I may have missed, and embedding my own reflections on the motivations and decision-making that may have led to different interactions and outcomes. Once I had an initial draft, I recognised I had failed to account for the differences between the pilot and refined TABPA workshops, thus, I also re-reviewed my analysis exploring and reflecting on how the changes to the TABPA workshop protocol could have influenced the findings.

In parallel to the methodological analysis, I conducted reflexive thematic analysis of the health-related findings. I read and reread the datasets on paper guided by RQ 4. I then uploaded the transcript to NVivo 14 and generated codes that focussed on community perspectives on the risk factors of diabetes and hypertension in both settings (RQ 4). I generated 15 initial codes across both Malawian and Scottish datasets and summarised these codes separately for each setting in Microsoft Word to ensure that the nuance of each context was not lost in my analysis. I then re-examined my analysis to focus on the causes/drivers and prevention of each disease and used a mapping process to integrate my analysis of each context into themes. Six themes were generated: 1) Diet, food and cultural identities; 2) Social Prestige; 3) Physical Activity; 4) Financial and Family Stress; 5) Migration, Discrimination and a Hostile System; and 6) Individual Mindset and 'Ignoring' Advice.

I initially wrote the report and presented the themes as a general overview of the health-related findings of the TABPA method, however, upon discussion with my supervisors we agreed that it would be more meaningful to present the themes in a way that showed how the method had drawn them out. I then restructured my analysis to tell the story of how the TABPA workshops contributed to this understanding. Finally, Rhoda and Christiana provided comments and feedback on my written analysis. Rhoda and my supervisor (CB) highlighted mistranslations where I needed to readjust my analysis. For example, one extract suggested people in Malawi, "*cannot afford to not eat white flour...*" suggesting a financial barrier to healthy foods, however upon discussion with CB and Rhoda, it was revealed that this was about taste preferences rather

than financial cost, as the alternatives to white flour are actually relatively affordable (see Chapter 8.3.1). Rhoda also provided culturally-situated interpretations of the Malawian data. With Rhoda's permission some of these interpretations have been directly included as data within the thesis

### 3.8.4 Developing the TABPA Framework

The final TABPA framework was directly informed by methodological themes from Phase 1 Community and Stakeholder Workshops and the methodological themes from Phase 2 and 3. These are summarised in Table 5.

**Table 5: Themes that directly contributed to the development of the TABPA framework**

Phase 1 Methodological Themes	Phase 2 and 3 Methodological Themes
1) Art forms and Facilitators and Barriers to Participation	1) Fostering a Safe and Supportive Environment
2) Relationship Building, Co-learning, and Challenging Power Hierarchies	2) Co-producing knowledge
3) Facilitation, Framing Content and Navigating Stigma	3) Practical Considerations
4) Workshop Accessibility	4) Ethical Considerations
5) Time-Management and Consent	

### 3.9 Ethical Considerations

The research was reviewed and approved by the University of Glasgow College of Social Sciences Ethics Committee (Phase 1: 400210264; Phases 2/3:400220285), Malawi's College of Medicine Research & Ethics Committee (COMREC) and Malawi's National Committee for research in the Social Sciences and Humanities Research (NCRSH) (Phase 1 P.11/19/2865, COMREC; Phase 3 P.06/23/770) (see Appendix 2: Ethics Approvals). The research brought many complex ethical issues to the foreground, which will be discussed in detail throughout this thesis. However, some of the key issues are touched on below. It is important to state here, that while there were some practical challenges gaining informed consent in workshops (see Sections 3.8.1 and 3.8.2 and Chapter 6.3.4 and Chapter 7.4), it was my first priority that everyone understood what was involved in their participation and provided informed consent, often choosing to sacrifice time rather than continue without participant understanding. Finally, during arts-based workshop activities, participants were video-recorded, and photographs

were taken. Participants were asked to provide specific informed consent for the use of their personal images in data analysis and research outputs (e.g. conference presentations).

### **3.9.1 Malawi: Informed Consent and Cultural Sensitivity**

Informed consent is primarily understood in Western conceptualisations as something that prioritises individual autonomy, however, this can be more complex in collectivist cultures like those in Malawi, where decision-making is often centred around the needs of the wider community (Abdulla 2021, Appiah 2021, Appiah, Raviola et al. 2024)). Recent scholars have highlighted the importance of adopting a tiered process of consent, first seeking consent from community gatekeepers and then seeking individual consent from participants themselves (Appiah 2021, Appiah, Raviola et al. 2024). Therefore, following the work of Abdulla (2021) and the guidance of my colleagues at MEIRU, it was fundamental to recognise the cultural authority of the Town Chiefs in Sector A and seek their consent before I sought it from individual participants (Section 3.4.1.2). As noted above, I met with the Chiefs to inform them of the project three times over the course of the research, once before the walkalong interviews, again following an election before Phase 1 workshops and once more when I returned for Phase 3. In each case, Miguel (Phase 1 Walkalongs), Luke (Phase 1 Workshops) and Rhoda (Phase 3) verbally communicated the study to the Chiefs in Chichewa to ensure they were fully informed, while I was available to answer any questions they might have. After each of these occasions, the Chiefs informed the community that we were visiting and helped us to recruit participants for both Phase 1 and Phase 3 workshops.

When seeking consent from individual participants, I also took several steps to ensure they were fully informed. All participant information sheets (see Appendix 3 for examples), consent forms, media consent forms and privacy notices were provided to participants in Chichewa, the local language, and each received copies of each form to keep. I had each form translated from English by a project partner and then checked by another Malawian colleague. Phase 1 forms were translated from English to Chichewa by Miguel and reviewed by Luke, while Phase 3 forms were translated by Luke and reviewed by Rhoda and a colleague at MEIRU.

The processes of gaining informed consent are described for each method below.

- **Phase 1 Walkalongs:** As described above, the Chiefs had informed the community that we would be conducting research in Sector A; therefore, Miguel and I went for a walk around Sector A and invited individuals moving through the community if they would like to participate in a walkalong interview. If people said yes, Miguel would verbally communicate the information to them, and provide them with a participant information sheet, and a privacy notice and consent form to sign.
- **Phase 1 Community and Stakeholder Workshops:** In the Phase 1 Women's Community Workshop, I provided participants with Chichewa copies of the participant information sheets, media consent, privacy notices and consent forms as they arrived at the workshop, so that they could read through the information and complete the consent forms while they waited for others to arrive. Luke went round the group and supported participants in Chichewa while I welcomed arriving participants. While participants were generally comfortable reading through the information, Luke and I realised that we were answering the same questions repeatedly and the process would have been much smoother had we verbally communicated the information to the group once everyone had arrived. The amount of paperwork also meant that my attention was divided as I tried to keep everyone's forms organised. These were important learning points and something that I should have better prepared for ahead of the workshops. While we could not change the forms ahead of the Men's Community Workshop as it was held the same day, in addition to providing the written documents, we decided to verbally communicate all of the information to the group at one time resulting in a much smoother consent process than in the Women's Community Workshop. We repeated this learning in the Stakeholder Workshop.
- **Phase 3 TABPA Workshops:** Having learned from Phase 1, we reduced the amount of paperwork in Phase 3 by combining the consent form with the media consent form, and information sheets were read out to each

group. In the Men's TABPA workshop, Rhoda had instinctively started verbally communicating the information before I had provided participants with the written information sheet, privacy notice and consent form. This caused some delay, as I was unsure if any of the information had been missed, and Rhoda repeated the information once participants had the documents to read along with. During the Men's TABPA Workshop, Rhoda verbally communicated the information sheet and accompanying documents while participants read along.

Finally, it was important that I adhered to cultural norms, making sure to dress modestly and wear an ankle-length skirt like other women in the area, and partaking in Malawian greetings where I could. Facilitators also advised that we should adhere to prevailing cultural practices for group meetings, thus each workshop would begin and end with a prayer led by participants. The protocols and research findings were reviewed with facilitators to ensure that neither cultural context was misrepresented.

### **3.9.2 Scotland: Informed Consent and Cultural Sensitivity**

While the role of community gatekeepers may be less formal in Scotland compared to Malawi, it was still important to have the support of local community organisations before recruiting participants. Unlike Malawi, my first contact with participants in Scotland was typically via email or WhatsApp. My project partners would share the advertisement flyer within their networks and with interested individuals' consent, would pass their contact details on to me (see Sections 3.4.2.4). This meant that I was able to provide information sheets in advance of each walkalong or workshop and could answer any initial questions over the phone. Finally, Community organisation 1 in Scotland were directly involved in reviewing the protocol and research findings to ensure that the cultural context was not misrepresented.

I describe the process of informed consent for each method below:

- **Walkalongs:** I asked the participant if they had had a chance to read the information sheet and verbally summarised the key points at the beginning of each walkalong. I then asked if the participant had any

questions before participating and provided them with a consent form to complete.

- ***Phase 1 Stakeholder Workshops:*** As the Phase 1 Scottish Stakeholder workshop took place online, participants were emailed all documents in advance including consent forms to sign and return via email. I also recorded verbal consent using Zoom before the start of the workshop. Each participant in turn confirmed they had read the information sheet and were happy to participate.
- ***Phase 1 Community and Phase 2 TABPA Workshops:*** As in Malawi, we had planned to run through the participant information sheet verbally at the beginning of each workshop. However, participants in both the Phase 1 Community Workshop and Phase 2 Women's TABPA Workshop arrived late. To address this in Phase 1, Christiana and I decided to provide one-to-one support as participants arrived, as too many people would miss the verbal summary. In the Phase 2 TABPA workshops, we allocated more time for latecomers and invited a third facilitator, Anna, to the Women's Workshop to support the consent process so that we could do the verbal group explanation. However, participants still required one-to-one support-this is described further in Chapter 6.3.4. In the Men's TABPA workshop, the research was explained verbally and on written information sheets to the group. As there were fewer participants in this workshop (N=3), the process was more straightforward.

### **3.9.3 Ethical Considerations in Walkalong Interviews**

Phase 1 Walkalong Interviews brought specific questions about ethics, including confidentiality and anonymity. Firstly, the walks were adapted to the abilities of each walkalong participant - all were informed that they could chose the location and duration of the walk and that we could stop at any time if they felt uncomfortable. Participants were also informed that confidentiality could not be guaranteed as walkalongs would take place in public spaces and they might be seen by others (Appendix 3A). The interviews were audio recorded using a mobile-phone, as a physical microphone or audio-recorder could draw attention to someone being interviewed. I was advised by my supervisor (CB) that this was

the best approach to use in the Malawian context and made the decision to also use this approach in the Scottish context. Finally, in cases where interviews were interrupted by non-participants (e.g. to say hello to their friend) or where interviews were conducted in close proximity to others (e.g. travelling by bus) and I was concerned that I would record other people's conversations, I would turn off the audio-recording and would not transcribe any parts of the conversation captured. I provide examples of these challenges in Chapters 4.2 (Malawi) and 5.2 (Scotland).

### **3.9.4 Navigating Sensitive Topics**

The research covered the topic of non-communicable diseases, specifically hypertension and diabetes, from a community perspective. However, we did not ask participants to disclose any personal medical information, nor did they have to have either health condition to take part. This was emphasised to community members both verbally as part of the protocol (see Appendix 1) and on the participant information sheet (Appendix 3B) and it was made clear that it was their decision if they wished to disclose any personal information. I also provided participants with resources on diabetes and hypertension risk from Diabetes UK, Blood Pressure UK, MEIRU and the World Health Organization.

Furthermore, while the research did not ask about immigration status, some community members in Scotland chose to disclose their status as asylum seekers. Where community members did share personal or sensitive narratives, the facilitators and I sought to promote a safe, supportive, and empathetic environment cautious not to probe in a way that could reinforce harms (see Chapters 5.3, 5.5 and 8.3). It was emphasised that participants could speak to the facilitators privately at any time if they felt uncomfortable or withdraw from the study without providing a reason.

### **3.10 Limitations**

This research has several limitations that may have impacted the findings. Firstly, there were substantial challenges in recruiting men in Scotland. There are well-documented gender disparities in health behaviour research (Ryan, Lopian et al. 2019), however, this gender ratio could be influenced by the fact

that snowball sampling was mainly facilitated by networks of women's groups (including Community Organisation 1).

Secondly, there were several challenges with translation and transcription. In Malawi, walkalong interviews were conducted in Chichewa and live translated into English. Due to funding constraints, only the English translations were transcribed, therefore the findings are undoubtedly shaped by substantially by the facilitator's (Miguel) own interpretations, and it is possible that there are some mistranslations in the analysis that are unknown. Regrettably, Chapter 4 was also not reviewed by Miguel due to resource and time constraints.

Similarly, Phase 1 and Phase 3 Malawian transcripts were translated and transcribed by different people and were not cross-checked. Again, this was due to funding constraints. However, having the lead facilitators conduct the translations and review the written findings, enabled them to capture contextual nuances that emerged during data collection. Furthermore, due to time-constraints following Phase 1, Luke was asked to prioritise the Malawi Phase 1 Community workshops and only transcribe and translate the key points from the Malawi Stakeholder Workshop in note form. This meant that I had fewer data extracts from the Malawi Stakeholder Workshops to draw upon when writing Chapter 6 compared to Scotland, where I had the full transcript. Chapter 6 therefore presents more extracts from the Scotland Stakeholder Workshop than the workshop in Malawi. Nonetheless, the findings were informed by workshops in both contexts. Finally, I failed to communicate the need for individual participant IDs to facilitators in Malawi. Therefore, some extracts are missing individual identifiers and may unknowingly be biased towards certain participants' views.

## **4 Walkalongs in Malawi: Community, Arts and Health**

### **4.1 Introduction**

To develop the transcultural arts-based participatory approach with communities in Scotland and Malawi, it was fundamental to firstly, define what ‘community’ meant in each setting and secondly, gain an understanding of the diverse contexts that might shape community engagement with the approach. As an outsider in both settings, I used walkalong interviews to gain an in-depth understanding of each community, including relevant forms and processes of everyday life, as well as initial perspectives and experiences of local arts, health, and noncommunicable diseases. I also sought to use this opportunity to build relationships with community members to develop an authentic and equitable participatory approach in practice. Through these processes of community familiarisation, I sought to answer RQ1: how do the perspectives and experiences of community members and stakeholders inform the development of and implementation of the TABPA methodology?

In this chapter I will present the findings of Phase 1 walkalong interviews with community members in Sector A, Lilongwe, Malawi (N=8) before exploring the findings from the Scottish setting in Chapter 5. I will begin this chapter by reflecting on walking as a method, including the strengths and challenges of the approach. I will then go on to consider the defining features of community, and explore everyday life as described by community members themselves and set in context using my own observations and relevant literature. In the next section I will examine community participation in local art forms with a focus on the facilitators and barriers. I will then explore the health contexts of each community, with attention to community experiences and perceptions of diabetes and hypertension. Lastly, I will provide a summary of the main findings of the chapter before reflecting on the implications for the development and implementation of the TABPA framework. It is important to specify here that Phase 1 methods, including the walkalongs, represent one component of the TABPA framework: a familiarisation process to develop an approach that is designed and can be adapted to reflect the contexts in which is applied. I will

discuss this further in Chapter 5.7.2 following my exploration of walkalongs in both the Malawian and Scottish settings.

Finally, as walkalong interviews in Malawi were live translated between English and Chichewa by Miguel (see Chapters 3.5.1 and 3.10), all quoted extracts in this chapter represent participant's perspectives as described by Miguel in English.

## **4.2 Walking in Malawi**

With the support of the local Chiefs, Miguel and I spent five days in Sector A conducting eight walkalong interviews with 11 members of the community. As detailed in Chapter 3.5.1, while all of the walkalong interviews explored community perspectives, half focused on health and noncommunicable diseases and half focused on local arts. The walkalong interviews were designed to give participants full control over the route (including the speed and duration of the walk) and participants could choose to incorporate the walks into their daily activities (e.g. visiting the market) if they wished. Community members were also invited to participate alone (N=5) or with a family member or friend (N=3).

The flexibility of the walkalongs meant that each interview was unique and involved varying degrees of time spent walking. Three interviews involved extended periods of walking, three interviews involved less than five minutes spent walking and two interviews involved no walking at all. In Table 6, I provide a summary of each of the walks showing the focus (NCDs or Arts), the participant(s), and a brief description of walking and interview conditions. In this section, I will reflect on walking as a method in the Malawian context and explore some of the reasons why interviews did or did not involve walking.

**Table 6: Malawi Walkalong Interviews: Summary of walks, participants and description of walking and interview conditions.**

<b>Walkalong Interview</b>	<b>Participant(s) (Pseudonym)</b>	<b>Brief description of walking and interview conditions</b>
<b>NCD 1</b>	Vaccar, Male	Entire interview was conducted while walking through Sector A.
<b>NCD 2</b>	Mpatso, Female	Met the participant walking home. Conducted majority of interview seated outside their home (<5 minutes walking)
<b>NCD 3</b>	Christa, Female	Interview started seated outside of their home but moved to their place of business at the Sector A market. (<5 minutes spent walking)
	Hanna, Female	
<b>NCD 4</b>	Alfred, Male	Walked to participant's home from Sector A market. Conducted remaining interview seated outside his home. (<5 minutes spent walking).
<b>Arts 1</b>	Wami, Male	Entire interview conducted while walking through Sector A to Area 25 market
	Shin, G, Male	
<b>Arts 2</b>	Grace, Female	Entire interview conducted while walking through Sector A
<b>Arts 3</b>	Monica, Female	Entire interview conducted seated outside their neighbour's home (no walking)
	Mary, Female	
<b>Arts 4</b>	Louis, Male	Entire interview conducted seated outside their home while they worked. (no walking)

One reason for the variation in time spent walking may have been due to the recruitment strategies used. To recruit participants in Sector A, Miguel and I walked around the neighbourhood and asked those walking or sitting nearby if they would be open to be interviewed and to go for a walk with us (see Chapter 3.4.1.4). This strategy meant that we often caught participants on their way to or from a pre-determined destination or those whose ability or motivation to walk were shaped by other activities within their day (e.g. work). For example, Mpatso was already on her way home when she agreed to be interviewed:

Mpatso is on her way home when we meet her. After Miguel explains the walkalong participant information, Mpatso says we can walk with her, it is not far, and then we can talk outside her home. We agree and begin the walk. We turn back towards the way we came...it feels as though we have only just started walking when we reach her home. We sit under a large tree to the right of her gate and continue the interview. [Fieldnotes\_Walk with Mpatso\_Female\_Malawi\_NCD Walk 2]

The spontaneous walkalong recruitment strategy was guided by researchers at MEIRU, who advised that booking interviews in advance could lead to high levels of cancellations/no-shows. This may be linked to how time is conceptualised in Malawi. In many African countries, time is understood through socio-cultural and cyclical meanings and structured in a slower, broader and more flexible way than linear Western conceptualisations (Mpofu 2016, Nnaji for 2016, Keough 2024). Therefore, communities' availability for a walkalong interview may have been shaped more by their present, rather than future, responsibilities (Ong 1982, Abdi 2009).

Some participants, especially young people (18-25 years), chose to provide us with an extended tour of their community. This appeared to be partly motivated by my status as a white woman, where participants like Vaccar wanted people in the community to observe our walk:

“[Vaccar] has chosen this way because there are a lot of people who would pay attention like- ‘what is happening’ - and on this road it has a lot of people who know him so it is also something great for him”  
[Miguel\_Walk with Vaccar\_Male\_Malawi\_NCD Walk 1]

While it could be claimed that this example highlights an element of performativity, it also presents a good reminder of my outsider status as a researcher where my whiteness served as a motivating factor for Vaccar's

participation. Returning to O'Neill's (2018) idea of a “*democratic imaginary*” (p.75), Vaccar's autonomy over the route provided an element of ‘play’ where he could also ‘show off’ and enhance his social status in the community by walking with a young white woman or *Mzungu* [white person or foreigner]. In this way, the walkalong provided benefits to both Vaccar and my research.

Walking as a method also highlighted traditional Malawian gender norms. Monica and Mary had expressed their interest in participating while we were on a walk with their neighbour Grace, however, when we met with them later in the courtyard of Grace's home, and asked if they wanted to go for a walk:

“They gave their excuses, Mary expressed she didn't feel ‘tidy’ enough to walk around the community while the Monica had much walking to do later” [Fieldnotes\_Walk with\_Monica and Mary\_Female\_Malawi\_Arts Walk 3]

Presentability, as highlighted by Mary's sense of untidiness was clearly important in Sector A. Similarly, Grace, ‘*was wearing a loose patterned purple skirt when we arrived. Before we leave for the walk she [ran] inside and remerge[d] wrapped in a longer chitenje*’ [local cloth often worn as a skirt] [Fieldnotes\_Walk with Grace\_Female\_Malawi\_Arts Walk 2] to make herself more presentable as we toured the community. Indeed, I was often complimented by other women for my modest dress when walking around Sector A, and on one occasion where I had been crouched on a step writing notes near the market, I was scolded to “*sit properly*”.

In Malawi, cultural gender norms about dress and presentability have been shaped by a series of precolonial, colonial, and post-independence processes (Semu 2002). Christianity and colonialism imposed patriarchal gender roles and contributed to the breakdown of women's autonomy which coincided with the re-invention of culture and African tradition in the form of customary law (McFadden 2001, Semu 2002). Customary law saw traditions and cultural practices becoming ordered rules and regulations controlled by the chiefs and was used to generate political support by anticolonial campaigners (McFadden 2001, Semu 2002). Following Malawi's independence in 1964, traditions (including cultural dress) were politically exploited by the single party government of Kamuzu Banda, including as a way to reinforce social control over

women and girls. In 1993, Malawians voted to end single-party rule, thus prompting the creation of a multi-party state in 1994 with human rights and gender equality written into the new constitution (Semu 2002, Tiessen 2008, Riley and Dodson 2016). While substantial progress has been made in women's rights in Malawi, the legacy of these historical and political processes can still be observed in persisting social norms where conservative dress and modesty are valued. Thus, it was easy to understand why Mary's concerns over presentability meant that walking was less appealing, and why she chose to conduct the interview in the courtyard instead.

The variability produced by interviewees' walking (or not walking) meant that the interviews lasted anywhere between 25 minutes and an hour. It was noticeable that when we had a longer walk, everyone (the participant, Miguel and myself) relaxed into it and we were able to have a dynamic, natural conversation rather than the more formal questioning that emerged in some of the shorter walks or sit down interviews. Thus, longer walks may have better supported relationship building processes. However, I argue that readily adapting the walks to participant's preferences and commitments was still important. Creating space for community members to adapt or shorten the walks supported participant's autonomy, built trust and likely contributed to more equitable community partnerships overall.

However, there were some additional challenges with walkalong interviews. Firstly, encounters with non-participants brought complex questions around ethics and confidentiality. These challenges have been cited by several scholars when using walking and other mobile interviews (Carpiano 2009, Garcia, Eisenberg et al. 2012, Finlay and Bowman 2017). While my whiteness meant it was difficult to not draw attention to the interviews, I tried to mitigate this where possible; for example, I used my phone to record interviews as I thought it would bring less attention than an audio-recorder. Furthermore, other community members would sometimes approach either me or their friends during interviews. During these encounters, I tried to preserve the confidentiality of non-participants by turning off the audio-recording and would not transcribe any parts of the conversation captured. Like Finlay and Bowman (2017), I would also try to follow participants' lead when encountering others they knew, only joining the conversation if introduced by the participant.

Secondly the combination of interviewing multiple participants at the same time, navigating live translations, traffic and noise could sometimes make it difficult to make additional observational notes (e.g. of the routes we were taking). Finally, whilst my phone was effective overall, I experienced common challenges with audio recording outside, particularly the fact that the audio was often distorted by sounds including traffic and wind (Carpiano 2009, Garcia, Eisenberg et al. 2012, Finlay and Bowman 2017) .

### **4.3 Everyday Life in Sector A, Lilongwe, Malawi**

The following section will provide an overview of the setting and practices that form everyday life in Sector A, Lilongwe Malawi. It will begin with a brief exploration of the households that form Sector A and why community members moved to the area. It will then explore Sector A as place, including local markets and economic opportunities, as well as more social elements including ideas of community belonging, social life and religion.

#### **4.3.1 Households and Mobility**

Households in SSA are often dynamic, where their composition can shift for reasons including migration, adoption, and marriage/divorce (Myroniuk and Payne 2019). Several younger community members had moved to Sector A with their families, either with their parents or with their spouse. Many also had their own children who, although not mentioned explicitly during the interviews, were often playing quietly nearby. Some shared that being born in and having family in Sector A was a reason to stay in the area, while others chose to stay even when immediate family members had since moved away.

Several community members discussed migration to and from Sector A in the context of economic opportunities. Vaccar explained that he now lived with his mum while his dad had been transferred for work to another town. Louis had moved to Sector A for work over 30 years ago after “*moving from one place to another*”. He initially worked “*as a revenue collector in the city council*” and later became “*a machine operator*” [Miguel\_Walk with Louis\_Male\_Malawi\_Arts Walk 4]. Sector A is situated within the larger urban population of Area 25 which holds diverse forms of employment (Crampin, Kayuni et al. 2016). Many

residents, like Louis, work in the civil service or commercial jobs in tobacco processing factories and nearby industrial estates (Crampin, Kayuni et al. 2016). Many are also students or involved in casual and informal employment, petty trading or are looking for work (Crampin, Kayuni et al. 2016). Wami, a much younger man said he was known locally for his trade as an electrician and mechanic and highlighted that this reputation meant that he “*cannot move to another destination*” [Miguel\_Walk with Wami and Shin G\_Male\_Malawi\_Arts Walk 1].

### 4.3.2 A ‘Peaceful’ Residential Area

Sector A is primarily a residential area, with a mixture of wide red dusty streets and narrow lanes (Figure 4-1). It was often quiet, and you could turn down several streets without really seeing anyone, especially later in the day. On the wider roads there would be an occasional car or bike, but for the most part people would be on foot. In several community members’ own words, Sector A is “*peaceful*”. It was clear that this was especially valued by the community, and often thought to be unique to the area, as noted by Mpatso, “*it is the only sector [in Area 25] that is very calm*” [Miguel\_Walk with Mpatso\_Female\_Malawi\_NCD Walk 2]. This may also have been linked to community perceptions of safety. For example, some participants praised Sector A for its high security. Indeed, the housing plots were surrounded by high brick walls and large metal gates.

However, Sector A and Area 25 were not without their own social challenges. Community members had mixed perceptions over rates of robbery and the impact of antisocial or ‘immoral’ behaviours on the community. ‘Immoral behaviours’ were primarily linked to alcohol, smoking, violence and stealing among young people. Hannah and Christa were interviewed together. While Hannah said that the “*only thing she hates about the community is the behaviour of the youths*” [Miguel\_Walk with Christa and Hannah\_Female\_Malawi\_NCD Walk 3], Christa noted that this was not a major concern for her. Several young men also discussed the presence of these behaviours among their peers; however, some recognised the financial circumstances that led to them:

“So, the main causes of the high crime are because most of the people in this area do not have money related activities, so most of them work hard just to find money to buy cigarettes or some drinks. But at the end of the day, they attack people who have some potential, who are working, in order to get their fortune out.”  
 [Miguel\_Walk with Wami and Shin G\_Male\_Malawi\_Arts Walk 1]

Youth unemployment in Malawi is high, with 31% of youth (15-24 years) not in employment, education or training: a figure that rises to 44% for the 20-24 age-group (Perry 2022). Thus, although there were some conflicts within the community, there was also a sense of empathy that sometimes behaviours are partly due to circumstances beyond an individual’s control.



Figure 4-1: Images from Sector A, Area 25 Lilongwe

### 4.3.3 Community as ‘One family’

According to Israel, Schulz et al. (1998) one of the key features of community-based participatory research (CBPR) is that community is recognised as a unit of “*collective and individual identity*” (p.178). This identity can be formed on shared interests, values, norms and social relationships, which may or may not overlap with geographic proximity (Israel, Schulz et al. 1998). A geographic area may be a community itself or may contain several communities within its boundaries (Israel, Schulz et al. 1998).

Sector A appeared to form its own place of community identity, with strong themes of community belonging, cohesion and support evident throughout the walkalong interviews. Indeed, community members' definitions of family appeared to extend beyond those they were directly related to, and many shared that they were friends with lots of different people not just those their own age or those that lived nearby. Several participants went as far as describing Sector A as "*one family*".

Community support and collaboration appeared to be important among participants in Sector A. Community members would describe how they would come together for "*community activities and developments*", terms used interchangeably to describe different activities including local ceremonies and celebrations (e.g. weddings, funerals), rallies, and meetings. Community members shared examples of how their own participation in these activities made them feel like they belonged to the community, as noted during our walk with Mpatso:

“[Mpatso] feels like she is very much a part of this community because one she is responsible and she's very much depended on, even when something is to happen here that involves the community members to take part she is also considered as one of the participants that should take part.” [Miguel\_Walk with Mpatso\_Female\_Malawi\_NCD Walk 2]

This sense of community belonging, and responsibility indicated a sense of cohesion among the community members, where they could rely on each other and provide support if needed (e.g. if someone got ill). Like Chiefs in rural Malawi (Grant, Brown et al. 2011, Hawkins, Dressel et al. 2022), Sector A Chiefs were also viewed as key figures in bringing the community together. However, Monica and Mary did suggest that there were sometimes tensions with how Chiefs would delegate responsibilities:

“During food preparation in these ceremonies and other things, there are old people that are always in the, ye know, kitchen preparing the food, so the youths are not given chances...

...When there are some developmental projects that have come into the community, since you know that every project has to go through the chiefs...they only chose those that are within their circles... maybe their friends or whatsoever. So maybe a bit of bias and such.” [Miguel\_Walk with Monica and Mary\_Female\_Malawi\_Arts Walk 3]

Like other community members, Monica and Mary were keen to get involved, reinforcing the idea that community in Sector A was more than simply geographic, but was instead interlaced with social responsibility and belonging. However, these tensions do serve as a reminder that although the Chiefs might support community identity, their hierarchical powers may sometimes serve as a barrier to equitable participation.

#### **4.3.4 The Marketplace: Food Security and Economic Opportunity**

Traditional markets form an important part of community life across Lilongwe, and Sector A was no exception. Almost all community members interviewed told us they loved visiting local markets and that they would visit both the small Sector A market and the neighbouring larger Nsungwi market at least once a week. Indeed, both markets were an important feature in our walks.

Although Miguel and I had walked past the Sector A market when entering the community, we were formally introduced to it during our third walkalong interview. We had met neighbours Christa and Hannah outside Hannah's home, where she had been sitting sorting charcoal into red plastic bags. They agreed to speak with us, but said we would have to join them at Hannah's business:

We walk for around five minutes before we are back at the small market consisting of a few stalls spread across an open space. We reach the first stall; it is made with sturdy branches and dark timber. Cloth hangs down the sides, keeping the sun out. It is full of produce including tomatoes, and other fresh veg. Hannah, adds some of the bags full of charcoal to the stall, and tells us that it is hers.

[Fieldnotes\_ Walk with Christa and Hannah\_Female\_Malawi\_NCD Walk 3]

While the small market provides a vital local service, with vendors providing accessible food and fuel to people in Sector A, it was also a place associated with work and community identity. Hannah's role as a business owner appeared to shape her understanding of community and particularly her role within it as a provider:

MJ: [Hannah] feels as if mostly she is part of the community because she feeds the community and the business, with the vegetables, the tomatoes and all that so she really is part of the community.

MB: So, this is all your business [gestures to market stall]?

MJ: Yes, this is all [Hannah's] business. [Miguel\_Walk with Christa and Hannah\_Female\_Malawi\_NCD Walk 3]

Quantitative evidence in Lilongwe shows that traditional markets are essential in local food security, with most people choosing them as their primary place to shop. This is especially the case in low-income areas where markets provide affordable and accessible access to food without the need for motorised transport (Chilanga, Riley et al. 2017, White, Kampanje-Phiri et al. 2017). Travelling to and from Lilongwe's central markets could cost as much as 3000 Malawian Kwacha (~£2.30). This cost is out of reach for many, with an estimated 72% of the Malawian population living below the poverty line of \$2.15 a day (~£1.63) (The World Bank 2022). While Hannah's role within the Sector A market might fulfil the need to "*feed the community*", as noted by Christa, the larger Nsungwi market was sometimes the more affordable option:

"So for [Christa].. she likes the market, Nsungwi, she likes the big market.. we went yesterday.. cause everything there is cheaper so for her...it is always better for her because she is able to afford whatever she wants in the market." [Miguel\_Walk with Christa and Hannah\_Female\_Malawi\_NCD Walk 3]

As one of the largest markets in Lilongwe (White, Kampanje-Phiri et al. 2017), Area 25's bustling Nsungwi market stands in stark contrast to the calmness of Sector A's smaller market. Nsungwi mostly runs along a long tarmac main road in the centre of Area 25 and weaves through some of the neighbouring pedestrian streets. It is a continually expanding array of wooden market stalls selling everything from meat, fresh produce, spices, and cooked foods, including chips and doughnuts, to other non-food goods, including timber and clothing. The stalls run alongside small stretches of concrete shop fronts, which house spaces such as Airtel and TNM (mobile data) shops, simple restaurants, hair salons and beauticians, off licences and general stores. The Nsungwi market was described not only as a favourite place to socialise among participants regardless of their age and gender, but, as noted by Grace, a place where the community could access anything they might need:

"[Grace] likes that market because it is readily available, the market, you can find whatever you want, a thing that you can find in town can

be found in Nsungwi. So, when we are going there, we don't have any doubts that we are not going to find anything there. They are very assured that anything they are going to look for they will find it there." [Miguel\_Walk with Grace\_Female\_Malawi\_Arts Walk 2]

Beyond food-security, markets in Malawi also facilitate second-hand clothing economies (Mhango and Niehm 2005). Vaccar would visit the market frequently to buy clothes to resell online and was keen to show us where in Nsungwi he could conduct business:

MB: Is there anywhere in the market that you visit a lot?

MJ: So yes, there is a little place that he actually used to visit. He definitely visits the place every day in the morning, so he likes visiting the place, the clothes market...so he does business. He is a businessperson, but he does it online. So, he just goes [to the market] picks the clothes and sells them online... He likes clothes that have a label because most people nowadays they like brands. Branded clothes...

So, he does not have a specific place [stall] where he picks his clothes, but he just selects where are the best clothes. But this is the street. [Walk with Vaccar\_Male\_Malawi\_NCD Walk 1]

Thus, both the Sector A and Nsungwi markets were fundamental in shaping everyday life in Sector A. They provide economic opportunity as shown by Hannah and Vaccar, while also supporting food-security through providing affordable access to local foods and creating a social space, further reinforcing community belonging and support.

#### **4.3.5 Social Life, Celebrations and Religion**

In addition to the market, social life in Sector A, was often framed around local ceremonies and celebrations, like weddings, bridal parties, and birthdays. On our walks we were shown some of the places these celebrations would take place. One young woman, Grace, took us to Green Gardens, a large garden space (only accessible by payment) and told us it was not only one of her favourite places to visit for ceremonies, but also to go with her friends to take posed photographs. Grace, Hannah and Christa also described a secondary school with a large outdoor stage as a favourite place to socialise. The secondary school later became the site for Phase 1 and Phase 3 workshops.

Places of worship were also a central feature of social life in Sector A. A number of participants told us that they enjoyed visiting their church (often Presbyterian) or mosque frequently. Friends and neighbours interviewed together appeared to have common feelings about religion, even when they were part of different congregations or faiths. Church appeared to facilitate many different community activities, from prayer and ceremonies to sports and creative activities. Indeed, religion and ceremonies provided a space for people to get together to sing and dance, art forms that appeared to be loved by the community, particularly women, as will be described below.

#### 4.4 Local Arts and Participation

The Chichewa word for art is *Zaluso*. Community members in Sector A shared several art forms that they or others in the community would enjoy or participate in, the most common being music, songs and singing, dancing, drawing, drama and poetry. However, *Zaluso* can also be translated to skill or talent, which sparked some interesting discussions with participants about what is actually considered an art form. The following section will explore community perceptions and perspectives on these art forms, with a focus on the facilitators and barriers to participation.

Music, songs and singing appeared to be very popular in Sector A. Most participants told how they would listen to music (Gospel, Dance, R&B and local music) at home, church and local ceremonies. Several female participants had also participated in singing at their church or mosque. Grace discussed how watching others sing at church had motivated her to get involved in music.

“Okay so for [Grace] to venture into singing, she used to see people at church when they were singing so that really motivated her to turn to music. So, whenever she sings, she is a solo singer, she sings alone.”  
[Miguel\_Walk with Grace\_Female\_Malawi\_Arts Walk 2]

Male participants said they would occasionally get involved in singing recreationally or at church but were less likely to be involved in singing groups. Louis highlighted that “*all types*” sing at church, “*young, middle age, elders...men’s group’s, women’s groups*” [Miguel\_Walk with

Louis\_Male\_Malawi\_Arts Walk 4]. However, he also said he was less inclined to get involved himself because of his age and other commitments.

“So, there is not really something that is hindering Louis from taking part [in singing groups]. But as he says there is always time where one would have to choose this is how I am going to do my life, depending on maybe age and how busy he is, so he just doesn’t take part because of his busy schedules and his age.” [Miguel\_Walk with Louis\_Male\_Malawi\_Arts Walk 4]

Ageing and financial responsibilities appeared to be a common barrier to participating in arts-based activities. For example, Shin G talked about his love of drawing as a youth, however, growing up brought additional responsibilities.

“[Shin G stopped drawing] because of adulthood. He was doing that for pleasure but now he needs to find something that he should do for his family. So, he stopped drawing because he is now more interested in finding monies to sustain his family.” [Miguel\_Walk with Shin G and Wami\_Male\_Malawi\_Arts Walk 1]

Furthermore, Shin G’s friend, Wami, said that the main motivation for his participation in art would be financial benefit.

“Financial benefit- not just doing it for pleasure, but if there’s financial benefit I would be engaged in art.” [Wami\_Male\_Malawi\_Arts Walk 1]

As touched on in Section 4.3, Malawi has a very high prevalence of poverty and youth unemployment (Perry 2022, The World Bank 2022). Therefore, it is understandable that as a young man, Wami would feel the need to prioritise financial opportunities.

Participants also highlighted how their participation in drawing and other crafts had been disrupted by a lack of access to arts resources and creative spaces.

“[Grace] wants to venture into other arts, especially you know hand sewing, she really wants to do hand sewing or even if she can be taught carpentry or whatever, but the problem is she does not have resources.” [Miguel\_Walk with Grace\_Female\_Malawi\_Arts Walk 2]

There were no designated spaces in Sector A to participate in arts-based activities outside of places of worship and traditional cultural ceremonies. Some

interviewees said they did not know where they could go, while others were aware of a venue in Area 25, the Nyamatambo Arts Centre. However, according to Monica and Mary, the centre is too far away. I was aware of Nyamatambo through my involvement in the Culture and Bodies Project (Chapter 1.2) and it was initially mentioned by Miguel as a possible site for the later Phase 1 and TABPA workshops. However, it was clear following the walkalongs that I should find a venue closer to Sector A to reduce participants' travel as much as possible. This decision led me to the school in Sector A (Section 4.4), which following walkalongs and consultation with the chiefs appeared to be a more significant and convenient space for the community. Therefore, we decided to host all Phase 1 and Phase 3 workshops on the stage pictured in Figure 4-2.



**Figure 4-2: A secondary school stage in Sector A that served as the site for all workshops in Malawi.**

Notably, according to Mary, the lack of resources and creative spaces in Sector A was a fundamental reason why people were not motivated to participate in arts-based activities outside of church.

“[Mary] does not know why people do not want to participate. But one [she noted that] there is no one here who encourages arts activities. As a matter of fact, there is not even an art theatre, or any place where people would go, so it could have been different if it had the

structure...to say that, okay, they have a structure where arts are being performed and why are people not going there, so they could come up with a reason of why people are not going there. So that is the reason why they participate at church and come back home and stay, because here in the community there is nothing that motivates them or shows them or guides them.” [Miguel\_Walk with Monica and Mary\_Female\_Malawi\_Arts Walk 3]

Finally, when discussing different art forms, some activities emerged that were linked to different meanings of *Zaluso* as skill or talent. When discussing local arts and creative activities, participants also mentioned baking, painting buildings as a trade and engineering. Wami, a young male participant, noted he was an electrician and queried whether I thought that this was an art form.

MJ: [Wami] does not take part in any art, so he is asking me, he is an electrician, so is electrician part of the arts or not?

MB: I guess if you think it is then yes, if you think it is an art form

MJ: So Wami thinks that it is just part of professional but if you consider it as an art, then yeah, he takes part in art. [Walk with Wami and Shin G\_Male\_Malawi\_Arts Walk 1]

## 4.5 Community Health and Noncommunicable Diseases

The focus of four walkalong interviews was to gain an understanding of community perspectives of, and knowledge about health, specifically noncommunicable diseases (NCDs). Views on overall community health were mixed. Some community members like Mpatso noted that the community were healthy, arguing that they “*take very good care of themselves*”, while others disagreed. For example, Hannah argued that community health was “*not to the expectation*” because the “*economic crisis*” meant people were struggling to provide for their families. These interviews were conducted in September 2022, when Malawi was facing multiple shocks. In May 2022, the national currency Kwacha had been devalued by 25% in response to shortages in foreign exchange which contributed to soaring inflation and had profound effects on the cost of food and fuel. These problems were exacerbated by the Russia-Ukraine war, the knock-on effects of COVID-19 and the impact of climate and weather-related shocks on agriculture (Phiri Kampanje 2022, IPC 2023, UNDP 2023). These issues combined to contribute to high levels of food insecurity in the country (IPC 2023).

### 4.5.1 Community Health Concerns

Community members shared a number of health concerns that ranged from poor hygiene, tuberculosis and NCDs (including diabetes, high blood pressure, asthma, stroke, and mental health), to the accessibility and affordability of healthcare.

Hygiene was a major concern for several community members primarily due to structural issues. Several participants described a water “*crisis*”, where the community had limited access to clean drinking water. When we were walking home from the market with Alfred, he pointed behind him to tell us that there was a place in Sector A where the community were told additional *boreholes* [water pumps] would be built. However, they had not actually materialised and now people “*are really suffering*”. The impact of poor water infrastructure on the community was reinforced by Christa, as seen in the following extract:

“So [Christa] says apart from the other crises that have affected the area. Here they also have hygiene problems because water in this community is a very, very... a challenge... most times tap water does not come out and mostly they opt to use boreholes [water pumps] for drinking and all that which by the end of the day causes problems for their health.” [Miguel\_Walk with Christa and Hannah\_Female\_Malawi\_NCD Walk 3]

Lilongwe’s historical development and rapid urbanisation has coincided with the development of inequitable water infrastructure, which has prioritised water access for high income areas (Velzeboer, Hordijk et al. 2018, Tiwale 2019). Poor water infrastructure is also reinforced by unequal practices, and the Lilongwe Water Board, who manage Lilongwe’s central water supply, have openly admitted that when water is sparse, they will divert water from low income to high income areas of the city (Velzeboer, Hordijk et al. 2018). As noted by Christa and Hannah, the impact of water inequity has profound consequences for community health; for example, some community members mentioned that the chief had recently brought them together to share good hygiene practices amidst a cholera outbreak. Cholera was seasonally endemic in Malawi between 1998 and 2020. However, cyclones, torrential rains and floods have severely exacerbated the problem, and in December 2022, Malawi declared a public health emergency, with an outbreak in May 2023 being the deadliest in the country’s history (Bagcchi 2022, Wise 2023).

Community member's concerns about NCDs were often driven by direct experience of the condition, either personally or among family members. For example, Mpatso had personal experience of asthma, while Christa's concern stemmed from how hypertension had impacted her mother:

“So, [Christa] says she is most concerned with hypertension in a sense because her mum, she is afraid that she is suffering from it to the extent that she has stroke. She has mobility problem she cannot do anything.” [Walk with Christa and Hannah\_Female\_Malawi\_NCD Walk 3]

Christa's experience with her mum indicates some of the long-term consequences of hypertension. Hypertension is a risk factor for stroke, and subsequent mobility problems highlight its impact on both health and lifestyle (Fuchs and Whelton 2020). Malawi has a high prevalence of hypertension, and several studies have highlighted low rates of control (Price, Crampin et al. 2018, Amberbir, Lin et al. 2019, Hoffman, Chibwana et al. 2021). It is likely that these factors were related to community members direct experiences of the long term impacts of the disease. A number of other community members had lost family members to NCDs, including Christa's neighbour Hannah, whose uncle had died from diabetes.

Community members spoke of how difficult it was to get a diagnosis for diabetes and hypertension. Mpatso shared a story of her close friend who had started displaying symptoms of diabetes, but had to make two trips to different health facilities to get a diagnosis:

“Okay, [Mpatso] says she has an experience. One of her close friends who was physically fit, was stressed, stressed. She was living a stressed life, so she started losing weight, so they took her to the hospital [so they could diagnose] her with any diseases. But she was not diagnosed with anything. But later on, a friend took her to a certain hospital where she was diagnosed with diabetes.” [Miguel\_Walk with Mpatso\_Female\_Malawi\_NCD Walk 2]

The Area 25 Health Centre is the primary site of health care for Sector A residents, situated an hour and a half walk (or 20-minute drive) away. However, the challenge to receive a prompt and accurate diagnosis for diabetes is not limited to Sector A. Most health systems in Malawi are largely unprepared for the growing burden of NCDs, often experiencing drug and equipment shortages (NCI

Poverty Commission 2018). For example, a study of five primary care clinics in the Dedza region of Central Malawi revealed that, while all had a measuring tape and blood pressure machine, only one had an effective weighing scale, only two had a glucometer to diagnose diabetes mellites and none had the capacity to conduct a HBA1c blood test to measure blood sugar (Wood, Viljoen et al. 2015). Furthermore, community members spoke of a lack of access to medication in Sector A. Alfred was particularly concerned about the growing population of Area 25 and noted that the health centre was oversubscribed as people were travelling from neighbouring townships to access medication. Christa however, linked challenges accessing medication for diabetes and hypertension to the limited budgets available to government-owned health facilities:

“It is a challenge that most public health facilities are owned by the government. Most times we do not have drugs available, so they are asked to purchase at private facilities which are deemed to be very expensive which poses a challenge for them to access treatment for it” [Miguel\_Walk with Christa\_Female\_Malawi\_NCD Walk 3)

NCD healthcare has been consistently underfunded in Malawi. For example, in 2015-2016, noncommunicable disease and injury programmes accounted for only \$2million (0.54%) of government funding for all disease programmes (\$370 million) (NCDI Poverty Commission 2018). Returning to Christa’s concerns over the local “*economic crisis*”, it was clear that having to purchase medication exacerbates community health concerns, especially around NCDs, which account for 14.7% of out-of-pocket health spending in Malawi (NCDI Poverty Commission 2018). In Lilongwe, patients with co-morbid hypertension and HIV reported that higher out-of-pocket expenses for hypertension contributed to poorer antihypertensive medication adherence compared to HIV (Hing, Hoffman et al. 2019). Thus, insufficient healthcare infrastructure will likely exacerbate community concerns about NCDs.

#### **4.5.2 Community Knowledge and Perspectives of Diabetes and Hypertension**

Much of the walkalong interviews focussed on health where I asked what community members knew about diabetes and hypertension. I wanted to gain a foundational understanding of the context of these diseases in Sector A and how

this might influence community engagement with a TABPA that focused on one or both of these diseases. Having established that the community were indeed concerned about diabetes and hypertension in Section 4.5.1, the following section will unpack specific community knowledge of, and perspectives on these diseases in more detail.

#### 4.5.2.1 NCDs, Diet and Local Food Preferences

Most community members appeared to be knowledgeable that diet was an important risk factor for diabetes and hypertension. Specifically, participants were conscious that too much salt, sugar, and fat were features of an unhealthy diet that could contribute to the conditions, and that they should be avoided to prevent and, in some cases, treat the diseases.

Some community members gave examples of local foods that were high in fat (e.g. chips) and sugar (e.g. sweet potato and maize flour). Maize is estimated to account for two-thirds of calories consumed in Malawi (Pauw, Verduzco-Gallo et al. 2018). *Nsima*, a high carbohydrate maize flour-based porridge, is a dietary staple in both rural and urban Malawi (Riley and Dodson 2016), and was very popular locally. Indeed, Miguel and I would often go to a local restaurant in Area 25 at lunchtime for fresh nsima, meat and vegetables. Community members noted that nsima could also be made with whole grain maize flour, *Mgaiwa*, as a healthier alternative to the de-husked and refined white flour, *ufa owera*. *Mgaiwa* is often recommended as part of type 2 diabetes management in Malawi due to its lower glycaemic index (Mlotha, Mwangwela et al. 2016, Ogunrinu, Gamboa-Maldonado et al. 2017, Chikumbu, Bunn et al. 2022). Although many interviewees were aware of the link between sugar and health, as discussed by Vaccar, community members preferred the taste of the more refined option and would still choose to buy it:

“Okay so from the maize meal, [Vaccar] has many stories where the mealer would tell people you know that we are doing business, but now this kind of flour is not good for your health. But people still cling to them because they like the taste, but now he knows some notable people in the community who are suffering from diabetes because of taking those kinds of food.” [Miguel\_Walk with Vaccar\_Male\_Malawi\_NCD Walk 1]

Several studies have indicated that the preference for the more traditional white flour is not unique, and even those who have been diagnosed with diabetes find the change difficult, as they dislike the whole-grain alternative (Ogunrinu, Gamboa-Maldonado et al. 2017, Vaughan, Dube et al. 2018, Chikumbu, Bunn et al. 2022).

Community members also highlighted financial barriers to the control of diabetes. Hannah emphasised that diabetes lifestyle modification could be hard to follow due to the cost of dietary supplements.

“[Hannah] has said that they are really experiencing problems because as we know most of the treatment requires lifestyle modification, especially food supplements. So, most people are suffering they are not able to meet, to buy those foods, so it really poses challenges for them.” [Miguel\_Walk with Christa and Hannah\_Female\_Malawi\_NCD Walk 3]

The cost and availability of recommended foods has been reported by several studies as a key barrier to a healthy diet and diabetes prevention in Malawi and wider SSA (Zimmermann, Bunn et al. 2018, Mphwanthe, Carolan et al. 2021, Bissett, Gray et al. 2022).

#### **4.5.2.2 Stress, Overthinking and Comorbidities**

A number of community members also talked about stress as a driver of noncommunicable diseases. Many linked hypertension to ‘overthinking’, ‘stress’ and a ‘high temper’ or ‘anger’. Mpatso went even further, noting how the stress of hypertension was linked to diabetes:

“People who have BP, hypertension, they are also prone to diabetes because they think a lot, they have stress from the environment, so the stress leads them to have diabetes.” [Miguel\_Walk with Mpatso\_Female\_Malawi\_NCD Walk 2]

Public health discourse typically frames stress as a risk factor for hypertension, with less attention to its association with diabetes. However, studies have demonstrated the link between psychosocial factors (e.g. stress and anxiety) and diabetes through both behavioural and physiological pathways (Hackett and Steptoe 2017, Issaka, Paradies et al. 2018, Chilunga, Schwerzel et al. 2023). Mpatso’s association between stress, hypertension and diabetes may also be

related to the prevalence of hypertension and diabetes co-morbidity in Malawi and wider SSA (Stanifer, Cleland et al. 2016, Price, Crampin et al. 2018, Ekoru, Doumatey et al. 2019, Munyogwa, William et al. 2020, Mohamed, Uthman et al. 2021) and commonalities between the lifestyle-related health advice provided to manage each condition (Birkinshaw, Nel et al. 2018).

It should also be noted that most studies examining the correlation between stress and diabetes stem from high income countries, and direct evidence from SSA is limited (Issaka, Paradies et al. 2018). Among Ghanaians, Chilunga, Schwerzel et al. (2023) found a negative association between stress from negative life events and diabetes, and no association between diabetes and stress at home or work. However, the authors theorised that this was partly due to strong social support structures in Ghana, which could also apply in the Malawian context. As highlighted above, the community in Sector A had a strong sense of social support, including when facing health issues. Indeed, Mpatso noted that when she was “*alone or in a stressed environment*” she would often visit a friend to “*rid herself of the stresses from the fear of suffering from diabetes as well as hypertension*” [Miguel\_Walk with Mpatso\_Female\_Malawi\_NCD Walk 2].

#### **4.5.2.3 Symptoms and the Impact on Productivity**

Community knowledge about the symptoms of hypertension and diabetes was mixed. Hypertension (>120/80mg/Hg) often presents with no symptoms (World Health Organization 2023). This was not mentioned by any of the community members, although when asked, some said that they did not know what the symptoms of hypertension were. However, Mptaso knew that people with hypertension had headaches and general body pains, while Christa mentioned that people have a fast heartbeat, tachycardia. These symptoms tend to present when blood pressure is very high (>180/120mmHg) (World Health Organization 2023), suggesting that the condition often goes undiagnosed and uncontrolled locally. As described in Section 4.5.1, this could be due to barriers accessing appropriate healthcare.

There were also some gaps in community members’ knowledge of diabetes symptoms; for example, Alfred said that he did not know any, while Christa

asked me to tell her about them. Where community members were aware of symptoms, they tended to be observable ones like weight loss, which Vaccar emphasised was particularly noticeable when “*fat*” people were affected. However, participants with more direct experience of diabetes were aware of additional symptoms. Hannah, who’s uncle had the condition, was aware at the onset of diabetes that people have “*episodes of hunger as well as lethargy, like body weaknesses*” while Mpatso, whose friend had been diagnosed, also highlighted that people with diabetes were “*unable to do daily activities*” due to incontinence. Therefore, it could be argued that direct experience of diabetes and other NCDs plays a role in community health knowledge.

Community members were also aware that the physical impact of diabetes and hypertension could have a profound impact on both the everyday life of individuals and the wider community. Alfred said that diseases were “*eroding people’s lives*”. The impact of diabetes and hypertension on individual and community productivity was further highlighted by Mpatso:

“[Mpatso] says looking at the community level there is underdevelopment. Most people who are affected by these diseases now spend most of their times maybe in the hospitals or bedridden. So, even at the home now, we see that there is not going to be productivity since most of the people will be suffering and most of the family members will be taking care of the person. As well as on the business aspect of work, it means that the person’s productivity will be low, maybe lose jobs, as well as the business going down there is nobody to take care of the activities.” [Miguel\_Walk with Mpatso\_Female\_Malawi\_NCD Walk 2]

Diabetes and hypertension are therefore perceived to not only cause physical disability, but also emotional distress for the wider family, as well as reducing economic productivity. This example once again reinforces a strong sense community cohesion in Sector A, while also outlining the harmful consequences of chronic disease on a community that is already facing financial hardship. Something that is further exacerbated by financial barriers to the medication discussed previously.

#### **4.5.2.4 Prevention, Education and Health Seeking Behaviours**

Community members often framed the prevention of diabetes and hypertension, and the promotion of good health around individual health knowledge and

community education. As previously noted, community members were aware that behaviours associated with sugar and salt reduction were key in the promotion of a healthy lifestyle. These behaviours were listed by Mpatso when describing her own understanding of good health:

“On her life [Mpatso] knows that good hygiene is very essential for health. She knows she should take care of the house, the home, also she has to wash hands before eating, she has to prepare good food, she has to have clean water, she has to take food [with a lower] concentration of salt as well as sugar to prevent hypertension and diabetes and all that” [Miguel\_Walk with Mpatso\_Female\_Malawi\_NCD Walk 2)

Beyond lifestyle factors, several community members also emphasised that prevention would be facilitated further by regular disease testing and access to health information. Community members highlighted that the best places to receive health information included the hospital, the Area 25 clinic, mobile health vans, church, and community rallies. Health professionals were viewed as a reliable source of health information.

“When [Alfred] goes to the hospital, through health education, health personnel there are able to give information to patients and in case they go there with someone who is suffering from either of these diseases, so they are able to understand these things from the service providers, so they are able to give them the information” [Miguel\_Walk with Alfred\_Male\_Malawi\_NCD Walk 4]

Healthcare facilities have been acknowledged by service providers in Malawi as a primary way to share information about NCDs with local communities (Lupafya, Mwangomba et al. 2016) and evidence has supported health professionals as a respected source of education (Ogunrinu, Gamboa-Maldonado et al. 2017).

#### **4.5.2.5 Arts and Health**

Arts, especially music, song, and drama, have also been demonstrated to be popular and effective methods of health promotion in SSA (Bunn, Kalinga et al. 2020), and are primarily used to generate awareness of infectious diseases like HIV/AIDS, Ebola and COVID-19, (Benavides, Caparrós et al. 2021, Thompson, Nutor et al. 2021). In Sector A, community members were familiar with songs and dramas used to communicate health information through the radio and television. According to participants, they had heard songs promoting healthy

behaviours like handwashing, adhering to drug instructions, and drinking water, as well as providing education on HIV/AIDs, COVID-19, diabetes, and hypertension. Monica noted how sharing and repeating songs about health could reinforce health knowledge both for herself and others in the community.

“There are lots of ways that people repeat the songs, for example, [Monica], she can be singing the song that she heard on the radio whilst maybe mopping or washing plates, in doing so it means that the information will stick in her as well as those who are around. The message will be spread” [Miguel\_Walk with Monica and Mary\_Female\_Malawi\_Arts Walk 3)

Monica believed that because songs could make information more memorable, they were an effective way to share information about disease. However, she did note that although she had heard songs about NCDs on the radio, she had not heard them repeated in the community in the same way as songs about infectious diseases. Alfred had an alternative view on the efficacy of songs, arguing that some people might misinterpret the information being shared and or not pay attention if they themselves do not have the disease. Alfred’s views could have been reinforced by the fact that these messages were from national health campaigns rather than local interventions, meaning they were likely less tailored to community concerns. Studies exploring the effect of nationwide radio and television health campaigns have had mixed results (Bunn, Kalinga et al. 2020). Radio dramas have been used effectively to improve perceptions of HIV/AIDs related stigma in Botswana (Lovell, Pappas-DeLuca et al. 2008) and have had a minor impact when used to promote cervical cancer screening uptake in South Africa (Risi, Bindman et al. 2004). However, when not tailored to communities or providing inconsistent health messaging (Booker, Miller et al. 2016), these strategies can have poor engagement or even reinforce problematic health practices (Bunn, Kalinga et al. 2020). This could also explain why Monica perceived community engagement with NCD-related songs as poorer, although this would have required further questioning.

## 4.6 Summary

In this chapter, I explored perspectives and experiences of community, local arts and health generated through walkalong interviews with those living in Sector A, Lilongwe, Malawi. In doing so I aimed to explore how community perspectives in

Malawi can inform the development and implementation of the transcultural arts-based participatory methodology (RQ1).

I began the chapter by reflecting on the walkalong interviews as a method and exploring some of the reasons for variation in the length of time walking. While the walkalong interviews were a beneficial way to learn about Sector A as place, particularly important spaces like the Sector A and Nsungwi Markets, recruitment strategies in combination with cultural and time-related barriers appeared to limit the time spent walking. Furthermore, walkalong interviews brought practical and ethical challenges with audio recording, privacy and informed consent.

I then explored Sector A as place and local perceptions of community, local art and health in turn. Sector A was described predominantly as a peaceful residential area, although like all neighbourhoods could experience some social challenges, particularly relating to antisocial behaviour among young people. Nonetheless, community was commonly described as one family, where community members would support each other and attend events and celebrations together. Religion also formed an important part of everyday life. Many community members had experience of arts-based activities through religious groups and community events. Music and dance were especially popular, particularly among women. However, there were several barriers to participation including limited access to arts-based activities outside of church, and a lack of time due to the need to prioritise work and financial benefits. Furthermore, participants highlighted that resources for drawing were too expensive, but said if they had access to creative resources they would enjoy participating.

Community members in Sector A had several health and economic concerns exacerbated by the impact of multiple shocks on Malawi. Diabetes and hypertension were also a cause for concern, with many participants having familial experience of one or both diseases. Participants were generally knowledgeable of the influence of diet on hypertension and diabetes, however, they highlighted a number of barriers to a healthy diet, including a dislike of the taste of recommended dietary options. Stress and overthinking were also understood as among the primary drivers of hypertension and diabetes.

Community knowledge and experiences of the symptoms and impact of diabetes and hypertension suggested the diseases were often undiagnosed and untreated, a finding consistent with wider literature on the topic. Participants indicated that health education was typically provided through health services including the hospital, which several community members argued was an important strategy for prevention of diabetes and hypertension. Lastly, according to participants, music and song also appeared to be a common strategy for sharing health information, however, their use for noncommunicable diseases was limited. This will be explored further in Chapter 6.2.1.

## **4.7 Reflections For TABPA Development and Implementation**

Having summarised the findings of the walkalong interviews in Malawi, it is important to reflect on the implications for the development and implementation of the TABPA framework. In addition to providing an in-depth understanding of the local context, community perspectives in Malawi informed the TABPA framework in several ways.

1. Many participants shared an active interest in arts-based activities supporting the feasibility of the TABPA. However, community members highlighted that their participation in art was generally limited to places of worship, local ceremonies and childhood. Therefore, steps are needed to support accessibility (e.g. resources, a nearby venue, financial compensation).
2. While the walks revealed community perspectives on the use of art in health promotion, more information was needed to determine community perspectives on the utility of arts-based methods for *health enquiry*. Thus, Phase 1 community and stakeholder workshops were designed to examine the practical utility of different art forms as a means to explore perspectives on diabetes and hypertension (see Chapter 6).
3. Community perspectives on diabetes and hypertension affirmed the cultural salience of the diseases to the community. Thus, the walkalongs

supported the choice to focus the TABPA workshops on the risk factors of these diseases.

In the following chapter I will continue to explore the findings from Phase 1 walkalong interviews and how they informed RQ1, with a focus on the Scottish setting.

## **5 Walkalongs in Scotland: Community, Arts and Health**

### **5.1 Introduction**

Having explored local perspectives and experiences of community, local arts and health in Sector A, Lilongwe, Malawi in the previous chapter; this chapter will explore the related findings of ten walkalong interviews in Glasgow, Scotland. The structure will mirror that of Chapter 5, beginning with an overview of my experiences of walking in Scotland, before exploring community experiences of everyday life with focus on experiences of migration and definitions of community. In the following section I will explore community participation in local art before describing community perspectives, knowledge and attitudes towards health, diabetes and hypertension. The chapter will conclude by reflecting on the contribution of walkalong interviews to the wider implementation of the TABPA and how walkalongs in Scotland informed the development of the TABPA framework.

### **5.2 Walking in Scotland**

As in Malawi, the walkalong interviews were designed to be flexible and participants could direct the walks as they saw fit. However, as all walks were organised for a prearranged time and date (see Chapter 3.4.2.4), participants had advance notice and there were fewer barriers to walking (e.g. presentability, prior commitments) than I had encountered in Malawi. Most of the interviews lasted around an hour.

As described in Chapter 3.4.2.4, walkalong interviews in Scotland were facilitated by snowball sampling, where community members who participated in walks, shared the details with their wider networks. Following her walk, Kathy [NCD Walk 2] asked if she could share the poster with her friends and other community groups. Within a few days she provided me with the contact details of seven more people. Two people I walked with explicitly told me it was Kathy who had put us in touch.

M: How did you meet [your close friend]?

P: From group, you know from group, we meet. It's good to be going in group. Unless you know another group a lot to be supportive. I call her, she just mentioned you, I say my friend why you not told me, she just says, write your name, I'll tell her to call you. That's how you are meeting me. [laughs] [Fatima\_Female\_Scotland\_Arts Walk 5]

Kathy's support with recruitment, and her recommendation to a close friend was an important reminder of the trust and relationship building that was supported by the walkalong interviews.

It should be noted that many participants in Scotland revealed that they went for walks regularly, with many saying it was their favourite form of exercise. Kathy highlighted how she enjoyed going for gentle walks and how walking also supported her fitness, a common experience which will be returned to later.

"But when I walk, I don't, I don't walk very fast. I walk slowly and if I walk very fast, I'm going to be tired, so I prefer to walk slowly, slowly, slowly because. Take my time. Yes, because no rush hour. Take my time. It's good. It's good for the exercise. It's good. It's very good. But I like walking. I love walking." [Kathy\_Female\_Scotland\_NCD Walk 2]

It is possible that advertising the research as a walking interview created a recruitment bias towards people who enjoy walking. However, this was not the case for all participants. For example, Rose explicitly said that she did not enjoy walking although she was content to participate in the walkalong interview.

The walkalong interviews took place across Glasgow, with participants taking me to a range of locations. Four walkalongs took me to supermarkets where community members would do their shopping, five took me to shopping centres where community members would browse, two took me into the city centre, one took me to a local park, and one partially took place on a bus. Visiting supermarkets was especially helpful in developing my understanding of local African foods, as will be discussed in Section 5.5.2. Several participants said that shopping centres and the city centre were among their favourite places in Glasgow because they could browse the shops. During our walk in a large shopping centre, Cocoloulou noted how the proximity to the shops was an important reason why he loved his local area.

M: Do you have a favourite place here in Glasgow?

P: My place where I live, it's just on the other side of the road - I really love where I live with my wife and family, you've got the shopping centre close, the motorway... I love my area

M: How often would you come here [the shopping centre]?

P: Oh, every week for sure. Maybe once, two, three, four, five times - so many. Even if I want to go for a walk this is the best place for me to go, just walk up and down, up and down, have a look in shops, see if there's any bargains available [Cocoloulou\_Male\_Scotland\_NCD Walk 5]

The walks took place in February, which meant that the weather was often cold, frosty or wet, so shopping centres were a helpful place to shelter on inclement days. 'Going shopping' with participants where we would chat about food and clothes, appeared to support the more natural and 'everyday' encounters described by other scholars (Kusenbach 2003, Carpiano 2009, O'Neill 2018). However, shops could also bring challenges similar to those in Malawi, particularly, because they were either outdoors or in busy public spaces. This meant that there was often a lot of background noise (e.g. music, traffic, wind), interruptions from sales staff, or there could be challenges with anonymity. For example, during a walk with Elizabeth in the city centre, another person walking past waved and said hello. Furthermore, when I got on a bus with Favour, I had to pause the audio-recorder to prevent me picking up other people's conversations in a confined setting. Thus, walking was an effective way to learn about and build relationships with community but as in Malawi, the method also brought challenges such as privacy concerns and practical issues with audio recording.

### **5.3 Everyday Life among African Communities in Glasgow**

The following section will attempt to unpack the forms and processes of everyday life among African communities in Glasgow that contribute to the diverse contexts within which this research is situated. This is not an exhaustive depiction but aims to bring together perspectives and experiences of community members, my own observations and established literature to explore multiple and complex experiences of migration, community and culture.

### 5.3.1 Mobility and Migration

The inclusion criteria for participation in walks in Scotland were deliberately kept open, in order to define the ‘African community’ in collaboration with those who identified as part of it. Of the ten participants who participated in a walk, all were first-generation migrants, originally from Nigeria (N=7), Cameroon (N=2) or Malawi (N=1). Therefore, at first glance, community in this context appeared to be formed of diverse cultural backgrounds situated in the defined geographical setting of Glasgow.

Participants’ reasons for migration to Glasgow included for education and employment, wanting to be near family and established social connections, and seeking safety and asylum. For example, Ay told me that having family living in Glasgow provided “*leverage*” to move to the city, and that his family had then decided to stay in Glasgow when he got a job elsewhere because they were comfortable and felt “*homely*” [Ay\_Male\_Scotland\_Arts Walk 3]. Furthermore, around half of those interviewed indicated that they had experienced the asylum system. However, due to the methodological focus of the research, I chose not to probe into these experiences, cautious to not contribute any further harm or trauma. Nonetheless, I think it is important to acknowledge these lived experiences in order to be aware of how they shape experiences of health and wellbeing. Glasgow has been the primary location in Scotland for housing people seeking asylum, accommodating around 10% of the UK’s ‘dispersed asylum population’ (Isaacs, Burns et al. 2022, Biggs, Minty et al. 2023). However, the UK’s asylum policies have become increasingly hostile, with negative implications for the health and wellbeing of those subject to the system through direct and indirect structural violence (Isaacs, Burns et al. 2022). Unpacking the impact of the UK’s asylum policies in detail is beyond the scope of this thesis, however, it is important to recognise that the research is situated within diverse contexts, with participants from a range of cultural, economic and political backgrounds, and that the methodological development needs to be sensitive to this. This will be explored in more detail throughout the thesis.

### 5.3.2 Multiple Definitions of Community

Participants in Scotland described community as one or more of the following: a support network, a group with a shared culture and background, and/or community formed through social integration. The most common thread across descriptions of community was the importance of kindness and support, both interpersonal and organisational. Several participants indicated that they enjoyed caring for and supporting others through personal challenges, and valued friends who did the same. This was even more beneficial when friends had experienced similar challenges. The support of local organisations and places of worship also appeared to be central to many participants' understandings of community. Many described how they went to a community organisation meeting/event at least once a week, including women's groups, support groups for asylum seekers and refugees, local African groups or groups at their local church. The activities ranged from creative activities (e.g. cooking, drama, sewing and other crafts), talking and sharing experiences of the asylum process or health issues, to just offering opportunities where people could get together and socialise. Elizabeth described her involvement in several community groups and the support they provided:

M: Do you think that you have a community?

P: Yeah, I have the community. I have the community. I have [community org supporting asylum seekers] community organisation, I have [Glasgow based organisation] African organisation, they support women. I went to woman projects. That is the community and I'm always going. [...]

M: How would you describe your community?

P: My community, they are very supportive. When you have a problem, they...if you will share with them, they try their best to have some... to solve it for you. [Elizabeth\_Female\_Scotland\_Arts Walk 4]

Migrant and refugee community organisations in Glasgow have been shown to support agency and self-determination through practices promoting solidarity, belonging, empowerment and resistance (Piacentini 2015). These organisations fill a significant gap in government policies, providing essential needs, information and resources for those subject to the asylum system, especially

while awaiting confirmation of refugee status (Mayblin and James 2019, Ramachandran 2021, Ramachandran and Vathi 2022). They also form an important site of social connection and informal protection, where migrants, asylum-seekers and refugees can connect through different activities and create trust (Jackson 2014, Ramachandran and Vathi 2022).

Several participants also valued having specific African communities in Glasgow. For example, Halle Berry discussed how her African church was a place where she could meet a range of people and get back to African culture, and how it had been a key factor in her moving back to Glasgow from elsewhere in the UK. The idea that community was something often formed of those with a shared culture, lifestyle, and background was not uncommon. Shan noted that while she did not have many Black friends in Glasgow, there was always a tendency to “*gravitate towards people who understand your language or understand your culture*” [Shan\_Female\_Scotland\_NCD Walk 1]. This was reinforced by Cocoloulou:

“What I’ve noticed is people from the same background they love creating a type of association and community, one, two, three people from the same place, they create a small community and try to share a similar life or culture, something like that.”  
[Cocoloulou\_Male\_Scotland\_NCD Walk 5]

However, the concept of community was not limited to only include those of a shared African background. Many participants also valued their broader connections in Glasgow, acknowledging it was possible to be part of both African and Glaswegian communities simultaneously. This appeared to be partly facilitated by views that Glasgow, generally, is a welcoming place. Cocoloulou emphasised that in Glasgow and in Scotland more widely, people welcome those from elsewhere and that it is “*easy to be integrated in the local community.*” Kathy also emphasised how positive her experience in Glasgow had been:

“Yes! Since I’m in Glasgow, it’s different things, everything different. How they can treat you, how they can talk to you. If you’re new, they can help you. If you go somewhere, you don’t, you don’t know any places, they are going to help you to find the place. That’s why I’m so, so happy in Glasgow.” [Kathy\_Female\_Scotland\_NCD Walk 1]

Positive experiences and integration into Glasgow also appeared to be supported by having a reciprocal relationship with neighbours. For example, Ay shared that while he thought there was “*no official community support system*” [Ay\_Male\_Scotland\_Arts Walk 3], there was still support among neighbours, where they would offer each other advice about their gardens and share skills or tools to do home improvements. Research has suggested that participating in the local community can create a sense of belonging among migrants where they could feel more included and build connections (Jackson 2014, Ramachandran and Vathi 2022).

Finally, experiences of integrating into Glasgow were not unanimously positive. Shan discussed how “*lonely*” she could find it “*in this country*” despite having her immediate family here, highlighting that she and her family had recently realised that “*people still like a lot of privacy*”, something potentially exacerbated by COVID-19 [Shan\_Female\_Scotland\_NCD Walk 1]. Furthermore, some participants (directly or indirectly) acknowledged incidences of racism and prejudice. Favour opened up about a racist incident she had experienced where someone had aggressively told her to “*go back to [her] own country*” while she was just making her way home, minding her own business [Favour\_Female\_Scotland\_NCD Walk 4]. Elizabeth spoke of racism more indirectly; when describing people in Glasgow she noted that “*not all of them are racist*” [Elizabeth\_Female\_Scotland\_Arts Walk 2]. Experiences of racism and discrimination can promote ‘difference’ and act as a barrier to belonging and integration into the local community (Ramachandran 2021). Furthermore, they can have profound impacts on mental and physical health which will be discussed in Section 5.5.1 (Isaacs, Burns et al. 2022).

Diverse experiences of integration with African and Glaswegian communities highlight the complex, dynamic and emotional forms of belonging among migrants, where through ties to their country of origin and their everyday encounters in the UK they simultaneously belong to the “*here*” and “*there*” (Waite and Cook 2011, Wood and Waite 2011, Jackson 2014). This plural belonging can shape communities engagement in health behaviours and self-care practices where practices linked to cultural identity are particularly valued yet can often be in conflict with health messaging (Henry Osokpo, James et al. 2021). Thus, this supports the development of the TABPA as a means to explore

community perspectives on NCD-related health behaviours and inform culturally-situated health promotion interventions.

Finally, some community members acknowledged the differences, and sometimes the disconnect, between ideas of community here and in their home countries. This sentiment was clearly expressed by Ay in the following extract:

“The Nigerian community is a different community from the community here. The community in Nigeria is more... maybe because I was not born here, that would be a factor, because my children seem to enjoy it...The way I *work* here is not the same way that I *worked* in Nigeria, and the community here is not the same as the community in Nigeria. The community in Nigeria is closer. Even the Nigerians in the UK, they are closer in Nigeria than when they are in the UK [*inaudible due to traffic*] - the cost of living in Nigeria is not high, and the structure of *work* is different. There seems to be more time which can be channelled to community bonding.

Also, in Nigeria there is nothing like an old people’s home. The old peoples home in Nigeria is like your grandchildren coming to tell you stories, so you have to take your children to their grandma, and the grandma will tell your children how you were naughty when you were small, what you used to do, and the children start looking at you like “oh!” [laughs]. So, these are the kind of things that happen in Nigeria. But here it’s not the same. Once you grow old, if you can’t stay in your home, you go to an old people’s home, a care home. Also, in Nigeria there’s a lot of parties, every weekend there’s a party. Every Saturday, every Sunday, there’s a party to attend. So, when you are looking toward the weekend you are thinking, which party am I going to? Maybe not everywhere, but the region I came from in Nigeria, in the west, that’s very socialised, in Lagos. We do a lot of parties. You don’t need to have money before you do parties, because people will donate. So, it’s a different ballgame when it comes to the UK. But even... my brother stays [*inaudible*] for almost two years; I’ve never been to his house. It’s a five-minute walk. But in Nigeria, every day, you want to see your brother. And the bills - if you look at, for example, the cost of a litre of petrol, here it is over a pound, almost up to two now. In Nigeria that is around 1500 naira. Here you spend more, so you need to *work* more. No free lunch. So that’s the difference. It’s difficult to be engaged in those kinds of activities like dancing clubs if when you are dancing, you’re thinking “how will I pay my bills?”. And you can’t dance for free here, you dance for free in Nigeria. Maybe because I am not from here, as I’ve said, but I still see so many Nigerians... like my brother, the hobby he has is just sleep.”  
[Ay\_Male\_Scotland\_Arts Walk 3]

Importantly, Ay highlights how the economic and cultural shifts between the UK and African countries can shape understandings and experiences of community,

socialising, work patterns and ultimately health and wellbeing. The social support systems of collectivist cultures like those in Nigeria are in stark contrast to the individualised nature of UK culture. In Nigeria, social support systems facilitate time and financial access to activities that promote fun, social connections and health-related activities, including dancing as a form of exercise. According to Ay, financial worries related to migration and the cost of living in the UK, compounded by limited familial support, mean that work is prioritised over time for social bonding, with important implications for physical and mental wellbeing. The complex impact of migration on engagement with health behaviours and participation in creative activities will be explored further in the Sections 5.4 and 5.5.

## 5.4 Local Arts and Participation

The walkalong interviews also sought to explore art forms that were familiar and accessible to community members. During the walks, community members and I discussed several art forms, including music, singing and dance, drawing, drama and crafts, such as sewing, knitting, and ceramics. The following section will consider some of these arts-based activities, with a focus on the facilitators and barriers to participation among African community members in Glasgow.

Enjoyment of different art forms and access to opportunities were the primary facilitators of participation in the arts. Music and dance were very popular among participants. Community members said they enjoyed listening to range of music including their ‘local’ music, Christian and Gospel music, RnB, Blues, Jazz and Afrobeats. Kathy touched on her love of *Makossa*, a Cameroonian urban and dance music (Nyamnjoh and Fokwang 2005), and highlighted the cultural significance of dance: “*our African people, we like dancing*” [Kathy\_Female\_Scotland\_NCD Walk 2].

Church appeared to be an important space where community members could come together to participate in music and dance. For example, Elizabeth said that “*when I go to church, we dance together as they play the music*” [Elizabeth\_Female\_Scotland\_Arts Walk 2]. Dancing is linked to both socialising and religious practices among African communities (Ibe-Lamberts, Tshiswaka et

al. 2018, Jakub, Turk et al. 2018). Halle Berry had been involved in African dancing as part of Father's Day celebrations at her local church:

“Well for the last Father's Day...we were like, let's just go dance. It was so funny, we did some dancing, some choreography...We just looked for one of those African dances, wore black dresses, we looked for an African print and just tied it across. Like six of us. So yeah we did a dance, it was so funny - most people were like “Oh no, we can't do it!” but in the end everybody had fun...We danced, we asked the media to play the music so we just did the choreography and the dancing - we asked one of the young ones to do the dance for us, and record it and post it on WhatsApp, and everybody was practising, so every time we came on Sunday after church we would do a big practice.” [Halle Berry\_Female\_Scotland\_Arts Walk 4]

Furthermore, Elizabeth noted how community celebrations provided an opportunity for people to share their different cultures and dances.

“We do community party like Winter party, we dance together... many cultures. Many, many, many, cultures, apart from my own country. Many cultures. They dance their own culture. If we see them, we can copy them. They will say come and dance with us.” [Elizabeth\_Female\_Scotland\_Arts Walk 2]

Halle Berry was also very involved in her local church choir. When asked why she had become involved in the choir, she highlighted a sense of belonging originating from her childhood in Nigeria:

“I think from when I was in Nigeria when I was little, my mum used to drag me to choir, I think I just grew up thinking yeah, this is where I'm meant to be.” [Halle Berry\_Female\_Scotland\_Arts Walk 4]”

While church and community organisations provided opportunities for participation in range of arts and crafts programmes (e.g. drawing), not all participants had regular opportunities to participate in the arts. Hannah had previously been involved in singing through a local church but had been unable to continue due to challenges with transport.

“In church I sing. There used to be a place in Glasgow, it's a church, I used to go there, but then they changed it to be in another place - with me moving from [other area] to here, the buses are not the same, so I would've been stranded in town. There's times when I would go to a church [in the southside] But I found it a bit difficult from here, that's why I dropped out.” [Hannah\_Female\_Scotland\_NCD Walk 3]

Other participants had a limited knowledge of local opportunities to participate in art, and some said they were unable to participate because they lacked time and had to prioritise their other responsibilities. Fatima was often unable to attend community arts-programmes because she had a young child .

“Yeah, yeah, you know if I no get time, I need to wait at home because sometimes they tell you don’t bring baby, I cannot, that group, I cannot, so I need to go outside, they tell you don’t bring baby, come, only adults, but I want to do it with my baby.” [Fatima\_Female\_Scotland\_Arts Walk 5]

A lack of access, time and childcare support appear to be common barriers to participation in arts-based activities among minoritised ethnic communities (Netto 2008, Arts Council of England 2018). Interestingly, while some community members did not, or could not, participate in arts programmes themselves, they supported their children to. Both Ay and Cocoloulou said that although they would like to play a musical instrument, they chose to prioritise it for their children instead.

“I don’t really practise [playing music with my kids], I would have loved to, but there seems to be no...there are more important activities, or more prioritised activities than that, because as a teacher I’m always busy preparing my notes, also as a Sunday school teacher in the church on the weekend, so that doesn’t give me much time to be involved with music instruments, though I would have loved to.” [Ay\_Male\_Scotland\_Arts Walk 3]

Some community members’ participation was also restricted by a lack of confidence. Both Rose and Ay said that they were too shy to participate in drama, while others, such as Rose, doubted the quality of their singing. Elizabeth also highlighted doubts about her drawing skills:

“I don’t know how to draw. If you say draw to describe your mood, I don’t know [laughs] But sometimes I try, sometimes I try.” [Elizabeth\_Female\_Scotland\_Arts Walk 2]

Finally, community members described how music, dance, drawing and drama could support both physical and mental well-being. The emotional benefit of music was poetically summarised by Ay:

“Music is like a food for the soul. When people listen to music, they become healthier. At times it lifts them out of their depression or

their worries... At parties [in Nigeria], the musician plays music and people dance. When they come home, they feel refreshed and have something to talk about, so they forget their sorrows.”  
[Ay\_Male\_Scotland\_Arts Walk 3]

Research with Nigerian migrants in the United States also demonstrated how Nigerian parties are an important space for dancing, with both psychological and physiological benefits (Ibe-Lamberts, Tshiswaka et al. 2018). However, some participants in the study indicated that parties can also encourage unhealthy behaviours such as excessive eating and drinking (Ibe-Lamberts, Tshiswaka et al. 2018). Later in the interview, Ay also suggested that although music and dance held benefits, they could be “*abused*” if done in combination with substance use.

P: So music is a food to the soul, it relaxes the brain, and if you can dance it makes you healthier, so its good thing for anyone who can do it without abusing it. Because it can be abused

MB: How so?

P: If you are saying you want to dance away your sorrows and you are on drugs, just because you want to be a dancer, then you will be destroying yourself, that will no longer be healthy.  
[Ay\_Male\_Scotland\_Arts Walk 3]

## 5.5 Community Health and Noncommunicable Diseases

Having explored definitions of community, experiences of belonging and participation in local arts, the following section will explore community perceptions of health, with focus on diabetes and hypertension.

### 5.5.1 Community Health Concerns

Community members in Scotland discussed a range of health concerns that were important to them including obesity, nutrition, cancer, mental health, diabetes and hypertension. When asked about health in Glasgow, there appeared to be some consensus among participants that health is generally poor in the city.

“Health in Glasgow... well I know a lot of people go to the hospital, they’ll pull out medications, people have prescriptions. Well, I don’t know if I’ll take a lot, but I’ve seen so if I...compare those who don’t have prescriptions, who are not on one medication or the other, to

people I know that do, I mean, I don't, it's quite higher. I know more people that have condition or the other and I mean I'm not saying that to put them down." [Shan\_Female\_Scotland\_NCD Walk 1]

According to the 2022 Scottish Health Survey, 37% of adults in Scotland reported a limiting long-term health condition (Scottish Government 2023). Glasgow has the lowest healthy life-expectancy (years lived in 'very good' or 'good general health) and the lowest overall life expectancy in Scotland (Whyte, Young et al. 2021). In Greater Glasgow and Clyde, 28% of adults were estimated to be obese between 2016-2019 (Whyte, Young et al. 2021). Scotland and Glasgow have well documented poor health profiles associated with deindustrialisation, high levels of deprivation and poverty (Walsh, McCartney et al. 2017, Whyte, Young et al. 2021). Socioeconomic positioning has also been linked to differences in health inequalities for ethnic minority groups. According to the Scotland 2011 Census, people describing themselves as African, Caribbean or Black are more likely to be living in deprived areas than the White population, which has important implications for health and wellbeing (Walsh, Buchanan et al. 2019).

It is important to consider these complexities, as the conditions in the host country can shape the health and NCD risk of migrants (Agyemang and van den Born 2019). For example, a study by Kearns, Whitley et al. (2017) found that the health of both social and economic migrants and asylum-seeker/refugee groups was often better on arrival to Glasgow than the wider population. The health of social and economic migrants declined with time spent in Glasgow, while for asylum-seeker/refugees, the pattern was more complex and influenced by migration route and status.

As in Malawi, diabetes and hypertension were also important to community members in Scotland. As highlighted in Chapter 1.1, African, and Caribbean communities have a greater risk of diabetes and hypertension than the White British population (Lane, Beevers et al. 2002, Agyemang and Bhopal 2003, Goff 2019). The majority of community members interviewed had some experience of one or both conditions, either personally or through friends and family. Cocoloulou highlighted that he had observed a high rate of diabetes and high blood pressure among his friends and communities:

“Diabetes is so many people, many people around me - African people, Cameroonian people. I’ve not heard about other communities, maybe it’s because we don’t talk as closely, but many people around me I can see it with them.” [Cocoloulou\_Male\_Scotland\_NCD Walk 5]

“I feel like [high blood pressure] is so common now, my friends say oh I wasn’t feeling well and the GP said I’ve got high blood pressure - I’ve heard that from many people and thought what’s going on, what’s happening.” [Cocoloulou\_Male\_Scotland\_NCD Walk 5]

Furthermore, Elizabeth shared her own experience of diabetes, highlighting her personal challenges with controlling the condition.

“[Diabetes is] a very terrible disease. It's not nice. It's not nice, very bad disease. You cannot control it. You cannot control it at all. You cannot control it. Sure, sometimes if you don't even take anything, if you don't watch it to test yourself two months, three months. If you believe that everything is OK, if you test you, we know that everything is not OK.” [Elizabeth\_Female\_Scotland\_Arts Walk1\_Scotland]

Elizabeth’s struggle to manage her condition is not unique, studies have highlighted that there are complex migration and lifestyle related barriers to diabetes management among African migrants, which are compounded by a lack of culturally-situated diabetes education and management programmes (Alloh, Hemingway et al. 2019, Goff 2019, Ntanda, Sia et al. 2024). These are explored in more detail in Section 5.5.2.1.

Finally, mental health and wellbeing also emerged as an issue of concern among many participants. Research has shown a high incidence of mental health issues, including anxiety and depression, among African migrants (James, Renzaho et al. 2022), and refugees and asylum seekers have been shown to be more likely to experience poor mental health than the general population (Tribe 2002). Migrants’ mental health is impacted by pre, inter, and post-migration stressors (Pavli and Maltezou 2017, Agyemang, van der Linden et al. 2021). Post-migration factors may include racism and discrimination, fear of deportation, poor living conditions, unemployment or a lack of social networks (Agyemang, van der Linden et al. 2021, James, Renzaho et al. 2022). As touched on in Section 5.5.1, Favour reflected on how experiences of racism in Glasgow had caused her anxiety, negatively affecting her and her daughter’s mental health.

“You know the community thing. If you're talking about the community, sometimes there are some racists and some kind people, Yeah, like you, already, you know, when you are with them you feel comfortable. You don't have anything bothering you, and there's some being, like, what are you doing here? In my country? Something like that. So, you find different kind of challenges. So, which is really affecting mental health normally because I have, for me for example, now like anxiety, something like that. So. I'd say it's both. They're just like sometime my, even my daughter, she's having some challenging in school like that, like some other people the way they are treating [her].” [Favour\_Female\_Scotland\_NCD Walk 4]

Racism and discrimination can not only impact mental health, but can also limit engagement in health behaviours, like walking, by contributing to anxiety in public spaces (Isaacs, Burns et al. 2022). Community groups can serve as a protective factor for mental health, where those subject to the asylum system could come together to share experiences or participate in creative activities (Ramachandran and Vathi 2022). Favour went on to describe how attending a local woman's group could be helpful when she felt down.

“Sometimes I, I take some woman's programme. I take some woman's programme which is helpful, which you share, you know sometimes when you don't see anybody you share your problem with, it can make me feel down, if I feel these thoughts, stuff, so things like that...” [Favour\_Female\_Scotland\_NCD Walk 4]

### **5.5.2 Community Knowledge and Perspectives of Diabetes and Hypertension (BP)**

The following section will explore community knowledge and perspectives on the drivers of diabetes. It will delve deeper into some of the cultural and migration-related influences on diet, including the availability of, and access to, traditional foods and cooking practices, and consider how these changes have influenced diabetes and hypertension risk. It will then explore facilitators and barriers to physical activity as described by participants, and some additional drivers of hypertension. The section will then touch on community knowledge of the symptoms and impact of diabetes and hypertension and conclude with a description of health-seeking behaviours.

### 5.5.2.1 Migration, Culture and Food

As noted in Section 5.3, participants came from diverse cultural backgrounds and discussed a range of food preferences. For those participants from Nigeria, jollof rice was often a staple. Fish, plantain and yams were also staple foods, particularly among those from West Africa; while Hannah from Malawi discussed foods like nsima, beans and pumpkin leaves. In Glasgow, the accessibility of traditional foods was mixed. Almost all participants were aware of local African food shops, although most noted that they would only visit them for something specific, like grey fish or cassava. As highlighted by Cocoloulou, this was primarily because specialised African shops were too expensive:

“Yeah, you’ve got so many African shops and they’ve got all of this, but the only problem is that they’re very expensive compared with when we go to Tesco or Asda to get something to cook or something to eat. You can eat African food like back home, but it’s really expensive.” [Cocoloulou\_Male\_Scotland\_NCD Walk 5]

Access to affordable African foods appears to be higher in areas of high diversity, for example, in cities like London, Birmingham and Manchester, where competition between several independent providers and mainstream supermarkets can keep prices lower (Asamane, Greig et al. 2019, Osei-Kwasi, Boateng et al. 2023). The size of Glasgow’s non-White ethnic minority population varies across the city, ranging from 2% to 56% in different neighbourhoods in 2011 (Kearns, Whitley et al. 2017, Walsh, Buchanan et al. 2019). During one interview in the northeast of the city (where ethnic diversity is reasonably high), Kathy pointed out an African shop we had just walked past, highlighting that she could access traditional foods both there and in her local Tesco.

P: Yes, this is our African shopping [shop].

MB: What kind of things do you get there? Do you go there a lot?

P: I don’t go there a lot. I go for our fish, fish, African, yam, yes. Fishes or fish or African meat or fried chicken, but also Tesco sell some African things. Yeah, because this area, there are many Africans live in the area, that’s why they also sell African things there. [Kathy\_Female\_Scotland\_NCD Walk 2]

Kathy enthused about how much choice she had at her local Tesco superstore and took me there during her walkalong interview. She showed me where she would buy lemongrass to make her tea, as well as vegetables including cassava and yams, and explained how she would prepare them. She also took me to another aisle that stocked more processed African foods like plantain chips, as well as Afro-Caribbean carbonated and malt drinks. However, not all supermarkets are so well stocked. On a walk with Favour, we went to two supermarkets, one in her local area and one in the city centre, to pick up chicken and long-grain rice to prepare jollof rice for her birthday dinner. However, neither supermarket had the specific rice she was looking for. Therefore, the accessibility of African foods appeared to vary with the level of ethnic diversity across the city.

Some participants highlighted that due to cost of African traditional foods, they had learned how to incorporate cheaper British vegetables into local dishes. Shan discussed how the combined cost and poorer quality of imported African foods had led her to adapt her cooking.

“...when I moved, I realised that the foods, even though they’re supposed to be the same, they were not the same...like the same I would eat back *home*, but it’s still not the same because they’re probably not sown here. I mean grown here. They’ve been brought in or not. So, they’re basically not grown locally. And most of them, they’re still imported. And then... and I like them... I like things fresh... So, I thought, well, okay you know what ... and then I consider it was also more expensive than the regular food I would eat here and then I thought, OK, look, if you have to do with my budget. I gotta be wise. What can I eat that is local? That I can enjoy and adapt you know. And so, I eat both, my own kinda food, but I use the food here to, you know, I mean, I just. Yeah, mix it up...” [Shan\_Female\_Scotland\_NCD Walk 1]

This finding is consistent with research on dietary patterns among Ghanaian migrants in Manchester, where substituting local ingredients supported the continuity of Ghanaian dietary practices while living in the UK (Osei-Kwasi, Powell et al. 2017). Hannah had similarly learned to integrate British vegetables into her Malawian cooking; however, she recognised that this was a challenge when she first came to the UK, because she did not know how to prepare them. Hannah described how sharing knowledge about food with friends and

neighbours meant that she could learn to cook British foods, while also sharing her own cultural food knowledge with others.

“Normally the foods I buy I would know how to prepare them, but there were some foods which I didn’t know how to prepare. There are some veggies, like now there is kale, which I’d always just cook the same as things back home - we have a vegetable at home which looks the same as broccoli when it’s still young, and we cook it and eat the leaves. Here you don’t eat big leaves. When I lived in England, someone was surprised at the leaves I ate, but then I prepared some for her and she loved it and started cooking it for herself. Just from watching one another you’ll know, and you can see the benefits. It’s just exchanging knowledge on how to prepare food.”  
[Hannah\_Female\_Scotland\_NCD Walk 3]

The preparation and consumption of African foods has been shown to be strongly associated with cultural identity among African migrants in the UK (Osei-Kwasi, Powell et al. 2017, Asamane, Greig et al. 2019, Osei-Kwasi, Boateng et al. 2023). Halle Berry highlighted that one way to engage members of the African community in NCD prevention initiatives was through food, an activity that was viewed as worthwhile among other financial and social pressures.

P: I think ways of engaging more African culture would be maybe a food activity, but also you can show one way and then an alternative - like this is your ingredient, or you can use this alternative ingredient, you know? I remember one time in church that was the way we were able to get people out, because there’s this lady, she’s always cooking for us, so as an activity in church we invited all the ladies over for a cooking session.

M:...What did she cook?

P: Famous jollof [laughs] her jollof is always very unique, so we said okay, what we’ll do is just have a day out on Saturday, and everybody just come in and she’ll show us how she does it, and we can all... of course, during that period there is chit chat and... I think that’s one way of really getting us, because most Africans coming [to the UK] initially, it’s all focused on work. So, any other thing is like extra, for good reason... [Halle Berry\_Female\_Scotland\_Arts Walk 4]

Qualitative research with ethnically diverse older adults in Birmingham found that attending groups organised by faith centres and community organisations influenced eating behaviours and similarly suggested that these groups could be explored further as means to support healthier, traditional cooking methods (Asamane, Greig et al. 2019). Furthermore, recent studies have supported the

feasibility of culturally and community situated interventions involving cooking lessons as an acceptable means to promote healthy eating among African-Caribbean communities (Goff, Rivas et al. 2021, Moore, Kundra et al. 2023).

Many community members recognised the association between diet, diabetes and hypertension. Consuming too much salt, sugar and ‘junk’ food, and too few vegetables were understood as some of the main causes of diabetes and recognised as aspects of diet that needed to be monitored in order to control the condition. Salt was also understood as a specific driver of hypertension. Cocoloulou highlighted that in his home country of Cameroon, diabetes was often associated with wealth due to the cost of foods high in sugar, and that these foods were generally more accessible in the UK.

“[Diabetes] is something very common in my community - we call it an illness for posh people. You get it from too much sugar, and the only people who have money to be eating chocolate are posh. In my country it’s not like here where you’ve got access to every food. For us, we understand that it’s from consuming too much sugar, but you can see there are so many factors beyond that.”  
[Cocoloulou\_Male\_Scotland\_NCD Walk 5]

The association between diabetes and wealth is common across sub-Saharan Africa, where research has demonstrated that communities perceive the association to be driven by factors linked to urbanisation (Zimmermann, Bunn et al. 2018). Elizabeth also recognised how the (Western) Scottish food environment had negatively influenced the health of members of the African community in Glasgow.

“Yeah, other things the way the people, or people, African people, the way they eat now here in Glasgow is, they eat, they eat too much. It’s not like in Africa, in Africa we control our diet. They eat too much, you know, sugar, sugar, sugar, they told me it’s high, because all the food here in the is here, in Scotland, they just put sugar, sugar. That was sometimes, some people, they have weight now, they gained weight now. I say oh my goodness, I see it’s true, It’s true. You told me the truth. But you have to control your weight, especially me too. I wasn’t like that when I came here, I was so, so slim. But we go for this food, I say wait, I have to control myself [laughs] I don’t want to gain weight.” [Elizabeth\_Female\_Scotland\_Arts Walk 2]

While there is much variation in the consumption of sugar and starch across Africa (Manyara, Mwaniki et al. 2024), studies have indicated that dietary and

lifestyle change associated with migration and a lower socioeconomic status can lead to increased access to and consumption of fast-foods, including those high in sugar and salt (Gilbert and Khokhar 2008, Ntanda, Sia et al. 2024). However, dietary acculturation is complex, and other studies have indicated that migration can contribute to healthier eating through processes such as social support and improved access to knowledge about nutrition (Osei-Kwasi, Powell et al. 2017).

Many African staples, including rice, yams and cassava, are high in starch and sugar. Research has shown that type 2 diabetes health messaging advises limiting carbohydrate intake, which, without culturally-situated communication and support, can be challenging for African patients (Alloh, Hemingway et al. 2019, Moore, Rivas et al. 2022). Several participants were aware of people who had experienced difficulty with dietary change following a diagnosis of diabetes or hypertension. Elizabeth, who has herself been diagnosed with diabetes, shared her personal struggles with avoiding rice despite knowing it could raise her blood sugar.

“I notice that you should reduce... when you come to some age, you should reduce sugar. If you notice what we are eating, like me, I notice when I eat rice, [my blood sugar] go up. Because I do take some tests. My GP told me it's high, I say I'm trying my best, but I don't know, what is, what is happening with it, but I know it's rice. We cannot avoid it. This is our food, you know, rice is a part of our food. I cannot do it without eating it, but I reduce it.”  
[Elizabeth\_Female\_Scotland\_Arts Walk 2]

The cultural importance of carbohydrates, practical challenges (e.g. in changing staple recipes) and social expectations from friends and family when sharing food together can create barriers to sustainable dietary change (Moore, Rivas et al. 2022). Thus, it is not surprising that cutting out rice is not a sustainable option for Elizabeth.

Several community members also indicated that dietary change was possible with appropriate discipline. Some argued that people in their community were aware they should eat more healthily, however, some did not care or found it too difficult. Others gave examples of how they personally had changed their diet, by not buying unhealthy foods, cutting down slowly or eating unhealthy

foods in moderation and increasing their fruit and vegetable intake. Favour highlighted that although her daughter preferred junk food, she would encourage her to eat healthily by not buying junk food routinely, and instead cooking healthy meals at home.

“I don't go out buying junk for my daughter. I don't do it. I eat, I cook in my house. I cook healthy food, I eat healthy food so that sometimes, you know, she's a child, I treat her sometimes, which is some wrap with veggies...that's it, it's not easy, but it's something someone can work on.” [Favour\_Female\_Scotland\_NCD Walk 4]

Finally, it was interesting to note that, although only two men were interviewed, neither were responsible for cooking in their family. Goff, Moore et al. (2021) reported similar findings from their study with UK African Caribbean communities, where male participants primarily relied on their wife or partner for food. Both Ay and Cocoloulou said that their wives were responsible for cooking in their household and preferred them not to get involved. The reasons for both men appeared to be linked to cultural gender norms. Ay pointed out that he felt that if he were cooking, he would think his time would be better spent doing other things, particularly work, whereas Cocoloulou said he had never really had to learn to cook because of the structure of his family at home.

“Where I come from, from my parents in Africa, we have a very, very big family. In our home there could be more than 20 people and so many ladies too. So, I've never had the opportunity to go into the kitchen [laughs]. I was also very lucky when I came here and met my wife, she's great at cooking and she loves cooking, so she never allows me to cook.” [Cocoloulou\_Male\_Scotland\_NCD Walk 5]

Kathy suggested that women might be even more affected by noncommunicable diseases because they are the ones making (and therefore tasting) the food:

M: Do you think anyone is more or less affected? Like young people, old people, men or women?

P: Yes, I think so, especially for women, yes, young women, all women, especially women, women or men, yes. But especially women because they, they eat too much. They're the people who cook first [laughs] you go when you cook, always you want to taste the food, taste, taste, taste it. [Kathy\_Female\_Scotland\_NCD Walk 2]

### 5.5.2.2 Facilitators of and Barriers to Physical Activity

While community members in Malawi rarely discussed exercise, participants in Scotland highlighted that it was a way to prevent and control diabetes and hypertension. Participants themselves engaged in a range of exercise from walking regularly to gym classes and organised sports. Enjoyment and a personal motivation to keep healthy were important facilitators of this, with several participants noting the benefits of walking or playing football with family.

“Yeah. You go for [a] walk to explore, you know, to have fresh air, I like to exercise, to be...to tell the truth. I like to exercise...that’s why I love walking, especially in summer.” [Hannah\_Female\_Scotland\_NCD Walk 3]

“Every Saturday except today...we play football, the children and my friends, as a way of hanging out together, we play football every Saturday from 4 o’clock to 6 o’clock, just to keep everybody fit.” [Ay\_Male\_Scotland\_Arts Walk 3]

However, not all participants had physical or financial access to designated exercise spaces. Some members said that they had previously been members of their local gym; however, due to the pandemic and rising costs they had to stop.

“I like this body attack [gym] class. I used to go but when, when the COVID came down, I stop because you have book to go there... And then when I want to go to sign up it was difficult for me to book it. They also they increase the price of the gym. I stop it...But if I have opportunity, they can put the price down for the gym for the body attack, I can go. I like it. I used to go two days, two times a week, Thursday and Saturday.” [Kathy\_Female\_Scotland\_NCD Walk 2]

A report by Sport England (2024) indicated that while participation rates in physical activity have remained stable since pre-COVID levels, rising energy costs associated with the Cost-of-Living Crisis have negatively impacted the physical activity levels of those from the most deprived areas and from lower socioeconomic backgrounds. Furthermore, some participants highlighted that they had no gym at all in their local area or did not know where they could go. The additional burden of having to travel to the gym was noted by Hannah:

“If I had time, I would go to the gym, but there are no gyms nearby...that’s the other problem, you have to travel to get to the gym.” [Hannah\_Female\_Scotland\_NCD Walk 3]

This extract highlights the additional time and financial burdens of trying to access fitness facilities by having to travel and pay for public transport. These findings are consistent with qualitative research highlighting the socioeconomic barriers to physical activity among Black communities, including the cost to access community exercise facilities (Ochieng 2011).

Finally, some community members discussed forms of physical activity that were more accessible. Favour emphasised that some people might be ‘lazy’, but doing chores, going for walk or engaging in online classes were a good and affordable way to keep moving.

“Some people they are lazy to even in their house to do some chores. House chores is part of exercise as well when you wake up in the morning, you begin to tidy up everything in your house. By the time you’re moving up and down, go upstairs, take the bin outside, cleaning the bathroom, tidying up the kitchen, cooking. Sometimes I spend four hours in the... doing my house something..., I’m doing this, I’m just sitting down. But if you can do that one, it’s still part of exercise, when you’re walking, you move your body. So, all the blood vessels, everything, is moving. It’s not that you sit down. Some people wake up in the morning, sits down in one place, eating after you say sit down. Everything is accumulating... and eating. So, I think if we can engage ourselves in some walking exercise, some people, it might be lack of maybe, they can’t afford, you know so like me, when I came, I was doing the YouTube [exercise videos].”  
[Favour\_Female\_NCD\_Scotland\_Walk 4]

The benefits of online physical activity were echoed by Kathy who highlighted how online dance classes via her a local community organisation had been an enjoyable form of exercise through the pandemic.

“I like it when you talk about dance. I like to do it; I remember during the COVID we used to have the gym dance on the online zoom during the COVID I went there for something like that. The put it in a community group, I went there. I used to do it during the COVID. At first it was every Thursday, something like that, but then it was the Body Attack, so it was exercising online, exercise, I was doing the same at home. It helped me a lot, it helped me a lot during the COVID” [Kathy\_Female\_Scotland\_NCD Walk 2]

Walking and dancing have been suggested as culturally-appealing forms of exercise among African communities in high income countries (Ochieng 2011, Moore, Rivas et al. 2022). However, as indicated in Section 5.5.1, it is important

to recognise that walking can also come with safety concerns due to racism and discrimination (Ochieng 2011, Isaacs, Burns et al. 2022).

### 5.5.2.3 Additional Drivers of Hypertension

Several community members also recognised that stress, overthinking and a lack of sleep can contribute to hypertension. Shan elaborated how stress could interact with physiological process and diet to contribute to the condition.

“So, I think your kidney needs to be in top shape to help with body pressure. And I think stress could also be, not could... I believe it is a huge contributing factor to how our body actually uses water intake anyway. If you're not having enough sleep, if you're, you're constantly under pressure, you're going to have high cortisol levels, so it's just going to all contribute to how is your body even having the time, the space, the room it needs. Do they even work? So, in addition to food, stress and your body organs, for me, play a huge role in high blood pressure.” [Shan\_Female\_Scotland\_NCD Walk 1]

However, even though participants mentioned several causes of hypertension, some were still confused by the condition, unsure of how the different risks might interact. This confusion was reinforced by Rose, who, following her own hypertension diagnosis, was still unsure as to what had caused it:

“I don't know what causes high blood pressure, they will say maybe when you are thinking, you are worried - but some people will say maybe it's in the blood, maybe your parents have it, it's in the genes - I don't know what causes it but at times I've just discovered that it'll just go up without anything, so I don't know.” [Rose\_Female\_Scotland\_Arts Walk 1]

### 5.5.2.4 Symptoms and Impact

Community members had mixed knowledge about the symptoms of diabetes and hypertension. Shan had heard that people with diabetes have wounds that do not heal, while Cocoloulou and Kathy highlighted that people with diabetes have extreme fatigue and could sometimes faint. Rose said she would experience headaches and arm pain from her high blood pressure. However, community members indicated that it was often difficult to know if someone had diabetes or hypertension, as the symptoms were rarely observable. Shan suggested that while there might be no observable symptoms for high blood pressure, if people

pay close attention to their body, they might be able to determine if something is wrong.

“I think that if you're going very familiar with your body, you can actually tell if something is alright, but the signs may be very faint. The symptoms may not even really be there, but you would the way the body has a way of speaking, even if it's softly. So, I think that if one pays attention even if you're not sure what it is, you can get checked [...] I think recognising the way our body presents it's a personal thing because it's not... I don't think it's something that will show physically, personally because I've seen people that seem very healthy and still die from high blood pressure. Yeah. So, I don't think it's something that would personally, you know, have signs and symptoms that would be really easily. No, no, there will be symptoms, now the symptoms you may see someone else may not notice. So, I think it's quite personal, once you observe, even if you're not sure what it is, just get checked. You know, so you have an idea what's been going on, you know?” [Shan\_Female\_Scotland\_NCD Walk 1]

Research has suggested that many African migrants use body cues to monitor, interpret and describe their symptoms (Henry Osokpo, James et al. 2021). One study showed that African participants trust their bodies to make them aware of changes in their blood pressure, so that they could then take action, including rest or seeking treatment (Beune, Haafkens et al. 2010).

Some community members were also aware of how the conditions could impact people's lives. Kathy said that the fatigue from diabetes could make it “*difficult to do anything you want to do with your life...you feel tired, you cannot go*” [Kathy\_Female\_Scotland\_NCD Walk 2], while Elizabeth, who'd struggled to control her diabetes, highlighted that it had not been easy for her:

“It is a disease for life, it is for life, ah it's not easy. You cannot eat what you like. You cannot, unless you control the amount. If you control the amount, you will control the sugar, you will not like it again. Sometimes we feel normal, but once in a while you will eat it, no matter if we control everything you want to control. You understand?” [Elizabeth\_Female\_Scotland\_Arts Walk 2]

This appears to be a common experience among migrants living in high income countries, where changes associated with migration can create cultural, social, and socioeconomic barriers to diabetes management (Alloh, Hemingway et al. 2019, Henry Osokpo, James et al. 2021).

### 5.5.2.5 Health Seeking Behaviours

Despite challenges in the control of diabetes and hypertension described above, participants described medical care and diagnosis as generally accessible.

Participants predominantly sought diagnosis and treatment from their General Practitioner (GP), who appeared to be a trusted source of health information and advice. For example, Kathy described her GP as “*very, very helpful*”.

Research with West African migrants has supported the sentiment that accessing care is feasible and affordable in the UK, particularly in comparison to West Africa (Alloh, Hemingway et al. 2021). Similarly qualitative research with African and Caribbean individuals with type 2-diabetes found that participants generally valued UK healthcare (Moore, Rivas et al. 2022). However, a qualitative systematic review highlighted broadly negative views and experiences of primary care among Black communities in the UK, including a mistrust of clinicians and the health system, language and financial barriers, cultural disconnects, prejudice and the social context of the primary care system (Ojo-Aromokudu, Suffel et al. 2023).

The main challenges with primary care for participants in the current study appeared to be systemic challenges with the National Health Service (NHS). Kathy highlighted that it could sometimes be difficult to get an appointment with her GP.

“The GP, the doctor now is difficult because many appointments that are so full at the moment, we don’t have any space to pay your appointment. All these things.” [Kathy\_Female\_Scotland\_NCD Walk 2]

Similarly, Shan said although her own experiences of accessing health care had been easy, she acknowledged that this may not be the case for everyone due to differences between individual GPs and work conditions in the NHS.

“Well for me, my family, we’ve been able to access care in this country, but I’ve also heard people say things like oh I’ve been on the list for that, waiting list for that, so I wouldn’t really know, if I speak to myself, it’s quite accessible. Yeah, you know, especially I think that if it’s pressing, urgent and they are aware, now in saying they, I’m also aware that they, medical professionals, are also different in the attitudes to their work, I mean, they know that, yes, they’re supposed to be caring people but, it’s like a teacher, on the surface every teacher wants to teach the child, but the truth is, it comes down to

the person... I think it's accessible, but I also think that the attitude and the responses of practitioners may affect this, and sometimes that attitude and response may not be directly due to their own fault, it might be the conditions of work, but I've experienced access, easy access when I needed, so yeah.” [Shan\_Female\_Scotland\_NCD Walk1]

The NHS is largely ‘free at the point of use’, yet it has been under immense stress due to a lack of capacity and growing financial and social pressures (Bhat, Easwarathan et al. 2022, Boyle 2023, Cooksley, Clarke et al. 2023). Scotland is also facing large challenges in GP recruitment and retention, with evidence suggesting a 3% decline in the number of full time GPs in Scotland between 2019 and 2022 (Public Health Scotland 2022, Donaghy, Huang et al. 2024). Thus, while community members in this study described care as generally accessible, communities are likely to still be affected by national healthcare challenges (Otu, Ahinkorah et al. 2020, Ojo-Aromokudu, Suffel et al. 2023).

Finally, community members were knowledgeable that diabetes and hypertension could be controlled through a combination of lifestyle modification (diet and exercise), adhering to medication and by monitoring blood sugar and blood pressure. This was well summarised by Favour when describing how to maintain good health.

“All what I can say is that it’s good when people check in on their health, go for regular check-up and then maintain your health. If you're diagnosed with diabetes or hypertension, high blood pressure, to follow the rules of the GP, what they tell you to be doing and take your medication regularly and engage yourself in exercise. Eat healthy is most important. Healthy... don’t eat healthy is the one that cause most sickness. Now you should eat healthy, do some exercise. It’s 20 minutes a day, 30 minutes a day. Engaging ourselves in some exercising. And check-up, I think check-up on Diabetes every, one year, I don’t know. After a year, you do check it again.”  
[Favour\_Female\_Scotland\_Arts Walk 4]

## 5.6 Summary

This chapter reported the findings from walkalong interviews with African community members in Glasgow, Scotland, exploring the complex and dynamic contexts that shaped the Scottish component of the TABPA methodology. Walkalong interviews were a useful and generally acceptable way to build relationships with community members, generating everyday encounters and

providing an in-depth understanding of daily practices, particularly walking and food shopping.

The African community in Glasgow is a heterogeneous population with a range of experiences, backgrounds and cultural practices. Participants were all first-generation migrants from Nigeria, Cameroon and Malawi, many of whom have been subject to the asylum system. The context of migration brings complex socioeconomic, cultural and social, political and environmental influences on how community members exist in everyday life, participate in local art and experience health, including diseases like diabetes and hypertension.

Community, as described by participants, is multiple and complex. Participants belonged to communities of care and support facilitated by community-based organisations and local churches, shared African cultural communities and the Glaswegian community. While experiences were broadly positive, racism and discrimination could also prevent social integration into Glasgow, with negative implications for health and wellbeing. Engagement and participation in arts-based activities was primarily facilitated through religion and community groups, who could also support engagement in culturally-specific forms of music and dance. However, there were still barriers to participation, including time, lack of opportunities and limited confidence.

Community members described a range of health concerns and revealed that diabetes and hypertension were prevalent and of concern in their communities. Several of the participants had been diagnosed with one of the conditions themselves. When sharing their knowledge on diabetes and hypertension, communities highlighted that diet and physical inactivity were key drivers of both conditions. Perceptions and attitudes towards diet were strongly related to cultural identity, migration, access to certain foods and health concerns. Participants in Scotland also appeared to value physical activity more than those in Malawi. They highlighted activities including walking, dancing and the gym as ways to stay active; however, the latter was often not accessible due to socioeconomic, access and time-related barriers. It appeared that knowledge of the symptoms and impact of diabetes and hypertension were mixed, where those with a diagnosis appeared to hold the most knowledge due to first-hand experiences. Finally, unlike Malawi, health care was described as generally

accessible, although there was still a recognition of systemic challenges in the NHS.

## **5.7 Reflections for TABPA Development and Implementation**

### **5.7.1 Walkalong interviews**

The Scottish walkalong interviews provided three key findings which informed the Phase 1 workshop and the development and implementation of the TABPA methodology (RQ1).

1. Community perspectives on local art revealed that community members generally had positive attitudes towards, and experiences of, a range of arts-based activities, most notably music and dance. This finding supported the feasibility of an arts-based approach by suggesting that community members would be likely to engage in a range of creative activities. However, the walkalong interviews could only provide a limited understanding of how community members might engage with these different art forms in a workshop setting and their utility as a means to explore perspectives on diabetes and hypertension. Therefore, Phase 1 community and stakeholder workshops were designed to build on this initial knowledge and explore what art-forms would be best integrated into the TABPA workshops (See Chapter 6.2).
2. Gaining an in-depth understanding of community attitudes towards diabetes and hypertension demonstrated the significance of these diseases for community members in Scotland. Therefore, the walkalongs supported the choice of hypertension and diabetes as a focus of the TABPA workshops for implementation in Scotland.
3. Some community members highlighted that although they would like to engage in creative activities, they could face barriers, including a lack of time and access. Thus, all Phase 1 and the Phase 2 TABPA workshops in Glasgow were organised at city-centre locations that could easily be accessed by public transport and possible dates and times were

negotiated around participant's commitments (e.g. work, school runs, other community groups) as far as possible.

### **5.7.2 Walkalong Interviews as Preparation for TABPA Implementation**

Overall, the walkalong interviews were fundamental as means to gain a deeper understanding of the cultural, social and political contexts that might shape community engagement with the TABPA. For example, gaining a fuller understanding of community members' backgrounds and experiences, better prepared me to navigate sensitive issues that emerged in later TABPA workshops, including participants' experiences of immigration and the asylum system (see Chapter 8.3.5). The walks were also important as a way to build relationships and establish trust with community members. Indeed, building connections through these walks directly supported recruitment for Phase 1 community workshops and Phase 2 TABPA workshops.

However, I recognise that these findings are particularly important given my status as an outside researcher. The culmination of this study aims to provide a TABPA framework that can be used by researchers, practitioners and communities themselves to explore community perspectives on health behaviours to inform culturally-situated NCD prevention interventions. Established community groups and practitioners who choose to utilise the TABPA framework in practice are likely already equipped with an in-depth understanding of, and shared experiences with, the communities they are working with. Therefore, they would be less likely to require walkalong interviews to familiarise themselves with the community and the wider contexts, although this will depend on their established relationships and expertise. This will be discussed further in Chapter 7.6.

## 6 TABPA Development in Two Contexts

### 6.1 Introduction

In Chapters 4 and 5, I explored the findings of Phase 1 walkalong interviews in Malawi and Scotland and reflected on how community perspectives on community, local art and health would inform the development and implementation of the TABPA methodology. While these walkalongs provided a thorough understanding of the diverse contexts within which this research is situated and suggested that communities were open to engaging in arts-based activities, further research was required to explore how communities might engage with the TABPA workshops in practice.

I conducted Phase 1 community arts-based participatory workshops in Malawi and Scotland to gain a better understanding of what art forms were compatible with community interests and adaptable to explorations of NCDs, specifically diabetes and hypertension. I also used the workshops as an opportunity to gain a practical understanding of how community members might engage in arts-based participatory workshops to reveal possible strengths and challenges with the approach and inform the structure of the Phase 2 and Phase 3 TABPA workshops. In Malawi, I worked with Luke (see Chapter 3.4.1.3), an experienced Malawian arts practitioner, to run two single-gender community workshops in Sector A. In Scotland, I recruited Christiana (Chapter 3.4.2.3), an experienced participatory artist, to support one women's community workshop in Glasgow. As previously noted, due to challenges with recruitment, we were unable to run another workshop for men in Scotland (see Chapter 3.4.2.4).

While community perspectives were fundamental to develop a TABPA framework that reflected their interests, it was also important to learn from the experiences of local stakeholders in Malawi and Scotland. I, therefore, organised stakeholder workshops in each setting to explore their perspectives on the local capacity for arts-based health research and their experiences of working with local communities. In Malawi, key stakeholders included the local chiefs, health surveillance assistants (community health workers) and local artists. In Scotland, key stakeholders included representatives from community organisations working

with minoritised communities and experienced in community arts, and the pastor from a local African church.

In this chapter I will explore the thematic findings from the Phase 1 community and stakeholder workshops in Malawi and Scotland. In doing so I will continue to explore how community and stakeholder perspectives and experiences can inform the development of the TABPA methodology (RQ1). The chapter will begin by considering what art forms are compatible with community interests and adaptable to explorations of hypertension and diabetes. This will be done by reflecting on what art forms community members chose to use in Phase 1 workshops and why, as well as stakeholder perspectives on why different art forms may be more or less appealing in community health contexts. Examples of creative outputs from the community workshops will also be analysed to illustrate how different art forms can be used to explore perspectives on hypertension and diabetes. The second half of this chapter will then explore findings from the Phase 1 workshops more broadly, considering the strengths and weaknesses of arts-based participatory workshops in practice. It will first consider how a flexible approach could contribute to relationship building, co-learning and begin to challenge research hierarchies. It will then consider the role of the facilitator and how best to frame content to handle health issues sensitively and avoid the perpetuation of stigma. The final section will reflect on some additional practical considerations around maintaining workshop accessibility and time management.

The data used in this chapter and the related codes used for participant and group extracts are summarised in Table 7. Due to challenges with audio quality and time-constraints that affected transcription (see Chapter 3.7), there are some limitations in the data worth noting. Firstly, individual ID numbers are provided where possible; however, they were often not available in the transcripts, particularly from Malawi. Secondly, as transcription of the Malawi stakeholder workshop was restricted to the main discussions, some of the stakeholders' responses were only provided in note form (see Chapter 3.5.3 and 3.7). Therefore, while all analysis included data from both settings, Section 6.3 includes more direct quotes from the Scottish context.

**Table 7: A Summary of Phase 1 Community and Stakeholder Workshops and Relevant Data Codes**

Phase 1 Community and Stakeholder Workshops					
Country	Malawi			Scotland	
<b>Workshop</b>	Women's Community Workshop	Men's Community Workshop	Stakeholder Workshop (mixed gender)	Women's Community Workshop	Stakeholder Workshop (mixed gender)
<b>Participants</b>	N=12	N=10	N=10	N=11	N=4
<b>Individual Data Code</b>	[Participant No_Malawi_Women's Workshop]	[Participant No_Malawi_Men's Workshop]	[Stakeholder No_Malawi_Stakeholder Workshop]	[Participant No_Scotland_Women's Workshop]	[Stakeholder No_Scotland_Stakeholder Workshop]
<b>Groups within each workshop</b>	N=3	N=3	N/A	N=3	N/A
<b>Group Data Code</b>	[Group No_Malawi_Women's Workshop]	[Group No_Malawi_Men's Workshop]	N/A	[Group No_Scotland_Women's Workshop]	N/A

## 6.2 What art forms are compatible with community interests and adaptable to explorations of hypertension and diabetes?

The Phase 1 community workshops used a scaffolding structure involving four key activities designed to promote creativity, discussion and reflection (Chapter 3.5.2, Table 1). The activities were also designed to be open and flexible to prioritise participant choice and encourage participation. This meant that each workshop functioned in slightly different ways.

In Table 8, I provide an overview of each of the community workshops in Malawi and Scotland and highlight how community responses differed for Activities 1 and 3, specifically. In Activity 1, participants were invited to choose a game to get to know one another with. Participants' responses varied and in some cases we (facilitators) also decided to introduce some games of our own. I will discuss this further in Section 6.2.1 and 6.3.1. In Activity 3, participants were provided with a range of creative resources (e.g. pens, paper, paint, speaker) and, in groups, were asked to use any art form they liked to develop a creative response to perspectives on hypertension and diabetes generated in Activity 2. This

activity was intentionally kept broad to focus on participants' choice of art forms and whether they were adaptable to explorations of hypertension and diabetes in practice.

As highlighted in Table 8, community members in Malawi and Scotland used music and dance, theatre and drama, drawing and poetry to explore a range of issues relating to diabetes and hypertension. With the exception of poetry, these art forms were also discussed by participants in the stakeholder workshops in each setting as art forms that were engaging to their local community. In the following sections I will explore community and stakeholder perspectives on each of these art forms in turn, with recognition of the wider cultural and social contexts in which they are situated and consider their utility as a means to share perspectives on diabetes and hypertension.

**Table 8: Summary of Phase 1 Community Workshops in Malawi and Scotland describing games used and participant's choice of art forms.**

<b>Phase 1 Community Workshops</b>			
<b>Country</b>	<b>Malawi</b>		<b>Scotland</b>
<b>Workshop</b>	Women's Workshop	Men's Workshop	Women's Workshop (only)
<b>Participants</b>	N=12	N=10	N=11
<b>Activity 1. Getting to know each other with a game</b>			
<b>Game Chosen by Participants</b>	<i>Call and Response Singing Game:</i> Group would stand in a circle and one by one each person would go into the centre. The group would sing and ask the person's name and the person in the middle would sing their response.	<i>Reaction Game:</i> Group Stands in a circle. You have to catch your neighbour's finger while stopping the neighbour to your other side catching your finger.	<i>No Suggestions</i>
<b>Additional Game Introduced by Facilitators:</b>	N/A	<i>Pairs Game:</i> Participants were matched according to famous duos (e.g. Jesus and Judas) and then they acted out a scenario that their character's would have. The remaining group would have to guess the famous pair being depicted.	<i>Shapes Game:</i> Participants would walk around room. The facilitator would shout a number and a shape. The participants would then form a group size representing the number and then make the shape with their bodies. <i>Dance Circle:</i> Everyone would stand in a circle. One by one someone would stand in the middle and do a dance move that would then be copied by the entire group
<b>Activity 2. Initial thoughts on diabetes and high blood pressure</b>			
<b>Activity 3. Using an art form of your choice develop a creative response to Activity 2</b>			
<b>Group 1's Art Form</b>	<i>Poem</i> about the causes of diabetes and high blood pressure	<i>Drawing</i> about the causes and impact of diabetes	<i>Drama</i> about the causes of diabetes and high blood Pressure
<b>Group 2's Art Form</b>	<i>Poem</i> about experiences of diabetes and high blood pressure	<i>Drama</i> about causes and impact of diabetes and high blood pressure.	<i>Poster/Drawing</i> of healthy and unhealthy behaviours
<b>Group 3's Art Form</b>	<i>Drawing</i> about the impact of diabetes and high blood pressure	<i>Song and Dance</i> about prevention of diabetes and high blood pressure	<i>Exercise Dance</i>
<b>Activity 4. Final discussion and reflection</b>			

### 6.2.1 Music and Dance

Participants in both countries emphasised the popularity of music and dance. Stakeholders in Malawi agreed that music and dance were probably the most engaging art forms for the community, while community members acknowledged that music was “*liked by most people in this generation*” [Participant\_Malawi Men’s Workshop]. Scholars have recognised Malawi’s longstanding relationship with song and dance, exploring how these creative forms have been embedded in historical, cultural, political, spiritual, and social processes (Lwanda 2003, Nthala 2009, Abdulla 2021). Abdulla (2021: p.73), drawing on the work of Nthala (2009) reflects that music and dance “*provide a space for generating meaning*” in response to social phenomena. This appeared to be true in the Malawi men’s community workshop, where Group 3 conveyed several ideas through a short song and dance (Figure 6-1).

ALL: It ain’t a joke

ONE: There is Diabetes

ALL: It ain’t a joke

ONE: There is also Blood Pressure (Hypertension)

ALL: It ain’t a joke

ONE: But prevention is easy

ALL: It ain’t a joke

ONE: Malawians let us be vigilant

ALL: It ain’t a joke

ONE: These diseases are deadly

ALL: It ain’t a joke

ONE: Malawians let us be vigilant

ALL: It ain’t a joke

ONE: These diseases are deadly

ALL: It ain't a joke

ONE: (Rap) Prevention is easy and it is also doable, stay home, stay calm, prevention is easy let us stand in unity not in isolation. [Group 3\_Malawi Men's Workshop]



**Figure 6-1: Image from Men's Community Workshop, Malawi. Men dancing while singing a song about diabetes and high blood pressure.**

The repetition of *“it ain't a joke”* and *“these diseases are deadly”* was performed against a playful percussive beat, made by the groups' clapping hands. The lyrics lend a sense of seriousness to what was otherwise a playful and jovial atmosphere. It could be argued despite community understandings that the impact of diabetes and hypertension can be severe; they are still optimistic about prevention. Furthermore, according to Nthala (2009: p.32), *“Chewa [majority ethnic group in Malawi] music and dance songs are synonymous with explicit packages of narratives laden with instructional content...”*. It could be argued that this example is no different, the lyrics are reassuring while directive that listeners follow their advice and *“stand in unity”*. Interestingly, the lyric, *“stay home, stay calm,”* appears to reflect COVID-19 messaging, suggesting that the structure may, at least in part, be borrowed from previous health promotion campaigns. Drawing on Lwanda's (2003) work on the appropriation of music in Malawi, this is not a new practice. Lyrics and rhythms from established and

cultural songs have a history of being adapted for alternative political or health promotion campaigns (Lwanda 2003, Kamlongera 2005). This is something to be aware of, particularly when using song as a means to generate data in a health context.

The popularity of music and dance in Malawi are also related to cultural and spiritual connections to folk media forms, including songs, dances and storytelling. When justifying why they had chosen to use dance in the above performance, one member of Group 3 argued that it would make the performance more engaging to the community, knowledge informed by the popularity of spiritual dances.

“We added the dance aspect to make it more attractive, because dance is a great tool to attract people. For instance, when we hear traditional dances like nyau being performed somewhere, people always flock there...” [Group 3\_Malawi\_Men’s Community Workshop]

The *nyau* dance, also known as the *gule wa mkulu* (*big dance*), is a masquerade dance signifying man, animals, and ancestral spirits, performed by the *Nyau*, an all-male secret society among the Chewa people (Kerr 1987, Abdulla 2021). Despite the popularity of traditional art forms or folk media in Malawi, their integration into health research is more complex. Folk media have a history of being appropriated as vehicles for ‘moral education’ and propaganda in colonial times, and there has been a resurgence of this through the incorporation of folk media into education and development strategies in recent years (Kamlongera 2005). Projects that view folk media as ‘tools’ that can be inserted into different contexts often lose important cultural histories and meanings: for example, dances with the same name may hold different specificities in different communities (Chinyowa 2005, Abdulla 2020, Abdulla 2021). Stakeholders in Malawi also acknowledged the complexity of integrating folk dances like *gule wa mkulu* into health research due to the potential for *juju* (*magic*). Therefore, the application of these art forms requires sensitivity to their origins and meanings, something that needs to be explored and developed with community members themselves (Abdulla 2020, Abdulla 2021).

With recognition of these cultural complexities, music and dance were still endorsed by participants as a way to spread health messages. Participants in

Malawi reasoned that simple songs would “*stick in the minds of the people*” [Group 3\_Malawi Men’s Workshop]. As noted below, Group 3 argued that health messages would also be easily shared amongst those close by, particularly young people.

“...In music as well, you know young kids are so easy to sway, because of the simplicity in message that music has, you just wonder when you hear kids humming the song thus passing on the messages.” [Group 3\_Malawi\_Men’s Community Workshop]

This view seemed to be informed by experiences of previous health messaging campaigns for infectious diseases like cholera, a finding reinforced by perspectives in Chapter 4.5.2.5 and by the popularity of music, song and dance in health promotion research across sub-Saharan Africa (Bunn, Kalinga et al. 2020).

In Scotland, music and dance were also thought to be engaging and effective art forms. Stakeholders emphasised that music and dance could be used as a means of encouragement, motivation and enjoyment, as noted by Stakeholder 4:

“Yeah, I mean, we do a lot of music, too. And we use music quite a lot as a medium to encourage people. And we encourage them to, you know, sometimes listen to the words to get motivation, and sometimes just enjoy, enjoy, enjoy the music, you know, and then that yeah.” [Stakeholder 4 \_Scotland\_Stakeholder Workshop]

“...we do a lot of dancing too and encourage, you know, and it really helps people to loosen up.” [Stakeholder 4 \_Scotland\_Stakeholder Workshop]

In the Scotland women’s community workshop, when participants were asked if they had any games or music, they would like to use in a warmup activity, there were no suggestions. After learning from participants during the walks that they liked dancing (see Chapter 5.4), I had planned some back up games, including one that used dance as a warm-up. The game involved everyone standing in a circle, and, one-by-one, someone would stand in the middle and do a dance move that would then be copied by the entire group. I thought that because the dance moves themselves would come from the participants, this might be a fun way to get everyone involved. It appeared that the lack of suggestions may have been due to shyness at the beginning of the workshop, which dissipated once the

activity started (see Section 6.3.1). Indeed, Group 3 later used the dance circle format in their own performance, swapping dance moves for exercises, like arm circles. When asked why they chose to create the dance, the motivation appeared to be less about the art form and more about the benefits of exercise in general as a method of NCD prevention:

“I think exercise is part of what they recommend for what we talked about today, both type 2 diabetes and high blood pressure, I think that we were talking about overweight, and one of the controls that would be recommended would be to exercise more in order to reduce your weight...” [Group 3\_Scotland\_Women’s Workshop]

Thus, although participants in the walkalong interviews (see Chapter 5.4) and stakeholders indicated that music and dance were appealing art forms, the use of the media in practice was more complex. Dancing appeared to be an effective warm-up in Scotland; however, it required more facilitator prompting than in Malawi and its utility as a means to explore perspectives on diabetes and hypertension appeared more limited.

Some of the differences between Scotland and Malawi may stem from the diversity of backgrounds and cultures in the Scottish workshop. This diversity may have led to more variation in music and dance practices among participants. Stakeholders in Scotland agreed that ideas of art and creativity may hold different meanings among different communities. As noted by Stakeholder 3, community members may have different ideas of what constitutes art or may not feel comfortable participating at all:

“... actually, our definition is different from community, community in the way that arts are used. And how to consider art, and not art, and we’ll be trying to, to leave the space for people to do so.”  
[Stakeholder 3\_Scotland\_ Stakeholder Workshop]

“Some communities also see the art is not their place, or like, or some people think, because in so many countries like maybe, like participating within the arts is kind of middle-class thing.”  
[Stakeholder 3\_Scotland\_ Stakeholder Workshop]

Minoritised ethnic communities experience several intersecting barriers to accessing and participating in the arts in the UK. Socioeconomic status has been shown to predict arts participation and living in areas of higher deprivation has

been associated with lower arts, culture and heritage engagement, which may disproportionately affect minoritised ethnic communities (Walsh, Buchanan et al. 2019, Mak, Coulter et al. 2020, Mak, Coulter et al. 2021). As briefly touched on in the previous chapter (Section 5.4), evidence has also indicated that common barriers to engagement and participation include: the cost of attendance at and transport to arts events, lack of time, lack of exposure or artistic cultural relevance, language barriers and a sense of feeling out of place or uncomfortable (Netto 2008, Arts Council of England 2018). These barriers are compounded by systemic racial and ethnic inequalities in the creative and cultural industries (Arts Council of England 2018, Byrne, Alexander et al. 2020). Notably, qualitative research indicated that older and first-generation migrants in Scotland were interested in preserving participation in art, particularly art forms related to their ethnic and cultural identity. However, accessibility was often limited by a lack of organisations to support cultural participation and funding barriers (Netto 2008). African community members argued that they were disproportionately impacted by funding issues compared to other minoritised ethnic groups “*due to their smaller size, their greater diversity, the dispersed nature of the population across Scotland, the lack of voluntary organisations and the lack of visibility of arts associated with the continent in public life*” (Netto 2008: p.58). Thus, whilst this has likely changed in the last decade, with the growth of the African population in Glasgow (Walsh, Buchanan et al. 2019), the context of the arts and voluntary sector has important implications for how communities engage in arts-based research.

Finally, perceived hierarchies in the creation of art were not limited to Scotland. Women in Malawi highlighted that although music and dance appealed to them, they chose not to use them because creating music “*needs expertise*” [Participant\_Malawi\_Women’s Workshop]. Stakeholders in Malawi similarly noted “*a lack of expertise*” as a possible barrier to participating in arts-based activities, and indicated that, when using songs, it could be hard to please the audience (e.g. people would boo). Thus, irrespective of differences in the application of cultural art forms in the Scottish and Malawian contexts, there is a clear need to work with community members to negotiate what their application looks like in a research context.

## 6.2.2 Theatre and Drama

Drama was another popular art form among participants in Malawi and Scotland. Groups in both contexts made dramas that effectively communicated some of their knowledge and perspectives on the causes and impact of diabetes and hypertension (see Table 8). The following short extract from the community women's workshop in Scotland contained several interesting points, including sugar as a cause of diabetes, individual attitudes and preferences and the importance of community support.

P1: Hi!

P2: Hi

P1: How are you?

P2: I'm good

P1: I can see you are having a meal? What do you have?

P2: I'm eating snacks?

P1: Ah, I've advised to reduce sugar, you are still taking sugar like this?

P2: I like it, I like eating it.

P1: You need to start learning to reduce sugar, my darling.

P2: There is nothing wrong with me, I can eat it. I love eating, I love sugar so much.

P1: Ah, but I don't want anything to happen to you, please.

P2: Please don't tell me, I like it. Please leave me alone.

P1: Okay... I'm going for exercise, can we go?

P2: Ah no, I'm not an exercise person, I don't like it.

P1: Why?

P2: I just don't...

P1: It's good for your health.

P2: There's nothing wrong with me, I am strong,

P1: Okay, I'm going for exercise.

P2: Okay, bye I'll see you later

[P1 leaves while P2 eats biscuits in the chair. P2 starts coughing and looking unwell]

P2: Somebody help me, I am feeling dizzy...

[Group 1\_Scotland\_Women's Workshop]

The above example demonstrates the valuable detail about community perspectives on health behaviours that can be gained from the use of drama in research. It introduces the perspective that individuals are responsible for their own health. Self-determination theorists argue that this individualised perspective can present in the form of 'introjected regulation' whereby an individual's behaviour is regulated by trying to avoid feelings of guilt or anxiety or to gain a sense of pride (Ryan and Deci 2000). However, as this source of motivation comes from external pressures rather than internal values, it can often be disempowering and reinforce feelings of guilt or failure when the person does not follow the 'healthy' behaviours (Ryan and Deci 2000). When individuals are provided with the right support to feel competent and make autonomous decisions, they can be supported to internalise their motivation to match their meanings and values towards more sustainable behaviour change (Ryan and Deci 2000). The primary character who "loves sugar", is not an "exercise person" and ignores her friend's advice, goes on to be diagnosed with diabetes later in the play. The second character tries her best to help her, calling her "my darling", and later in the play does successfully encourage her friend to go running with her. Therefore, the performance conveys multiple complex drivers of behaviours where guilt is an ineffective motivator yet with understanding, help and patience from others, behaviour change can be supported.

Drama was also highlighted by participants in both countries as an engaging method. In the Scotland women's workshop, Group 1 justified their use of drama

by arguing that that people in the African community have little patience for lots of writing and are more likely to pay attention to drama. Notably, the women said, in reference to written narratives and art forms, “*if you want to sneak something in, do it in writing*” [Fieldnotes\_Scotland\_Women’s Workshop]. This statement indicates that drama could also be used as a more trustworthy way to communicate information than written narratives, particularly among those with a range of languages and English literacies. The community distrust of written narratives may also reflect colonial legacies that imposed the written word over oral traditions of narrative and storytelling as a form of communication and education across sub-Saharan Africa (Abdi 2009). When participants used drama in the men’s workshop in Malawi, the audience appeared more connected with the visual elements than the narrative itself. For example, during Group 2’s performance, one enthusiastic young man chose to explain the story before it was performed, providing some additional voice-over while others acted out the scenes. The audience praised the overall performance, however noted that the narrative element had been too much. Thus, the visual elements of theatre appeared to be particularly engaging to community members as a means to explore health issues.

The popularity of drama in both contexts could be linked to prior experiences with the approach in a health context. Reviews of studies conducted in both sub-Saharan Africa and with minoritised communities in high income contexts, has suggested that theatre and drama are among the most popular forms of art used in health research (Chinyowa 2015, Coemans and Hannes 2017, Abdulla 2020, Bunn, Kalinga et al. 2020). Theatre traditions also have a history of use as low-cost methods for political and health-related messaging in post-colonial Africa (Roscoe 2007, Bunn, Kalinga et al. 2020). In the UK, drama is similarly a popular, affordable tool used by community groups to support wellbeing and expression. Therefore, theatre and drama appeared to be promising art forms to integrate into the future TABPA framework.

However, stakeholders and community members did note some challenges with the method. Stakeholders in Malawi highlighted practical needs like accessing appropriate props and costumes. However, in Grotowski’s ‘Poor Theatre’, he argues that stripping theatre of anything not essential (i.e. props, costumes etc.) can reveal the “*deep riches*” (p.63) of the approach (Grotowski,

Wiewiorowski et al. 1967). Furthermore, props and costumes can be creatively sourced: for example, Group 2 in the Malawi men’s workshop and Group 1 in the Scotland women’s workshop used makeshift props such as *‘saltshakers made from water bottles’* [Fieldnotes\_Malawi Men’s Workshop] and the snacks available for their break, respectively. Another concern among women in Malawi was that to make a drama they would have *“needed numbers”* [Participant\_Malawi Women’s Workshop]. This concern is simple to address by making group sizes bigger in later workshops. Finally, as identified by stakeholders in Malawi, another possible challenge with drama was *“stage fright”*. Unfortunately, as with all performance, challenges around *“stage fright”* are highly likely, but arguably can be reduced by creating a supportive and safe environment, as will be discussed in Section 6.3.2.

### 6.2.3 Drawing

Drawing was another popular art form in both Scotland and Malawi. Community members and stakeholders thought drawing was an engaging art form, and as shown in Table 8, it was selected by one group in each of the community workshops. Like music and drama, drawing appeared highly compatible with explorations of diabetes and hypertension, where community members effectively used the art form to communicate health information. Group 3 in the Malawi women’s workshop drew an image of somebody bedridden in hospital, showing the impact of diabetes (Figure 6-2). The image is described by the participants below:

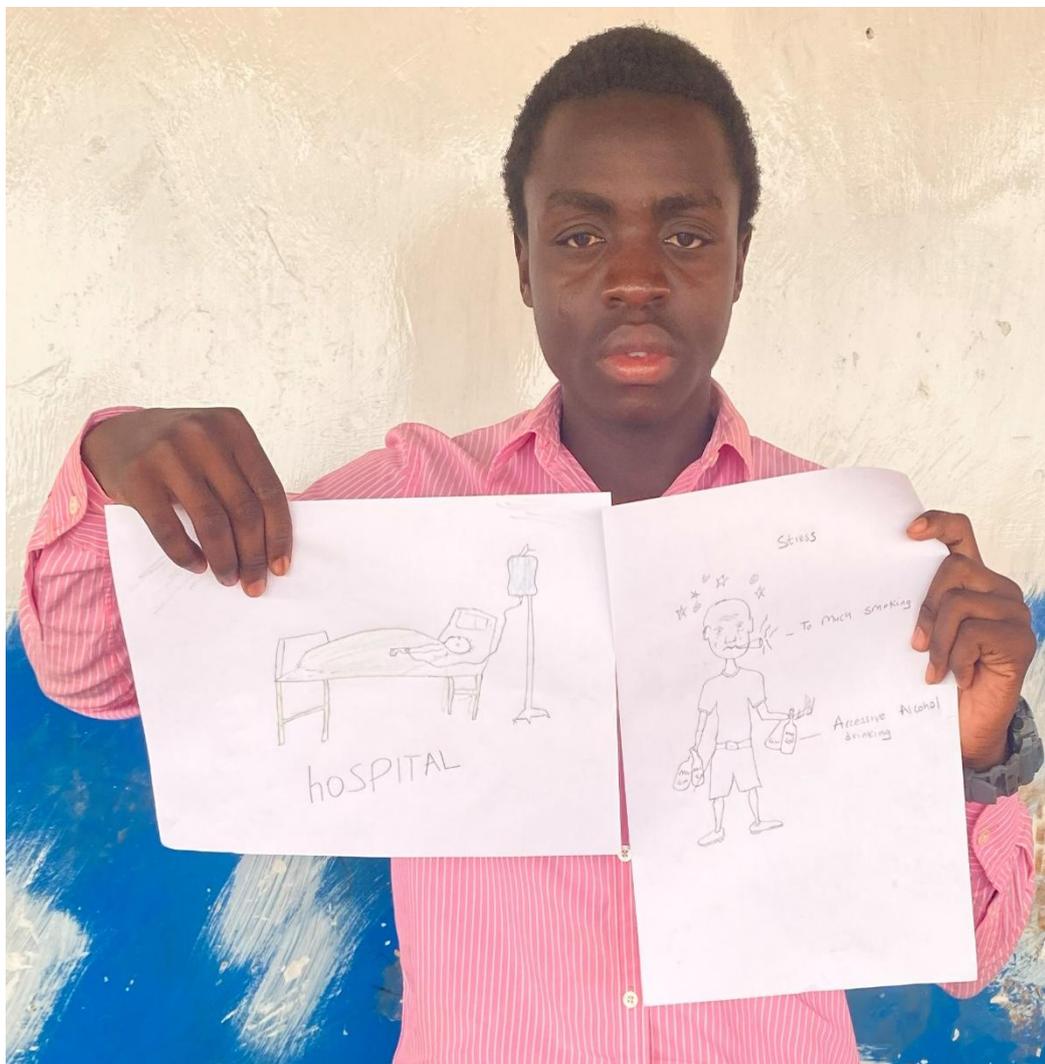
“Here is our person, for everything we have heard about these two diseases [diabetes and hypertension] this is the end part being admitted in the hospital where you are put on oxygen and water drip. We can even see a tube to help the person urinate. So, this is the end result of the diseases, which just confirms that they are deadly diseases. The image is showing a person on a sick bed at the hospital which shows the seriousness of the diseases. This in a way is the climax of the problems that comes with the two diseases.” [Group 3\_Malawi\_Women’s Workshop]



**Figure 6-2: Images from Women's Community Workshop Malawi. The top image shows Group 3 drawing the image. The bottom image shows the final drawing. The description of the drawing by community members is provided on page 138.**

Group 1 in the Malawi men's workshop drew images of a young man surrounded by risk factors for diabetes and hypertension, and a second image of the same man in hospital (Figure 6-3) notably not dissimilar to the women's drawing. This is described by the participant below.

And here comes stress. After being stressed he wants to calm down thus he excessively smokes, and then later on as we can see in the picture, he is drinking alcohol... as you can see a bottle of Malawi gin and other alcoholic drinks. So, what is happening here? Eventually the person gets sick because there is nicotine in the cigars he has been smoking and it is this nicotine that blocks the blood vessels thus the blood cannot freely circulate since the veins already have small cavity for blood circulation. The excessive drinking has affected his digestion since the kidneys have been affected badly thus, he starts suffering from diabetes. [Group 1\_Malawi Men's Workshop]



**Figure 6-3: Image from Group 1 in Malawi Men's Community Workshop: Man holding two drawings. The participant's description is provided above (p. 139).**

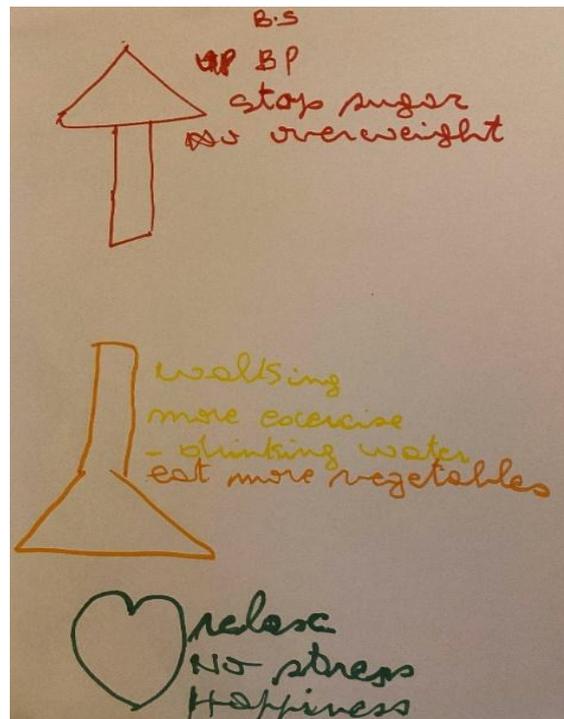
Group 2 in the Scotland women's workshop made a poster, using the colours of a traffic light to highlight healthy and unhealthy behaviours and lifestyles (Figure 6-4). Interestingly, the traffic light colour system is commonly used in UK health messaging. For example, traffic light labelling on the nutrition content of food packaging has been used to highlight 'low' (green), 'medium' (amber) or 'high' (red) levels of total fat, saturated fat, total sugar and salt in food in UK supermarkets since 2006, and has been found to influence consumer purchase decisions (Scarborough, Matthews et al. 2015, Cole, Peek et al. 2019). Therefore, similar to the men's use of song in Malawi (Section 6.2.1), women in Scotland appeared to adapt familiar health messaging strategies for the workshop.

P1: Here blood Sugar Rises, Blood pressure is too high, what we need is we must stop sugar, overweight, sometimes it happens that when you are overweight you cannot move around, as the red shows you, something that is very risky, very dangerous. This orange one tells you, is feel better, more walking is more exercise, do exercise, drink more water, eat more vegetables, that is the orange one. The blue (green) one is telling you that you are better, you must have no more stress, just happy, make yourself happy, no one can make you happy but yourself, only you can make yourself happy, make sure you make yourself happy, don't let anything stress you, even if you have bad news, go for a little walk, do some exercise, there are those close to you that you can talk to. Don't stress yourself. That is it.

P2: I want to add here (orange), you can eat more fish also, fish, yes.

P1: chicken also. Chicken is better

P2: yes, fruits, more fruits, apple, oranges, yes. Also for the green one, it is good to socialise with people, friendship is very good, it is not good to be alone. Have people around you so that you can be more happy as my sister says. [Group 2\_Scotland\_Women's Workshop]



**Figure 6-4: Image from Group 2 in Scotland Women’s Community Workshop. A drawing depicting factors that impact health according to the traffic light colour system. The image is described by participants above (p.140).**

These images effectively communicated health information to other participants in the workshops. For example, women in Malawi said that they learned from the drawing group that they should “*go to the hospital before things get worse*” [Participant\_Malawi\_Women’s Workshop]. Drawing as an accessible and engaging means of sharing information was reinforced by women in Scotland when reflecting on their choice of art form:

P2: Everybody can understand the drawing, everyone can understand. Even if you go out on the street, everyone can read [the drawing]. Even if you cannot read or not understand.

P1: In this country, drawing is very important, they will tell you what you love, they will tell you everything through drawing! They will understand more what you are talking about. [Group 2\_Scotland\_Women’s Workshop]

The participants in the Scotland women’s workshop recognised the benefits of drawing as an effective way to share information with those who have lower literacies. Indeed, many have acknowledged this as one of the biggest strengths of creative methods in health research, where the approach can provide an accessible alternative to traditional methods (Coemans and Hannes 2017). The

diversity of languages spoken among members of the African community in Scotland means the use of visual arts may not only help people understand information, but also encourage people to participate. These benefits were acknowledged by stakeholders in Scotland when discussing what art forms had been effective at engaging community members during sessions organised by their respective community groups:

“...things that don't require a lot of language is really good, so music and cooking is what [our community group] did a lot of the last couple of years, and, like general visual arts and drawing and painting.”  
[Stakeholder 1\_Scotland\_ Stakeholder Workshop]

Overall, drawing was a highly accessible and promising art form to explore experiences of hypertension and diabetes.

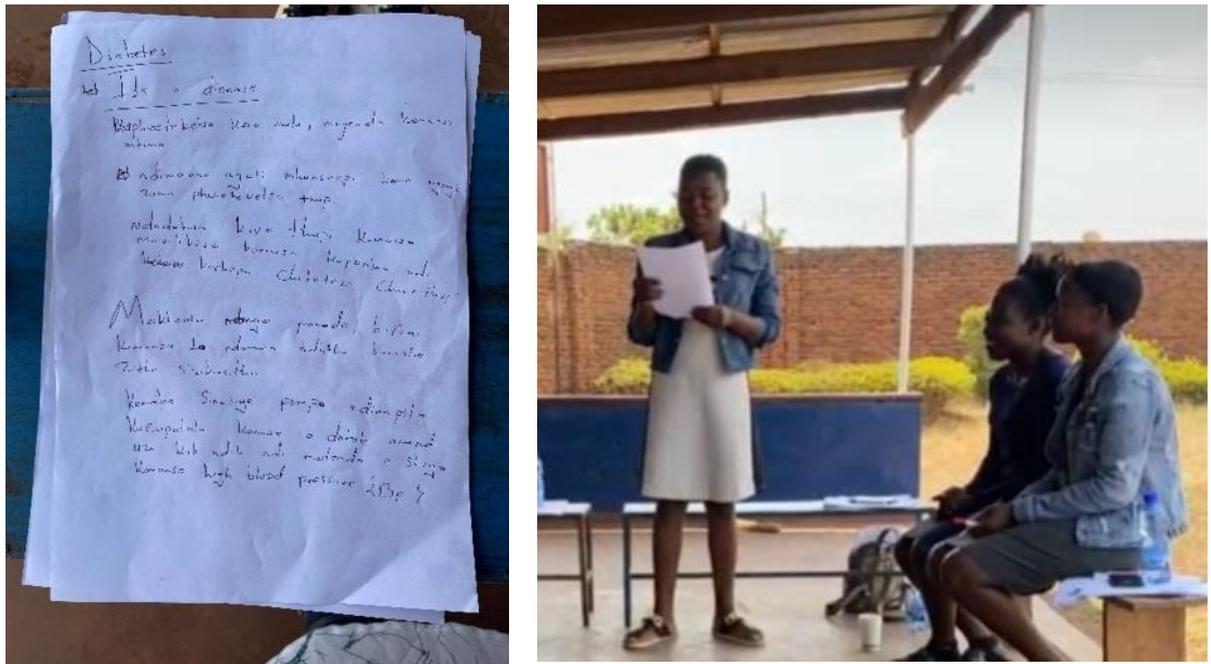
#### **6.2.4 Poetry**

Poetry was chosen by two groups in the Malawi women's workshop. It was also mentioned by the men's group as an art form they could have tried but did not. The reason for this was not provided and unfortunately as I could not speak Chichewa, I was unable to probe for more detail. This was one of the key challenges when working across languages in Malawi; although Luke was available as an interpreter, his responsibilities as a facilitator to the group meant that he was not always available to live translate the discussions. Nonetheless, like the art forms above, poems were used to effectively communicate perspectives of diabetes and hypertension, and arguably to communicate more personal perspectives, as shown in the following example by Group 2 in the Malawi women's workshop:

<p style="text-align: center;"><u>Diabetes</u> <u>It's a disease</u></p>	<p style="text-align: center;"><u>Diabetes</u> <u>It's a disease</u></p>
<p>Diabetes and BP [High Blood Pressure] are the diseases that causes headaches, body pains and heartaches,</p>	<p>Kuphweteketsa kwa mutu, miyendo komonso mtima</p>
<p><b>I thought</b> I was just adding weight, but no, it's hurting (affecting) my body</p>	<p>ndimaona nguti mkunenepa koma yoyi zuma phweteketsa thupi</p>
<p><b>I have been</b> wondering why I have been having body pains time and again plus general weakness and reduced immunity in the body.</p>	<p>ndadabwa kuva thupi kuwawa mowilikiza komaso kufooka ndi kuchepa chitetezo chamthupi</p>
<p><b>I have tried</b> various medications like Panado [paracetamol], bufen [ibuprofen] and LA [malaria drug] but still no changes,</p>	<p>Makhwala mbnga panado, bufeni komonso la ndamwa ndithu komabe zithu sizikusitha</p>
<p><b>I didn't stop there;</b> I went to the hospital where the doctor said I have diabetes and high blood pressure.</p>	<p>Komabe sinasiye pompa ndinapita kuchipatala komwe a dotolo anandi uza kafi ndili ndi matenda a shuga komonso high blood pressure</p>

The repetition of “I” creates a more personal, pessimistic tone, creating a sense of the confusion and frustration about what diabetes and hypertension are and how they are treated. This confusion is reinforced further by the mention of painkillers and drugs used to treat malaria, suggesting that the participant is trying to make sense of diabetes by exploring familiar medications and health discourses. It is important to acknowledge here that this poem was written and translated from Chichewa (see Figure 6-5), therefore some of the meanings might not be as intended. However, upon discussion of my understanding of this poem with a Malawian friend who is also involved in arts-based health research,

we agreed this translation. According to Furman, Collins et al. (2006) “*poetic truth is not only judged by a poem’s capacity to meaningfully symbolize and express something encountered in the internal and external worlds but is also judged by its capacity to meaningfully express the relationship between the poet and his or her internal or external worlds*” (p.332). It could be argued that this is shown in the above poem where truth and underlying personal and emotional meanings are captured within and between the lines.



**Figure 6-5: Images from Group 2 in Women's Community Workshop Malawi. The image on the left shows the written poem in Chichewa. The image on the right shows a participant reciting the poem.**

Interestingly, the main reason Group 2 said that they had chosen poetry was because they had thought it would be an “*easy*” art form to perform. Group 1 noted that they started with a short story but changed to a poem when they “*saw [a short story] would be hard to present*” [Participant\_Malawi\_Women’s Workshop]. In reality, the poem was not necessarily ‘easier’ to present. During Group 1’s presentation, one member had been chosen to read it aloud; however, when they finished their recital, they asked a member of the Group 2, who had more experience of poetry, to perform it more creatively. Interestingly, poetry was not mentioned in any of the stakeholder discussions. Poetry is, therefore, a promising method to explore in TABPA development, but its application will

depend on participants' (and facilitators') confidence and experience with the media.

### 6.2.5 Alternative Forms of Art

Other art forms and creative activities mentioned, although not discussed in detail, were general arts and crafts (Scotland, stakeholder), movies and film (Malawi, men; Scotland, stakeholder), photography (Scotland, stakeholder), and sculpture (Malawi, stakeholder).

Interestingly, in both contexts, activities emerged that stretch the definition of 'art,' including football, social outings, and cooking. Football was mentioned by men in Malawi as an art form they could have explored in the workshop. In the stakeholder workshop, participants noted that they had observed football being used for "*community [health] mobilisation*" and ranked it as one of the most engaging art forms. In Scotland, stakeholders also discussed how football could be used as an "*enjoyable*" way to support physical and mental health, specifically to get people in the community moving and exercising. Cooking was similarly discussed in Scotland as a creative activity that can support wellbeing, both by teaching people to cook healthy meals as an activity, which like the art forms above, do not require a lot of English and facilitate "*cultural stories...like identities through food, as an informal way of bringing on those discussions*" [Stakeholder 3\_Scotland\_Stakeholder Workshop]. This was reiterated by Stakeholder 1, who also highlighted the social bonds that can develop from shared cooking and eating:

"The reason we did the cooking was actually because we were in lockdown, and we had to find an activity we could do on Zoom so we would send packages, and then we would all have ingredients and cook together on zoom, and we ended up making a cookbook actually from that. And it was a really great way to learn about how other people cook, the similarities between different...because we'll have young people from all over the world, so realizing that a young person for Vietnam cooks the same way as a person from Sudan, and they have that common, that created a lot of bonds and a safe way to talk about culture when a young person maybe doesn't feel comfortable talking about their background while they're still in that first phase of em kind of like recovering from serious trauma. But I think cooking is a really it gets people chatting if you're chopping up veg or and it gets...also, if you're talking in a health context like, it's quite related to what you're talking about in terms of diabetes and blood pressure I

mean it doesn't... It's like celebrating food as a positive thing and how it's like nourishing and nutritious, but also delicious. So, it can be a really fun activity. I think" [Stakeholder 1\_Scotland\_Stakeholder Workshop]

These art forms and activities could all prove useful to consider in the wider context of creative health research approaches in both Scotland and Malawi. However, due to time, lack of experience and practical considerations they were not explored further in the present research. Nonetheless, they should be explored further in future projects.

In summary, the above section explored community and stakeholder perspectives on, and experiences with, different art forms to help inform the TABPA development. There were a number of key reasons why different art forms were chosen, most notably: ease, engagement and accessibility. Poems and drawing were chosen by women in Malawi because they were “*easy*”. Music and dance were considered the most engaging and “*attractive*”. Music, drawing and drama were highlighted as the most accessible, as they can traverse language barriers, a challenge highlighted by stakeholders in Scotland and Malawi. Notably, all of the art forms used by community members appeared to be compatible with community interests *and* adaptable to explorations of the two NCDs and any might be used within the TABPA framework.

### **6.3 Arts-Based Participatory Workshops in Practice: Strengths and Challenges**

Having outlined community and stakeholder perspectives on the use of different art forms as a means to explore diabetes and hypertension, the second half of this chapter will unpack the strengths and challenges of using arts-based participatory workshops in practice to inform the development of the TABPA. Drawing on the perspectives of community members and stakeholders, as well as observational fieldnotes, the following sections will: consider how the workshops can be used for relationship building, co-learning and challenging power hierarchies; consider the role of the facilitator, including how to frame content and handle health issues with sensitivity; and outline practical considerations relating to workshop accessibility and time management.

### 6.3.1 Relationship Building, Co-learning, and Challenging Power Hierarchies

While relationship building had begun in walkalong interviews in each setting, connections were strengthened in the Phase 1 community workshops. We started each workshop by asking participants if they knew any games or activities that we could do as a warm-up. As highlighted in Table 8, the participants' suggestions varied between workshops, and we also introduced some games of our own.

In the Malawi women's workshop, one participant suggested a call and response song to learn everyone's names. Everyone would stand in a circle, then one at a time, one person would go into the middle. The group would sing and clap together, asking the name of the person in the centre. The individual would then sing their name, and the group would sing it back in unison. In the Malawi men's workshop, one man introduced a reaction game where everyone would stand in a circle and hold out their hands. The aim was to catch the finger of the person on your right without letting the person on your left catch yours. As this game passed quickly, Luke (Malawian facilitator) also introduced a roleplaying game where we could get to know one another more. In pairs, we each had to act out famous duos (e.g. Jesus and Judas) and then the rest of the group had to guess who was being portrayed. Luke had initially written out a selection of famous Malawian duos on scraps of paper and the groups chose randomly; however, he forgot to include us (facilitators). As we were keen to get involved, we let the group choose who we should portray and ended up playing the Queen and a Prince which prompted much laughter from the group. The Malawi stakeholder group chose a song and response game from their childhood, similar to that of the Malawi women's workshop. Standing in a circle, one person would go into the middle and the remaining group would sing the following: *What is your name? What is your brother's name? What is your boyfriend's name?* In between each question, the person in the middle would sing their responses.

As discussed in Section 6.2.1, in the Scotland women's workshop, participants were more hesitant to choose a game. Christiana (Scotland co-facilitator) and I introduced the shapes game and a dance circle (Table 8, Section 6.2.1). The shapes game involved everyone walking around the room. I would then shout a

number and a shape. Everyone would then have to quickly form a group representing the number of people I had shouted and then use their bodies to represent the shape (e.g. ‘2 triangle’ would involve two people making a triangle shape). Finally, as the Scotland stakeholder workshop was conducted as an online consultation rather than a practical workshop (Section 3.5.3), I decided not to include a game, and instead stakeholders introduced themselves and their relevant background to the group.

In each of the workshops, as we played games, everyone smiled, clapped, and laughed, getting to know one another and Luke (Malawi), Christiana (Scotland) and I as facilitators. Abdulla (2021: p.150-160) discussed a similar experience in her work on folk media and HIV/AIDs in Malawi where playfulness associated with games and singing songs from childhood, created “*a sense of liberation*” among participants and helped to break down “*social adult rules*”. This was most observable in the Malawi stakeholder workshop, where the games appeared to break down established hierarchies between the Chiefs and the other participants (artists and health surveillance assistants). This shift was supported by Luke, who, aware of how the power dynamics might present in a workshop with the Chiefs, asked everyone to “*act as if you are 13 and have fun*” [Luke\_Fieldnotes\_Malawi\_Stakeholder Workshop]. Importantly, during the warm-ups in both Scotland and Malawi, we [facilitators] participated in the games, allowing ourselves to be enthusiastic and playful alongside the participants. By taking part in the activities like singing, dancing and roleplay, we allowed ourselves to be childlike and ‘silly’ rather than distancing ourselves from participants. Our active participation here helped us to develop more informal relationships and begin to narrow the distance between us as ‘researchers’ and ‘the researched’ [community members] (Daniels 2003, Coemans and Hannes 2017, Gerber, Biffi et al. 2020).

The relationships were developed further through activities designed to facilitate teamwork and openness among the groups. In the community workshops, participants were asked to work together to share whatever they wanted about diabetes and hypertension and explore these ideas with any art form they liked [Activity 2]. When asked how they found the process of working together, women in Malawi said they had found the group work “*easy*” [Participant\_Malawi Women’s Workshop] while Malawian men had “*a sense of*

unity” [Participant\_Malawi Men’s Workshop] which supported the development of their artwork. The benefits and longer-term impact of this relationship building process were reinforced by the following male participant:

“Always when people come together there is always a bond that develops. Look at us when we just arrived, we barely knew each other and interacted, but now as we grew into the workshop, we have become more friends that you will see that when we will be going, we will be friends. Also, the fact that all are here means we are all willing participants thus ready to give our all.”  
[Participant\_Malawi\_Men’s Workshop]

The above extract emphasises the bond that has developed between participants. Women in Malawi also praised the workshop as a space where *“everybody is open to contribute their ideas”* [Participant\_Malawi Women’s Workshop]. This openness appeared to be a strength of the participatory elements of both community and stakeholder workshops in Malawi, as noted by one stakeholder:

“You have made us more open and, as you can see, we are now more open to speak now [following the workshop] than when we just came in, mainly due to the participatory nature of this workshop.”  
[Stakeholder\_Malawi\_Stakeholder Workshop]

The flexible participatory workshop structure not only contributed to a sense of openness, but it also appeared to make the workshop more enjoyable and interesting as noted by one male participant in Malawi:

“I loved the flexibility of the workshop. We came here without pre-conceived ideas and that made it all interesting in that we had an open mind.” [Participant\_Malawi\_Men’s Workshop]

In Scotland, stakeholders also emphasised the importance of flexibility and providing participants with autonomy when exploring issues using creative activities. This was emphasised by Stakeholder 3 when reflecting on his own experience of participatory arts projects:

“We find that just to bring people into a space, and a creative space, where people can express and talk about what they actually want to do and what they, what everything means to them to through this activity is very good as a start to understand how we can tackle those issues.” [Stakeholder 3\_Stakeholder Workshop\_Scotland]

By providing a space for flexibility and teamwork, the workshops became a safe space for reflection and co-learning. In the first activity of the community workshops, participants were asked to write the first thing that came to their mind about diabetes and/or hypertension. One man in Malawi said the activity had prompted him to “*wonder what really causes these diseases*” [Participant\_Malawi\_Men’s Workshop], while another reflected on his own personal experience of hypertension:

“I could be feeling cold, the next [minute] hot. Weak and the next strong. So, this reflection just took me back to that moment.”  
[Participant\_Malawi\_Men’s Workshop]

Several women in Malawi also shared reflections on how the first activity had made them consider how others are affected by these diseases.

F: What did reflecting on what comes to your mind when you hear the words diabetes and hypertension do to you? How did you find it? Was it easy or hard? Any emotions that came with it?

P1: it made me reflect on the challenges that people with diabetes and hypertension go through.

P2: it’s a disease I never wanna hear or talk about and just made me wish more never to be diagnosed with the two diseases because they are deadly. [Malawi\_Women’s Workshop]

Therefore, it appeared the activity prompted personal and empathetic understandings of community perspectives on the diseases, and similar to our previous work created a space where participants felt comfortable to voice some of their fears (Bissett, Gray et al. 2022). In the Scotland women’s workshop, Participant 9 said that hearing other people’s contributions had helped her to reflect and make sense of her own understanding of diabetes and hypertension.

“First of all, you think, what? What do you want to write? Definitely we know, we know we have some... most of us have some idea about Diabetes and BP, so blood sugar and BP is high blood pressure. So, some of us have their idea. But in that moment, you will be thinking what are the causes, how can you maintain [control it], what are the things you can do to maintain [control] it? So then... when one of us share it, that will come up and we’ll be like yeah, yeah, I know that”  
[Participant 9\_Scotland\_Women’s Workshop]

Indeed, Activity 1 prompted further questions and discussion amongst the participants in the Scotland women's workshop, with some asking others to expand on their answers.

When reflecting on the community workshops overall, participants emphasised how the process had contributed to their own knowledge. In Malawi, perceptions of the workshop as an educative process may be linked to community exposure or understandings of the use of arts in 'educating' development initiatives (Kamlongera 2005). For example, one male participant in Malawi praised the community workshop, noting, "*as we are helping you research, we are also learning from the discussions and thought processes*" [Participant\_Malawi\_Men's Workshop]. Furthermore, an older male participant emphasised how the workshop was a co-learning process, especially between older and younger participants:

"It was a great learning experience for me being an old man in the group of these brilliant young men from whom I have learnt so much. There was a great exchange of generational knowledge."  
[Participant\_Malawi\_Men's Workshop]

This idea was reiterated in the Malawi women's workshop where women also praised the overall workshop as a co-learning opportunity. As noted by one woman, the activity "*stimulates learning, especially for those that are slow learners, they learn from the quick thinkers as the workshop goes*" [Participant\_Malawi Women's Workshop]. Therefore, the workshops appeared to create a space for mutual co-learning both between facilitators and participants, and between participants themselves. This reciprocity indicates the potential value of the approach beyond merely a tool for data collection, but also as way to generate trust, strengthen relationships and offer value to community members. However, co-learning also becomes more complex when discussing health information, where the messages may cause harm by reinforcing partial or incomplete information. This will be discussed more in Section 6.3.2 and Chapter 7.3.1.

### 6.3.2 Facilitation: Framing Content and Navigating Stigma

Some other important considerations that came from the community and stakeholder workshops in both countries was how to frame the content and facilitate a supportive, ‘safe’ space. Stakeholders in Scotland highlighted that discussions around health should be conducted with awareness of cultural complexities. For example, they suggested that many members of African (and other minoritised ethnic) communities do not feel comfortable disclosing or discussing health problems. This was emphasised by Stakeholder 2 in Scotland in relation to HIV:

“With sexual issues, people are not keen to talk, oh, I have the HIV, I contaminated like this, oh I need help, they are not keen to disclose that, because what if society will talk about them...but because what people surrounding them talking, they put them off, they don't want to test, even if the test [result] is that they are okay, it is hard for them to go see a GP.” [Stakeholder 2\_Scotland\_Stakeholder Workshop]

HIV is still strongly stigmatised in both countries (Antabe, Sano et al. 2023, Flint, Günsche et al. 2023). In the Scotland women’s workshop, one person shared their experience with a friend who had diabetes and suggested that some people might want to hide that they are on medication. When I asked the group if they thought there was a stigma about noncommunicable diseases like diabetes, there was some debate:

P1: For me, the diabetes is not a stigma because it's something that can happen naturally to anyone. It is not a stigma, it's not a something that, somebody can be diabetic, it's an illness and the person that will take care of itself.

[...]

P2: I find that is, you can't say it as a stigma, but most of us, our culture, most of Africans, we are very secretive when it comes to our health issues. We don't want to share.

ALL: Yeah, yeah. [Talking and noises of agreement]

P9: You're looking at someone like he has this, he has that. Mentally, that's what people are thinking

P: Yeah

P9: Stigma, yeah, that's what people are thinking. Like if I say something, like if I tell like, people will look at you, like she has this, OK, like even 'you know, the way she says that, she has diabetes'. That's it, so people know, so people prefer to keep [their diagnosis to themselves] instead of telling people, because at the end of the day she might [have] heard it from someone else. Like, I heard that you have this... So, [they] might not be okay with it. So, they rather keep it. That thing is killing a lot of people when they keep silent, they want to speak out. [Scotland\_Women's\_Workshop]

While participants in Scotland had mixed beliefs about whether diabetes held the same social stigma as diseases like HIV, they did acknowledge that members of the African community generally hide health issues. International studies, including those in the UK and Malawi, have suggested that diabetes is a stigmatised condition (Nicolucci, Kovacs Burns et al. 2013, Zimmermann, Bunn et al. 2018, Bissett, Gray et al. 2022, Chikumbu, Bunn et al. 2022, McKechnie, Broomhead et al. 2024, Speight, Holmes-Truscott et al. 2024). Part of the stigma in sub-Saharan Africa may stem from confusion between diabetes-related weight loss and HIV (Zimmermann, Bunn et al. 2018). A recent UK survey also indicated that those in minoritised ethnic groups, including Black, Black British, Caribbean, and African, are more likely to report negative attitudes from others about diabetes than White ethnicities (McKechnie, Broomhead et al. 2024). Therefore, there needs to be awareness of how communities perceive health and illness so that issues are discussed with sensitivity.

Whether something is stigmatising or not may also depend on the context, culture and language used. Stakeholders in Scotland emphasised that something viewed as offensive in one culture or language may not be intended as such in another:

S1: you know, I've been on residential trips when young people have, because they're from different places, and we're speaking from different cultures, and maybe a young person will call me like, Oh, if you lost 10 kilos you'd be up this hill in two minutes. But it's you know, I'm like that is completely normal. Because they're like from a different culture where they talk about weight, and they talk about health in a more direct way

[...]

S3: ...Kinda like what P1 shared about the different cultures or how different people talk about things. And I think from Arab backgrounds,

if I translate some stuff that in English, might become very rude, but in my own language is just fine to say this... [Stakeholder Workshop\_Scotland]

Although there were no obvious instances of stigma or tension around health issues observed during the workshops, there were a few interactions worth noting. Firstly, discussing hypertension and diabetes did tend to cause an atmosphere shift, especially in both community workshops Malawi, where many people expressed that they were “*deadly*” diseases in the first activity, and the long-term impact of hospitalisation was observed in several artistic outputs. This atmosphere shift was noted in fieldnotes when reflecting on Activity 1 in the Malawi women’s group where, ‘*the atmosphere definitely became more sombre when talking about serious things, and most seemed scared when talking about death*’ [Fieldnotes, Malawi Women’s Workshop]. Furthermore, in Malawi, women performed a poem that linked ‘*gaining weight*’ to diabetes and hypertension. However, ‘*during the performance there was laughter when someone from the audience joked about being targeted [by the poem] because she was gaining weight*’ [Fieldnotes, Malawi Women’s Workshop]. The same participant reiterated this point when reflecting on the poem, “*when they talked about adding weight and being diabetic, I felt attacked.*” [Participant, Malawi, Women’s Workshop]. While this all appeared to be in good humour, it is worth reflecting on how these interactions could reinforce stigma and how they can be better prevented.

The possibility of reinforcing stigma through creative activities was touched on in earlier work (Bissett, Gray et al. 2022), where an activity about smells potentially perpetuated stigmatising views about diabetic wounds. Therefore, in the present research, stakeholders were specifically asked about how to prevent and/or respond to possibly stigmatising or harmful discussions within the workshops. Stakeholders in Scotland argued that keeping discussions/questioning broad to avoid “*pinpointing people’s problems*” and to instead promote a more “*holistic*”, “*health positive*” setting is key [Stakeholder 1\_Scotland\_Stakeholder Workshop].

“... [it’s] looking at things holistically and like talking about health in a more rounded way, and that actually, that is less stigmatising anyway, because you’re not like, here’s, here’s like a secret thing, that’s like a smelly thing, that’s a gross thing and they’re here. So, like acceptable

conversation. It's like health is intertwined with all of your body - you can look very good and smell amazing, and you've got terrible health. So, I mean that, you know, it's like reducing that, is talking about it in a bigger picture, I think would help, maybe. Instead of pinpointing specific parts of the body or that, has always got so much room for strange things to be discussed, people's bodies, I mean diabetes, talking about weight, talking about body image, those are really triggering topics as well.” [Stakeholder 1\_Scotland\_Stakeholder workshop]

In the community workshops, participants were not asked to disclose their health status, and were told that if they opted to do so, it was through their own choice. Indeed, only one participant did explicitly note that they had hypertension (see Section 6.3.1). In Scotland, Stakeholder 3 agreed with “*non-obvious*” diseases like diabetes and hypertension, it is better to avoid singling people who have those conditions out for questioning:

“...So it's also like a way that people could participate in such art projects that may be aimed to increase their health and without include, without saying, oh I'm diabetic...where people can share general art projects that maybe there's elements of health and mental health and improving it, that people who are not maybe diabetic or have high blood pressure, and people work together in this to understand without well giving the people the options to [not] participate, they don't have to include that they have any of these disease...” [Stakeholder 3\_Scotland\_Stakeholder Workshop].

Stakeholders in Scotland and Malawi agreed that it is the facilitators' responsibility to support this safe space and avoid instances of stigma or tension. Reflecting on his own experience in participatory workshops, Stakeholder 3 noted:

“it's the practitioner responsibility to do a risk, is doing the risk assessment of what they should try to avoid maybe...And for me, for example, my own team, we tried to, all art projects, we actually talk about cultures and a difference, and about things but we're trying to control, not, I mean control, as you control the composition, trying to lead some of the conversations in a way, in a positive way, in a way that people casually still feel comfortable and continue on not to go into, and to I'm not saying that this will not happen, will not feel overwhelmed with so many and things, but that's here, just to try to understand what we can connect with” [Stakeholder 3, Stakeholder Workshop, Scotland]

Thus, while there are always going to be possible triggers when discussing health and illness, there is a need for researchers and facilitators to be cognisant of

how questions are framed and the broader context in which these discussions are situated to create a safe environment.

Beyond the question of stigma, stakeholders in Scotland shared how facilitators could further support a positive environment. Stakeholder 2 highlighted how it was important to take measures to support people to speak freely without interruption.

“Because everything is like spoken once. We don’t tell people to sign here or write what they say. We wanted to make our space as safe and as free space as we can. So, we try to avoid [limiting] people or to create an obstacle for them to speak. So, we let the, what they wanted to say to come fluently. Then I take notes, most of the time I scribble on a paper, but I would remember what a person have said, yeah, or I have someone taking the notes of what they are saying”  
[Stakeholder 2\_Scotland\_Stakeholder Workshop]

Stakeholder 4 similarly argued that facilitators should be empathetic and good listeners to support people to feel safe.

And I think for us one of the things that we see all the time is that we need to be empathetic. You know, when we, when we engage with people, because we get different people come with, you know, different sort of issues and all that. And it’s to try as much as possible to yes, [put yourself] in their shoes, and be a good listener, you know, so that you wanna make the other person feel like [Stakeholder 2] said, you wanted to feel that, like this is safe. [Stakeholder 4\_Scotland\_Stakeholder Workshop]

Finally, it is important to promote an environment of mutual respect among community members. While the workshops appeared to have supportive environments overall, there were a few instances that should be noted. For example, in Malawi some men were critical of one group’s acting skills:

“I loved their storyline; it is to the point and clear. Of course, they could do better in the acting” [Participant\_Malawi\_Men’s Workshop]

Furthermore, in the Scotland community workshop, some participants were talking over another group’s performance and *‘when I looked at the performers there was some obvious irritation at people not listening’* [Fieldnotes\_Scotland\_Women’s Workshop]. I tried to encourage everyone to be quiet, however, I was overly polite, cautious to reinforce pedagogical

hierarchies and therefore had a minimal impact. Therefore, it is important to be reminded that there is still a need for confidence and clarity as a facilitator to remind participants to support each other and promote an environment of mutual respect.

### 6.3.3 Practical Considerations: Accessibility

In addition to the findings above, one of the biggest practical considerations from the Phase 1 stakeholder workshops in both settings was how to improve access to arts-based participatory research. The following section will explore some of the possible challenges with recruitment and access.

As previously discussed, many members of minoritised ethnic communities in Glasgow are subject to the immigration and asylum system. As noted by Stakeholder 3:

“[Our] community members are affected with the whole political situation...and changes within the asylum process within Home Office within the financial... nowadays, like we have an increase [in the cost-of-] living, but that the asylum supports still the same. And also, like that, like the challenge and the stress that people live under is actually not motivating many people to actually participate in our [organisation’s] projects and activities.” [Stakeholder 3\_Scotland\_Stakeholder Workshop]

However, Stakeholder 3 also highlighted that it was important to recognise these contextual barriers to participation are nobody’s failing, so long as the facilitators create a trusting environment.

“If there’s trust and there is like space that people know that they can come back to, that’s the key to it, and we don’t really blame ourselves or the people that we work with all over the attendance, because we understand that what people are really going through.” [Stakeholder 3\_ Scotland Stakeholder Workshop]

Furthermore, Stakeholder 2 emphasised that due to the financial barriers community members are facing, they often “*don’t have the money*” to travel to workshops, so need to be reimbursed [Stakeholder 2\_Scotland\_Stakeholder Workshop]. These contextual and financial challenges certainly applied for many of the participants in Scotland (see Chapter 5.3), while participants in Malawi faced their own contextual challenges with poverty and stress (see Chapter 4.3).

Transport costs were provided in both Scotland and Malawi, and recruitment was generally successful in both contexts. However, there were notable difficulties recruiting men in Scotland which may reflect these broader contextual factors, as well as general barriers to male recruitment in health behaviour research (Ryan, Lopian et al. 2019).

A second access concern was the need to provide childcare. In the stakeholder workshop in Malawi, one woman brought their baby along, while several community members brought their children to the workshop in Scotland. This was viewed as a positive and, generally did not interrupt the workshop (despite causing some distractions: e.g. due to crying). However, as noted by Stakeholder 2 in Scotland, inviting children into the workshop can negatively impact the mother's experience as a participant.

“Yeah, because as a mother when they have children, and they wanted to participate, you know, when a child is beside them, they can't concentrate...” [Stakeholder 2\_Scotland\_Stakeholder Workshop]

Additionally, the presence of children brought considerations around media consent. Even if the participant had consented to photographs and videos, there was a need to be cautious to avoid taking images that showed children in the background. Stakeholders in Scotland recommended that it would be ideal to provide childcare during the workshops: for example, *“if you have some other partners there who maybe can run a session with younger children, while also giving people a break from childcare is quite nice”* [Participant 1\_Scotland\_Stakeholder Workshop].

### **6.3.4 Practical Considerations: Time management and Consent**

The following section will continue to explore some of the practical findings from the workshops with focus on time management and the consent process.

As outlined in Sections 6.2 and 6.3.1, the participatory workshops and the use of different art forms were generally praised by participants for being engaging. However, there were some instances where it seemed that participants' attention started to wane. At times I would observe different participants chatting about unrelated issues, sitting on their phones, or leaving the workshop

to take phone calls. It could be argued that the use of phones in a group space is an inevitability, particularly where participants have different responsibilities, and may even have been reinforced by the informality of the workshop.

People also clearly became more restless towards the end of the community workshops. Attention span and restlessness may also have been due to the workshops' length and the time allocated for break from activities, particularly in Scotland. Participants in both countries were given the opportunity for a break; however, all declined and opted to use the extra time to develop their performances. In Malawi, it also appeared that participants in workshops that took place in the afternoon (Malawi, men and stakeholders) had less energy by the end than those who participated in morning workshops. In Scotland, the women's community workshop finished around lunchtime, which may have also led to restlessness. Therefore, there is a need to consider how time is used in the workshops so that the activities do not become a burden to participants and/or they do not lose interest.

Finally, time was lost in both countries due to a long consent process. The consent process was complicated by multiple forms and staggered arrivals, which meant it was difficult to keep track of all the documentation, and the same questions about the content or confusing language were repeated. From fieldnotes, it appeared the consent process in the Malawi men's workshop was smoothest, as the local facilitator read the information to the group as a whole, and the second facilitator (myself) supported latecomers while the game started. The Malawi men's transcript also appeared to have the most reflection, possibly due to the pacing supported by a smoother consent process. Therefore, it was recognised that consent-taking would be helped in future workshops by involving a third facilitator to support time management. The extra facilitator would be also able to support any late-comers or other practical issues without disrupting the flow of the workshop.

## **6.4 Summary**

This chapter sought to further explore how the community and stakeholder perspectives from the Phase 1 workshops could inform the development of the TABPA methodology (RQ1). A range of art forms were both compatible with

community interests and adaptable to explorations of diabetes and hypertension. These included music and dance, theatre and drama, drawing, and poetry. With the exception of poetry (which was only selected by women in Malawi), the choice of art forms was generally similar between those in Scotland and Malawi. Music, dance and theatre were described as engaging, enjoyable and an appealing way to share messages; while drawing and theatre were considered an effective way to communicate information to those with a range of languages and literacies. While music, dance and theatre are embedded in everyday life in Malawi, African communities in Scotland come from a range of cultural backgrounds and may face barriers to artistic engagement in the UK. Therefore, these different contextual factors will likely influence how communities engage in different arts-based activities, particularly music and dance (RQ6). Finally, the Phase 1 workshops had several strengths (e.g. relationship building, challenging hierarchies) and practical challenges (e.g. time-management) that should be considered.

## **6.5 Reflections for Development**

Like, walkalong interviews, Phase 1 community and stakeholder workshops were an important process in building my familiarity with the African communities in Scotland and Malawi and understanding how they might engage with the TABPA. However, as discussed in Chapter 5.7.2, the Phase 1 familiarisation process forms one part of the TABPA framework, intended to provide sufficient context and understanding in order to inform the implementation of culturally-situated TABPA workshops.

Overall, there were five key findings from both Scotland and Malawi that informed the development and implementation of the TABPA workshops in Phases 2 and 3.

1. Many different art forms can be effectively used to explore hypertension and diabetes, but the art form needs to be culturally engaging and there should be at least one option that requires minimal language (e.g. drawing).

2. Flexibility and participant choice over the art form and the content supports participant engagement, relationship building and co-learning. Steps should be taken to remove any possible barriers to choice (e.g. increasing group numbers and providing support to improve participant confidence with different art forms).
3. Facilitators play a significant role in rebalancing power and creating a safe, supportive environment. This can help to reduce any harm from stigmatising or triggering content.
4. It is vital to make the workshops accessible. This can be supported by providing financial support and childcare, if possible.
5. Time management can be a challenge, it is necessary to be responsive to this when organising future workshops to allow more time for latecomers and recognise where additional support (e.g. another facilitator) may be required.

## 7 TABPA Method as Findings

### 7.1 Introduction

This chapter presents the findings from the pilot and refinement of the TABPA workshop with communities in both Scotland and Malawi, with a focus on the methodological development in each context. It will explore four overarching themes: i) fostering a safe and supportive environment, ii) co-producing knowledge, iii) ethical considerations and iv) practical considerations. In doing so, it aims to address the following research questions:

- RQ2 To what extent can the TABPA minimise researcher-participant hierarchies and encourage inclusivity among participants in practice?
- RQ3: What factors influence the feasibility and acceptability of the TABPA for use with African communities in Scotland and Malawi?
- RQ5: What skills, knowledge and resources are necessary to support wider implementation of the TABPA?

The chapter will begin by outlining how the TABPA workshop structure was developed from Phase 1 community workshops. It will then explore the strengths of the TABPA as an approach that fosters a safe and supportive environment through the generation of trust, personal narratives and relationship building. The following section will consider how the co-production of knowledge was negotiated and shaped by interactions between researchers and participants. As highlighted in Chapter 6.3.1, participants in Phase 1 valued the community workshops as a space to learn about health issues. In this chapter, I will explore the implications of these expectations further by examining conflicting expectations between researchers and participants about whether the process is a form of health enquiry and/or health promotion, with focus on the relational aspects of power. I will go on to explore the strengths and challenges of interdisciplinarity, particularly diverging expectations of the academic and artistic legitimacy of arts-based health research and reflect on the processes that led to the refinement of the TABPA protocol. The chapter will then consider some of the ethical and practical considerations that emerged, particularly

around the formality of informed consent in a creative approach, and how games can be used to support a shift in atmosphere. Finally, the chapter will conclude with a summary and highlight the implications for the final TABPA framework.

### **7.1.1 Developing and Refining the TABPA protocol**

The previous chapter explored how the findings from the Phase 1 community and stakeholder workshops informed the development of the TABPA methodology. These findings were originally intended to guide the design a new TABPA workshop protocol that integrated specific art-forms chosen by each community in Malawi and Scotland. However, upon recognition of the value of participant choice, the strengths of multiple different art forms as a means to explore perspectives on hypertension and diabetes, and participant's positive responses to the Phase 1 activities, I decided to model the pilot TABPA more directly from the Phase 1 community workshops themselves. Overall, the pilot TABPA workshop followed a similar scaffolding structure to the Phase 1 community workshop, although there were some key changes. Informed by the research aim and the recommendations in Chapter 6.5, I describe these differences below.

Firstly, several changes were made to focus the TABPA workshops specifically on community perspectives and experiences of the drivers of diabetes and hypertension. Therefore, the focus of Activity 3 was narrowed from a broad exploration of both diseases in Phase 1 community workshops to explore the *risk factors* of either diabetes (Women's TABPA) or hypertension (Men's TABPA) in the pilot TABPA (See Chapter 3.6 for gender justification). The pilot TABPA workshop also included the addition of another activity (Activity 4) where participants were asked to think about the possible solutions or prevention of the NCD risk factors they had explored. To accommodate these changes and provide a more in-depth exploration of participants perspectives, the duration of the workshop was extended from two-hours in Phase 1 to three-hours in the pilot TABPA. The number of groups within the workshop were also reduced. In the Phase 1 community workshops, participants were split into three groups for Activity 3. For the pilot TABPA workshops, participants were separated into two groups for Activity 3 and 4. This decision was made so that each group could have one facilitator who could be present to probe into their decision making to gain a better understanding of community perspectives on diabetes and

hypertension. Finally, to encourage participant's creativity and bring out underlying perspectives on diabetes and hypertension, Christiana (Scotland, co-facilitator) suggested that I modified the language in Activity 2 (initial thoughts on diabetes and hypertension). This involved introducing more abstract questions (see Chapter 3.6) and encouraging participants to close their eyes and visualise the condition (diabetes or hypertension).

In addition to the changes above, the pilot TABPA was guided by the five recommendations described in Chapter 6.5:

1. As in Phase 1 community workshops, Activities 3 and 4 in the pilot TABPA workshops were designed to accommodate a range of different art-forms.
2. Participants were provided with as much choice as possible over the art form they wished to use. As in Phase 1, a range of creative resources were provided. Furthermore, to remove possible barriers to participant choice and improve participant confidence with different art forms (Chapter 6.2.1), group sizes were increased (see Chapter 6.2.2). During Activity 3 and 4 the facilitator sitting with each group was also available to provide reassurance, encouragement and artistic support (if the group wished).
3. Facilitators were reminded to create a safe and supportive environment. In addition to providing support during group work (see previous point) the language of the protocol activities was designed to emphasise the TABPA workshops as a safe space for participants to play and have fun.
4. As in Phase 1, participants were provided with financial compensation and travel reimbursement (see Chapter 3.4.1.5 and 3.4.2.5). In response to stakeholder recommendations in Scotland, childcare was also arranged for the Scotland women's pilot TABPA workshop (see Chapter 6.3.3).
5. Due to challenges with time-management in the Phase 1 community workshops, more time was allocated for latecomers and the consent process in the pilot TABPA protocol. I also arranged for an additional facilitator to be present in the pilot TABPA workshops to support practical needs (e.g. consent processes) (see Chapter 6.3.4).

In collaboration with facilitators in each setting, I conducted pilot TABPA workshops with women in Scotland in August (facilitators: Christiana and Anna) and men in Malawi in October (facilitators: Rhoda and Trust). We then adapted the approach before conducting refined TABPA workshops with women in Malawi in October and men in Scotland in November (see Chapter 3.6.1: Figure 3-2).

Table 9 highlights the key changes to the protocol for the pilot and refined TABPA workshops. The duration of each activity was adapted to accommodate recommended refinements that emerged following the TABPA pilot workshops. I will discuss the processes that led to these changes in more detail throughout the chapter.

Table 9: Summary of Pilot and Refined TABPA workshops in Malawi and Scotland.

TABPA Workshops				
Pilot/Refined	Pilot		Refined	
Country	Scotland	Malawi	Malawi	Scotland
Gender	Women's Workshop	Men's Workshop	Women's Workshop	Men's Workshop
NCD Focus	Diabetes	Hypertension	Diabetes	Hypertension
Participants	N=11	N=10	N=10	N=3
Activity 0	Welcome and Consent Process			
Activity 1	Getting to know each other with a game			
Duration	15 mins			
Activity 2	Visualisation Task			
Duration	20 mins		15 mins	
Activity 3	Causes of NCD		Causes of NCD and Possible Solutions	
Duration	45 mins		1 hour	
Group 1	Drawing	Drama and Song	Drama	Participant 1: Story
Group 2	Drama	Drama	Song	Participant 2: Story
Group 3	N/A	N/A	N/A	Participant 3: Drawing
Activity 4	Solutions and Performance		Performance	
Part A	Develop Art Form with Focus on Solutions		Performance only	
Part B	Performance			
Duration	45 mins		40 mins	
Activity 5	Discussion and Reflections			
Duration	15 mins		10 mins	

## 7.2 Fostering a Safe and Supportive Environment: “You made us express ourselves freely”

This section will explore some of the strengths of the TABPA, with focus on how the approach contributed to the generation of personal narratives and fostered a safe and supportive environment.

Activity 2 asked participants to close their eyes and consider the first thing that came to mind when they thought of hypertension (men’s TABPA workshops) or diabetes (women’s TABPA workshops). The open nature of this activity generated a range of responses, from the causes and symptoms to the impact of the diseases. However, many participants, particularly women, used the space to reflect on their personal or familial experiences of the respective condition. For example, women in both Scotland and Malawi said the activity had reminded them of their fathers’ experiences with diabetes.

“OK, so for me. Diabetic the topic is... a very delicate one for me, cause I mean my dad died of being a diabetic patient and talking about diabetes, and telling us to close our eyes and think, I had a picture of my dad. I I’m not going to cry, but I I mean, I went far back to my country now thinking of closing my eyes and thinking about what my dad went through when he was diabetic. Like, you have to inject him every day. You know he has to eat some certain food and that is, I mean, someone that loves to enjoy himself, for being diabetic he had to stop a lot of things. And you know, we were able to manage it for some years and eventually he passed on. So, closing my eyes, I have a picture of my dad, so that was it for me.” [Participant 5\_Scotland\_Women’s TABPA\_Pilot\_Activity 2]

“When I heard about diabetes, I thought of my father. He is diabetic. A diabetic person really needs to eat frequently. A diabetic person usually feels hot. The feet get a burning sensation, and they swell as explained by my fellow participant.” [Participant 8\_Malawi\_Women’s TABPA\_Refined\_Activity 2]

Both women framed their understanding of diabetes through the impact it had on their fathers. While the participant in Malawi framed her experience more directly around the symptoms of diabetes, the participant in Scotland’s lived experience is framed more emotively, acknowledging that her personal loss means she finds diabetes a “*delicate issue*” to discuss. Evidence has indicated that negative familial impacts of chronic disease can contribute to a greater perception of risk or personal vulnerability to the condition (Walter and Emery

2006). Therefore, by freeing people to talk about their personal experiences, the TABPA workshops may be able to draw out some of the complexities of why community members might engage or not engage with different health promotion initiatives.

Several women in the Scotland women's pilot TABPA workshop also used the first activity to voice some of the fears, worry and risk they felt about diabetes and hypertension. One woman spoke at length about her personal challenges with gestational diabetes.

“When I close my eyes, I reflected on myself. My last pregnancy I got gestation diabetes so as since I was in Africa, it wasn't easily got, diagnosed that I had diabetes. Every time I was complaining of infection after infection. I would find when I could not wash myself properly because there is a [can't make out], those who know it can. You can wake up when you are really burnt with acids, you don't know. So, I didn't know what to do then they told me that you have gestational diabetes. You overcome it. So, I reflected on myself. But after delivery, the diabetes refused to go away. Now I'm realising so many changes in myself....

Another thing which I thought that... about that... I'm talking about my own experience. You find yourself in a situation that you have to be padded yourself all the time because there's when urine can stop, can refuse to be stopped, and it has to just get out. And so, you must be padded because you don't know when it will come, so instead of being ashamed in people, say no, I better pad myself before I move out of this house. So, it makes you to be uncomfortable, whether you are in periods or not periods, you must be padded yourself, because that's what has affected you with... Another thing which I thought, I thought about I talked about change of skin. You find you are becoming as if somebody who is in our country. So, people who sit around fire, there's a way they their skin tans but it makes your skin even if you're not in that situation to tan and you cannot do anything about it because the sickness is in you. Another thing which I thought about are about the infections, the bands of the private places you find you cannot wash yourself the way you want because you feel your pain. You have a lot of pain, even touching water in your fingers. You have a lot of pain because of diabetes...so diabetes, I find it a killer, a chronicle [chronic] disease, a very dangerous sickness. It's not about. It's not about what you eat, it's not about genetics. All because in my family, nobody has diabetes apart from me. And you can try to control it and refuses to go, when it refuses so diabetes, I call it a killer.”

[Several Participants start clapping]

[Participant 8\_Scotland\_Women's TABPA\_Pilot\_Activity 2]

The participant touches on several personal and sensitive subjects, including her own challenges with incontinence, washing and pain. These narratives convey a sense of vulnerability, perhaps emphasised even more by the analogy of diabetes as a *'killer'*. Stuckey and Tisdell (2009) found that the use of narrative interviews and processes of creative expression (using imagery, photography and written reflections) shaped similar emotive and negative narratives about illness experiences from diabetic patients as they created a space where participants could take time to focus inwards. It could be argued that in Activity 2, the open nature of the question and the quiet space for participants to close their eyes and reflect, contributed to a space where participants (especially those with direct or familial experience of the disease) felt empowered, even in a small way, to make sense of their experiences. Notably, the emotional presentation of these personal experiences, affected the other participants too. When reflecting on the Activity 2, Christiana and I, as facilitators in Scotland, noted how generous the women had been with their contributions and that the honesty created a sense of trust and support among everyone in the room. This was exemplified by a shift in tone among the participants, *'everyone had been quite talkative at the beginning of the activity, but when people started sharing very personal stories everyone was quiet and respectful, people stopped whispering to each other or told others to pay attention'* [Fieldnotes\_Scotland\_Women's TABPA\_Reflection on Activity 2]. As can be noted from the extract above, some participants even started gently clapping following Participant 8's emotive narrative. According to Lucero, Boursaw et al. (2020):

“Trust development in community-academic partnerships is characterized as having an emotionally and culturally safe, respectful environment based on shared group values to promote a sense of responsibility to the partnership while working toward shared goals” (p.373).

Therefore, both the presentation of, and responses to, personal narratives contributed to a trusting and supportive environment, where participants felt free, supported and able to reflect on their personal experiences of diabetes. This is an important step towards an approach that challenges researcher-participant hierarchies to re-centre community perspectives and encourages a sense of inclusivity among participants (RQ2).

The Scotland men's refined TABPA workshop also appeared to foster a safe and supportive environment. Though the participants had no prior relationships with each other, they seemed to quickly bond and support each other throughout the process. For example, during the final activity, when one of the participants reflected on the experience of his father, the eldest man tried to reassure him.

Participant 1: Like my dad, before he passed on, it has been one thing. You know, even though he died early at age of 67, that was low blood pressure, you know? My father wasn't worried about anything, then it came to me as a shock. Does it mean not even worried about anything can be a problem? [everyone laughs] When you're worried, that's a problem. He doesn't worry, he doesn't care, you know? Even engineer, you know, he tells you-

Participant 3: He does care but he knows how to control himself. Like he realised the situation and he said, "Well I'm going to tackle it, but this how I'm going to do it, without worry." If you go to Heathrow and you find a pilot, you know, [whistling sound] like this, or you go to hospital and they say, "Well, you know, we have to perform a heart operation on you," and you see the surgeon and everybody panicking, you don't want them there at all. You see? You see them calm, quiet, professional; they know what they're doing.

Participant 1: It was kind of, I don't want to be as calm as that, you know? [laughs] He died at the age of 67. [Scotland\_Men's TABPA\_Refined\_Activity 5]

Participant 1's openness to share such personal information again points to a trusting and inclusive environment where he felt safe and comfortable to share with strangers, while the response from Participant 3 also appears to demonstrate a sense of empathy and care for Participant 1 that had been developed in a short period of time. When asked how they had found the workshop overall, Participant 1 reinforced the idea that the TABPA workshop was a comfortable space.

"It was okay, it's comfortable, it's serene, you know? It doesn't make someone to think, I want to go." [Participant 1\_Scotland\_Men's TABPA\_Refined\_Activity 5]

Therefore, it could be argued that the trust and comfort generated through TABPA activities could both mitigate researcher-participant hierarchies (RQ2) and positively influence the acceptability of TABPA workshop for African communities in Scotland (RQ3).

It should be noted that trust development is a dynamic process that is shaped before, during and after the research process (Lucero and Wallerstein 2013, Lucero, Boursaw et al. 2020, Wallerstein, Oetzel et al. 2020). It is possible that the time and care taken to build and maintain relationships in Phase 1 of the research contributed to the generation of a trusting environment. This seems particularly likely in Scotland, where participants were recruited through known networks, and many were familiar with Christiana and I through participation in previous stages of data collection. In Malawi, different recruitment strategies and the addition of new facilitators in Phase 3 (Chapter 3.4.1.3) would suggest that the generation of trust ahead of the TABPA workshops was weaker than in Scotland. This is reinforced by one woman in the final activity in the Malawi refined TABPA workshop who had initially been scared of what the workshop would be like.

“The workshop went well. When we were coming, we were a bit scared, we didn’t know what to expect in terms of kind of people we were to meet. Honestly speaking, you made us express ourselves freely, we were not shy, it was as if we are the same [translation note: equals, like there is no difference between us]. So, I loved it.” [Participant\_Malawi\_Women’s TABPA\_Refined\_Activity 5].

Rhoda, the primary facilitator in Malawi, indicated that this fear was likely linked to participants’ understandings of hierarchical research processes “*where they had been thinking of whether their answers would be right or wrong OR whether or not they would be useful for the research and how the researchers would react to that*” [Rhoda\_Communication on Analysis]. Importantly, despite this initial fear, the TABPA workshop processes appeared to support a safe space where participants could express themselves and felt that their contributions were valued. As argued in the Chapter 6.3.1, while the workshop activities might set a foundation for this by using games and a flexible format that gives everyone the opportunity to contribute, the facilitators’ role in creating a positive atmosphere cannot be underestimated (RQ5) (Chapter 6.3.2). As in Scotland, by creating an open and supportive environment, the TABPA activities and facilitators appeared to play important role in reducing researcher-participant hierarchies, and thereby promoting the acceptability of the approach with the community in Malawi.

Finally, during the final reflections, one woman in the Malawi women's refined TABPA workshop highlighted that the workshop had made them feel "*free*" to express views that other's might disagree with, while also helping to fill gaps in her own knowledge:

"I want to say I have learnt a lot through this session. I have been watching on TV when they talk about diseases, sometimes they hide a person's face and sometimes they don't, depending on their agreement. This session made us feel free. I have also learnt some things I didn't know. My mother had diabetes when I was 15, up to now she is still diabetic, and she injects herself. We just knew that there was diabetes, it is now that we know that there are two types of it. This issue about insulin, I didn't know. I just thought it is the injection that she gives herself, but now I know it's about sugar in the blood. I have known that now. It means learning is continuous. When you are older, it doesn't mean you know everything. There are things I have learnt from these young participants. I am the oldest here, but I have learnt from them. I am so happy that I was among them. And I have learnt from you too. So, it would be great if you keep coming to teach us through research like this. You will hear our views and we will hear your views too, this way we can defeat a lot of diseases"

[Participant 10\_Malawi\_Women's TABPA\_Refined\_Activity 5]

The participant indicates that the mutual and intergenerational exchange of knowledge during the workshop helped her to understand her own familial experience with the disease. By inviting us to return and learn together, the participant also suggests that mutual co-learning is an important factor in the acceptability of TABPA workshops (RQ3). However, community expectations of TABPA workshops as a form of education and health promotion have complex implications which will be discussed below.

### **7.3 Co-producing Knowledge**

This section explores the use of TABPA workshops as a means to generate co-learning between participants and researchers/facilitators. While this can be viewed as a strength of the TABPA and an important principle of participatory research (Israel, Schulz et al. 1998), co-learning and the co-production of knowledge in arts-based participatory health research can be a complex process. There were several challenges in how these processes were negotiated by and between participants and researchers in the TABPA workshops. The following section will first explore how the workshop activities navigated community understandings or expectations of the research as an educative process while

considering how power influenced this knowledge generation process. The second half of this section will then explore how power and interdisciplinary expectations can influence the legitimacy of arts-based health research from both academic and artistic perspectives and how this may influence the acceptability of the TABPA.

### **7.3.1 Health Enquiry vs Health Promotion: Navigating Participant Expectations**

As in Phase 1, community members could use any art form they wished to communicate their perspectives on diabetes or hypertension. As noted in Chapter 6.2, participants in the community workshops would choose certain art forms with the rationale that they were an easy, engaging and accessible way to share health information. This reasoning was also present in the TABPA workshops. For example, for Activity 3, Group 2 in the Malawi men's pilot TABPA workshop chose to use drama as an entertaining and visual way to share information and support stress relief for those with hypertension:

Participant: We chose a play because it can explain better to those who would pay attention during the performance. We will be having conversations accompanied with actions. As for a song, you just sing the song, but you can't see the action. It only concentrates on what the audience hears, but a play is about hearing and seeing.

Participant: In addition to that, a play is entertaining.

Participant: Yes, it entertains. Even when a person with HBP watches a performance, he feels lighter. it reduces stress [Group 2\_Malawi\_Men's TABPA\_Pilot\_Activity 3]

In the final activity, participants in the Scotland women's pilot TABPA workshop also recognised how their artistic outputs could be used to support the prevention and control of diabetes and hypertension by educating others:

“Yes, I'll say also for, for those who have diabetes, they can follow everything done today. They can follow all these, what they want to avoid just follow what we say today, so you can, you can avoid, do exercise or all these things. It was helpful, yes.” [Participant 9\_Scotland\_Women's TABPA\_Pilot\_Activity 5]

However, sharing information via TABPA outputs becomes more challenging when community members only have partial knowledge or unknowingly communicate misleading information. As previously discussed (Chapter 1.2 and 6.3.2), one of the key challenges in the use of arts-based participatory workshops during the Culture and Bodies Project was the generation of narratives that could contribute to stigmatising perspectives on diabetes (Bissett, Gray et al. 2022). The Phase 1 stakeholder workshops highlighted that talking about health will always bring challenges; however, the impact can be mitigated by keeping questions broad and creating a safe and supportive environment (see Chapter 6.3.2). In the present research, the information shared in each of the TABPA workshops was broadly in line with health messaging; however, it often lacked important and nuanced details that are important to ethically communicate health advice.

Participants in the Malawi women's refined TABPA workshop shared their understanding of diabetes symptoms during Activity 2. This included "*burning in the legs*", a symptom that is associated with diabetic neuropathy, a long-term complication of the condition. During the break, Rhoda, the primary facilitator, had approached me to voice personal concerns about the symptom; however, I tried to explain that this would often come with other symptoms of the disease that she should look out for and provided her with some resources on diabetes. Rhoda felt comfortable to share this worry with me, yet it is possible that other participants experienced similar concerns that were not voiced but might have been exacerbated within the workshop. Thus, while it could be argued that the open and flexible TABPA structure and supportive facilitators did mitigate the opportunity for stigma, this did not remove harms associated with the spread of partial or misinformation. Abdulla (2021) highlighted similar challenges with her own work, where "*the conducive environment of the [creative] workshop space can provide a platform*" for the communication of narratives that could negatively impact community "*health seeking attitudes and behaviours*" (p.196). It could be argued that this could happen in other forms of health research such as focus group discussions; however, the openness of the workshop and the goal to prioritise community perspectives over biomedical knowledge may exacerbate the effects. To prevent these harms and support the feasibility of the TABPA workshops (RQ3), it is important to find a way to balance

community member's 'freedom' (Section 7.2) with measures to clarify misinformation. This will be discussed further throughout this section.

Importantly, many TABPA workshop participants appeared to expect the facilitators to provide clarification about diabetes and hypertension when they were unsure. As a researcher, it was challenging to know when to provide additional information and when to pose the question back to community members. In the Scotland women's pilot TABPA workshop, several participants generously shared personal and familial experiences with diabetes during Activity 2. When asked if they had any questions or reflections from the activity, several participants turned to me to ask questions about the disease:

Participant: Can you live as long? [Like with HIV medication]. So, does it apply to diabetes as well? On your regular medication and keep to it and maintain your healthy diet, can you still die from diabetes? So, does it get worse? Or is it because they are not having the right medication or why do people still die from it?

Facilitator 1: It's very complicated, but what they do say about Type 2 specifically is that if you are controlling it, if you find the right balance of medication and lifestyle change, then you can control it and you can, if you continue that, then you would be able to live...that your symptoms would decrease, that you could go kind of back, but it wouldn't necessarily be cured, but I'll give you all some resources at the end. I've got some resources that you can take away with you.... Is that OK for now? [Scotland\_Women's TABPA\_Pilot\_Activity 2]

This interaction conflicted with my expectations as a researcher that the TABPA workshop was a space to centre community perspectives. Scholars argue that by approaching knowledge production in this way, the researcher actually reinforces their position of power, centring the production of difference between the researchers and the community (Cooke and Kothari 2001, Kapoor 2005, Janes 2016). In the moment, I struggled with how I should navigate these power-dynamics. There were several possible overlapping reasons for this: i) following participants honest contributions I wanted to be responsive to their concerns; ii) with a research background in diabetes and a biomedical undergraduate degree, I did hold some knowledge; and iii) I was worried that if I did not present myself as knowledgeable, I would lose participants' trust. The latter is an uncomfortable recognition and undeniably linked to my 'outsider' status within the community. While we as facilitators had tried to adopt a more

informal role during the TABPA workshops and integrate ourselves into the group, there were still expectations that my role as a researcher was as an expert and that this expert knowledge should be shared. Janes (2016) draws on Spivak (2005: p.7) to highlight that the dynamic role of the researcher and their potential to “*put aside difference and self-synecdochise to form collectivity*” with the group, is a privilege that is unlikely to translate to members of the community. To self-synecdochise, an individual chooses one part of their identity to represent as their whole self (Spivak 2005). Janes (2016) highlights that where researchers can adapt their identity to fit within the broader dynamics of the workshop (i.e. form collectivity), community members may be less able to readily change roles or adapt their identities. Thus, despite the positive relationship building processes, my epistemic privilege as a researcher was reinforced by how I was viewed both by the participants and by myself (RQ2).

In Malawi, community members had similar expectations of an educative process. Having learned from the Scotland women’s pilot TABPA workshop, I had advised Rhoda to emphasise to participants that the TABPA workshop was not intended to communicate health information. During the introduction to the Malawi men’s pilot TABPA workshop, Rhoda, therefore, ‘*explained that the workshop was designed for us to learn from the participants using creative activities, not to teach them about high blood pressure. One man responded by saying ‘still you are medical people, we should learn, that is why we are here’*’ [Fieldnotes\_Malawi\_Men’s TABPA\_Pilot]. The participant’s response again suggests that the acceptability of the TABPA workshops is influenced in part, by their utility as a form of health education (RQ3). In the Malawi women’s refined TABPA workshop, participants also asked for clarification following Activity 2:

Participant: The question I have is on what I presented. I want to ask about the white blood cells. I presented white blood cells surrounded with sugar. I want to know if indeed there is any relationship between diabetes and white blood cells.

Facilitator 1: Ooh I hear you. So, at this point I cannot give you an answer because as a researcher I want to know what you know or heard. However, let me ask the group if anyone knows something. Its possible someone can respond. So, that’s the question.....she wants to know if the cells responsible for disease prevention get affected by

diabetes to the extent that they fail to function.... what do we know about this?

Participant: Not that I have heard about it.... but I just want to share my thoughts. It's possible that those cells get affected because there is a disease affecting the body and the sugar is not diluted. So, the rate of the responsible cells can go high or low. You may find that the cells are eaten up and can't perform well. These are just thoughts.

Facilitator 1: She has shared her thoughts that the cells may indeed get affected and fail to function well. Is there anyone with additional thoughts? (after silence). I also need comments for the other presentations [Malawi\_Women's TABPA\_Refined\_Activity 2]

[see Chapter 8.2, Figure 8-4 for participant's visualisation]

Unlike the interaction in Scotland, Rhoda redirected the questions back to the group instead of trying to answer them herself. While this approach helped to re-centre community knowledge, it, again, did not address community concerns. In the final activity, one participant in the Malawi women's refined TABPA workshop proposed that there should be a post-workshop debrief where the "*right information*" could be shared.

Facilitator 1: Is there anything that you would want us change in the way we have conducted the workshop?

Participant: I was thinking that .... well maybe because its research and it would be wrong to give us the correct information....maybe after the whole session the recording could be stopped, and the researcher could give the right information concerning the disease so that the participants should know the truth. If participants talked about causes or symptoms that are not correct, sharing the right information would help. [Malawi\_Women's TABPA\_Refined\_Activity 5]

This exemplifies the idea that the pursuit of centring local knowledge meant the TABPA actually diverged from community expectations and interests. It could be argued that this highlights the complexities of navigating colonial and biomedical legacies in the country, where community expectations likely stem from a history of health promotion interventions that have imposed Western biomedical understandings as 'correct' information (Myers 1993, Kamlongera 2005). However, as discussed earlier in this section, there was also the potential to spread harm through insufficient health information. While this could be a challenge within any health research, the priorities of co-learning and mutual

benefit within community based participatory research (CBPR) (Israel, Schulz et al. 1998, Minkler 2004, Ortiz, Nash et al. 2020), means there is a need to be responsive to community concerns.

While some general educative resources were provided, it was clear that community members wanted specific advice and information, which, given no-one in the session was a qualified medical professional, was something that we could not provide. I left the workshop feeling some guilt that I had not had the foresight to incorporate this into the method. However, after reflecting, I realised that I might be able to arrange for a medical professional to speak to the group before I left Malawi. With the support of my first supervisor (CB), I arranged an hour-long Q&A session with a qualified nurse who had experience in NCD research. Participants were invited back on a voluntary basis to ask any questions and voice any concerns they might have had about diabetes or hypertension. On my return to Scotland, I set out to organise a similar session for local participants and managed to make a connection with a person at Diabetes UK who had recently trained volunteers of African descent to provide information about diabetes. I arranged for one of these volunteers to support a Q&A session at the weekly meeting of community organisation 1 who had supported recruitment to the Scotland women's pilot TABPA workshop.

By combining the Scotland information session with a community meeting, I hoped to provide reciprocal support for the participants and stakeholders. Reciprocal relationships are an important feature of community based participatory research processes (Ortiz, Nash et al. 2020) and my transcultural CBPR conceptual model (Figure 2-2) because they are an important way to build trust and promote co-learning with community partners. As participants and community organisation 1 had supported my research through their participation and help with recruitment, I wanted to reciprocate by responding to participants' requests for health information and by supporting the community organisation to provide health messaging to their wider service users. As the community organisation was a women-only space, I was unable to invite the male participants to this workshop and, unfortunately, I did not have capacity to hold a similar session for only three participants. Instead, I reached out to the male participants in Scotland individually to provide additional resources on hypertension, including relevant information helplines and specific dietary

advice for African Caribbean communities. These events and resources were well received in both countries and allowed participants to clarify some of their understanding. As the sessions were a last-minute addition designed to thank participants for sharing their contributions (rather than intended to be part of the research from the outset), I did not have ethical approval to collect data to explore their utility in more detail.

Thus, the application of the TABPA workshops highlighted how participants and researchers can have different expectations of the research process which may influence the feasibility and acceptability of the approach and exposed where this could reinforce power hierarchies (RQ3). However, the process also revealed that researchers can and should be responsive to community concerns (RQ2/3). It should not be assumed that the debrief sessions alleviated the epistemic power that presented itself in the research process. However, this experience does demonstrate the importance of humility and learning from these more complex interactions, as well as a commitment to developing long-lasting and trusting relationships, which are central to CBPR (RQ2) (Ortiz, Nash et al. 2020).

### **7.3.2 The Legitimacy of Arts-Based Methods in Health Research: Navigating Interdisciplinarity**

Having learned the importance of providing flexibility and participant autonomy to choose the art forms in Phase 1, the TABPA workshops were also designed to give participants choice over what art forms they used to explore the risk factors for diabetes and hypertension. However, community members in Malawi seemed more confident with this choice than those in Scotland. In each TABPA workshop (aside from the men in Scotland where numbers were low) the participants were split into two groups, and each was assigned a facilitator. The group work was designed to be participant-led, while the facilitator's role was to support the group and probe for more details on the causes and solutions participants discussed. In Malawi, participants appeared confident in instigating creative activities and needed little support from the facilitator. Notably for Activity 3, Group 2 within the Malawi women's refined TABPA workshop even asked Rhoda to leave while they developed their initial ideas:

Facilitator 1: I am here just to follow your discussions, don't worry about me.

Participant: Why don't you go to the other group? We have just started.

Facilitator 1: There is another facilitator there.

[Participants laugh]

Participant: Ok. We want to discuss first and

Facilitator 1: I want to be recording what you are discussing.

Participant: I thought you would record later.

Participant: Maybe this one should hold the phone.

Facilitator 1: Are you shy to discuss in my presence? Ok, if you want to discuss first then go ahead, I will join you later.

Participant: What should we do? A play or a song

Participant: If it's a song then we need to have messages of diabetes... [Group 2\_ Malawi\_Women's TABPA\_Refined\_Activity 3]

Group 2's responsiveness to using art forms supports the idea that engagement with the TABPA is linked to the embeddedness of folk media forms in Malawian culture and health messaging (Lwanda 2003, Kamlongera 2005, Abdulla 2021) (see Chapter 4.5.2.5 and Chapter 6.2.1). While the participants demonstrated their readiness to develop art forms, it was helpful to have a facilitator present to remind participants of the specificities of the task. For example, Rhoda returned after five minutes and noticed Group 2 had created a song about the symptoms and prevention of diabetes but had forgotten to include the causes.

Participant: Maybe we should just write the song

Participant: I think that will take us time, you want us to have a reference?

Participant: We can just write and read it through

Participant: When one writes a poem, you recite it. A song goes viral, remember they will ask why we have chosen a song

Participant: [Singing] Listen listen, how can we prevent diabetes... my sister tell me

Participant: That's where you will say reduce fat, salt or sugar, don't eat starch

Participant: Don't eat a lot of rice...

Facilitator 1: Ok I want to understand one thing you have talked about prevention and symptoms. What about the causes of diabetes? Remember there are three topics we need to cover; causes, symptoms and solutions. So I can't hear the causes in the song.

Participant: It's the food that we eat

Participant: Oooh ok, yes, the causes. So, let's put them in a song  
[Group 2\_ Malawi\_Women's TABPA\_Refined\_Activity 3]

Group 2 seemed strongly engaged in the process and had a clear rationale (going viral) for choosing the song as a means of health promotion, indicating a sense of ownership over the process (RQ2). However, the facilitator was able to provide support to ensure that participants also answered the key questions from the research. There had been a similar dynamic in Activity 3 of the Malawi men's pilot TABPA workshop where Rhoda acknowledged it had been a "tricky" process for the participants to fully integrate community knowledge into the art form.

'It was a bit tricky, because there was a combination, first they had to discuss what art form then the causes. The art form part did not take that long. When I got to the group, they had already chosen an art form, they said they were going to do a play, during that discussion they started talking about the causes. They could separate the causes from the signs and symptoms. They had agreed at first, the first scene they were going to show a man who had been told some unpleasant news and he was going to faint. So, I asked so what are the causes of BP [High Blood Pressure], so we talked about the causes again, I asked, 'shocking news causes BP?' and they said, 'ah no'. I think they said if someone faints it means the BP is already there, they already have something going on in their body.'  
[Rhoda\_Fieldnotes\_Malawi\_Men's TABPA\_Pilot\_Reflections on Activity 3]

Rhoda's reflection highlights the tensions that can emerge around "*academic legitimacy*" (p.3) in arts-based health research, particularly with regards to the dichotomy between structured research processes and more flexible and open arts-based processes (Boydell, Hodgins et al. 2016). While the community members appeared confident in the creation of their drama, Rhoda gently

probed participants to consider how well the play represented the causes they had discussed, as it could be used to show more of their knowledge. In this way, Rhoda could reintegrate a sense of structure into the process with the aim of supporting the community members to portray the depth of their knowledge. While there is an argument that the facilitator stepping in diminishes the participants' power to direct the research process in a way that is meaningful, it could also represent the dynamic nature of the research process. Some scholars have discussed a feeling of guilt or failure to develop CBPR that is "*participatory enough*". Janes (2016: p.9) argues that approaches which focus more on the "*quantity, rather than the quality of participation*" miss a fundamental principle, that knowledge generation should be a complementary and mutual process "*rather than the tyranny of everyone participating in everything*". Thus, Rhoda's reminder of the workshop focus could reveal how the process of knowledge production was negotiated between community members and researchers/facilitators (Boydell, Hodgins et al. 2016, Phillips, Christensen-Strynø et al. 2022). This process of negotiation ultimately influenced how power was constructed and shared between researchers and participants in the TABPA workshops (RQ2) and influenced their feasibility as a means to explore perspectives on diabetes and hypertension risk factors with communities in Malawi (RQ3).

As noted above, the negotiation was still a '*tricky*' process, not only for navigating academic legitimacy, but also artistic legitimacy (Boydell, Hodgins et al. 2016). Following the Malawi men's pilot TABPA workshop, Rhoda argued that '*we didn't have enough time for the process...the art[istic output] was compromised, it needed more time to be developed*' [Rhoda\_Fieldnotes\_Malawi\_Men's TABPA\_Pilot\_Reflections on Activity 3]. In the Pilot TABPA workshop protocol, the community members were asked to consider the causes of the NCD and prevention/solutions as two separate activities which would build on one another. However, in the Malawi men's pilot TABPA workshop, as we were running behind on time and the groups did not want a break, the two activities were combined to focus on the causes and solutions together. Rhoda suggested that we intentionally combined the two activities in the Refined TABPA workshop protocol. This would provide more time for community members to focus on developing their artwork and to probe into

their decision-making (Table 9). The duration of all activities in the refined TABPA workshops were adapted to accommodate this change.

The decision to combine the causes and solutions/prevention did help the Malawi women's refined TABPA workshop to run more smoothly. Yet following the workshop, reflecting on the Activity 4, Rhoda was still concerned that there had been an '*injustice to the artistic output*' and that the approach had not shown '*to what extent art can unveil people's experiences*'

[Rhoda\_Fieldnotes\_Malawi\_Women's TABPA\_Refined\_Reflections on Activity 4]. Rhoda argued that the lack of time for participants to develop the artwork, combined with limited time to probe their decision-making meant that the art itself was less effective at revealing the depth of the participants' knowledge. However, the present research aimed to produce quality insight rather than quality art, where the discussions, negotiations and creativity could come together to build understanding of community perspectives on the risk factors for diabetes and hypertension. Therefore, while I agree with Rhoda's view that art holds more capabilities than were presented in the workshop, the focus of the TABPA is on the knowledge generated through the production of art rather than the artistic output itself. The TABPA workshops are intended to be a time-efficient process to build the necessary understanding to develop culturally-situated interventions to prevent diabetes and hypertension. In their arts-based research in Kenya, Elliott (2024) highlighted the extensive time, resources and artistic training required to produce both high-quality research and high-quality art. As a half-day workshop, the TABPA was designed to prioritise knowledge generation over the quality of the artistic outputs. In future work it is important to consider further how diverging perceptions of legitimacy could affect the feasibility of the TABPA and explore how they can be negotiated throughout the research process.

Rhoda's concern as a practitioner also related to participants' experience with art. She highlighted that the community members are not artists and, when asked to produce an artwork to share their experiences in two-three hours, '*it may be easier for those who are already artists, who follow basic rules or principles of 'art''* [Rhoda\_Fieldnotes\_Malawi\_Women's TABPA\_Pilot\_Reflections on Activity 4]. This was something that emerged from the Malawian women themselves when reflecting on the workshop:

Facilitator 1: Okay. She [member of Group 1] says all members of her team were acting for the first time, but they made it anyway. How about others? What about the group that composed a song? Did you find it hard to compose a song?

Participant: No, it was not. We [Group 2] had an idea of what had to go into the song, but we are not singers or musicians. So, if we were to give the content to a musician or a song composer it would have been perfect.

[A hand clap from fellow participants]

We knew what we wanted to convey through the song. It was hard, yes but not very hard. [Malawi\_Women's TABPA\_Refined\_Activity 5]

This extract suggests that women in Malawi also viewed their lack of artistic expertise as a limitation of their artistic output. It was emphasised in both the pilot and refined TABPA workshop protocols that participants should be encouraged to '*Have fun and don't worry about how professional or polished the artwork is*' [see Appendix 1: TABPA Refined Workshop Protocol]. It is possible that this direction may not have been given during the Malawi women's refined TABPA workshop. Community members' responses may also reflect existing expectations of artistic outputs as something that would typically be performed as part of community ceremonies and religious events (see Chapter 4.3.5 and 4.4) or community education and development strategies (see Chapter 6.2.1). Therefore, further care is needed within the TABPA workshops to encourage playfulness and support participants to focus on the process rather than the output.

In Scotland, participants were also confident in sharing their knowledge and understanding of diabetes, however, they appeared more hesitant in choosing the art form they would use to present it. For example, when working with Group 2 in the Scotland Women's Pilot TABPA workshop, the decision-making process around art forms was more restrained than in Malawi:

Facilitator 1: Okay, what about art forms? Is there anything anyone wants to play with? Do we wanna try different things? Do we wanna do a wee drama. Do we wanna do a song? A dance? A Poster?

[Participants Laugh]

Facilitator 1: What are we thinking?

[long pause...a few awkward laughs, some participants say No]

Facilitator 1: No? [Laughs]

Facilitator 1: Yeah, we could... make a drama.

Participant 10: Make a drama, yes.

Facilitator 1: Drama? Or or we've got loads of paints and colour and things. If you'd rather draw it and do a poster...?

Participant 1: Drama, yeah drama

[Participants laugh]

[Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

As previously discussed, it is possible that the uncertainty in choosing an art form in Scotland was linked to the diversity of cultures, languages and experiences in the room. For example, these complexities may have meant there were fewer specific culturally-situated choices for participants in Scotland compared to those in Malawi (see Chapter 6.3.1) or that community members were daunted by too many artistic choices. Furman, Singh et al. (2019: p.9) acknowledge that there is a lack of discourse around the fact that arts-based research approaches can often be 'awkward', particularly when engaging with marginalised communities, who, as discussed in Chapters 5.4 and 6.2.1, may experience several barriers to participation in arts-based activities. They argue that more time should be spent familiarising participants with different arts-based techniques to improve their confidence (Furman, Singh et al. 2019). While this could reinforce the production of artistic legitimacy, assuming a need for training may also reinforce assumptions that community members want or need to develop their skills. Once Group 2 in the Scotland women's pilot TABPA workshop had decided to use drama for Activity 3, I prompted participants on how they might develop it (e.g. by asking how many characters they wanted to include, and if they needed any props); however, participants chose to focus the discussion on the content. By trying to support participants to frame the drama, I imposed my own expectations of what a drama would look like, when, in

reality, participants were not concerned with developing a formal structure. This was most evident when I asked if the group wanted to write a script:

Facilitator 1: Do you want to write specific words, or do you want to freestyle it?

Several Participants: Freestyle [laugh] [Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

Participants' confidence to '*freestyle*', or improvise, the performance contradicts the idea that they were hesitant to engage in the artwork. Instead, the group embraced the informality of the space and created a compelling performance, which incorporated much of the discussion about diabetes we had been having in our group. This experience contrasts with Malawi, where participants appeared to be more concerned about the quality of their artistic output. This may be due to subtle differences in how the playfulness of the activity was framed in Scotland and Malawi, as well as differences in the context of local art. For example, it is likely that when community groups in Scotland use art and creative activities, they typically focus on the process (e.g. to support wellbeing) rather than the quality of art (see Chapter 5.3.2 and 6.3.2). Nonetheless, the openness and flexibility of the TABPA workshops supported power and decision-making to be carefully negotiated in the space (RQ2) and the feasibility and acceptability of the workshops could be supported by readily adapting the creative processes to participants preferences (RQ3).

This flexibility was reinforced further by the Scotland men's refined TABPA workshop. As there were too few men to divide into groups, the participants were given the choice to work on their output individually or all together. As with Group 2 in the Scotland women's pilot TABPA workshop, the initial presentation of the task was awkward, however, after some negotiation, the participants worked individually on their creative outputs, creating compelling stories and drawings about hypertension. When reflecting on the men's TABPA workshop, Christiana suggested '*that it might be better to rephrase the task-considering something more abstract like: 'if you had to communicate something in a new way, how would you do that'?*' She suggested that limiting the choice of art a little would provide more direction which would help participant confidence' [Christiana\_Fieldnotes\_Scotland\_Men's

TABPA\_Refined\_Reflections on Activity 3]. This suggestion could be easily integrated into the final TABPA, however, given the difference between responses in Scotland and Malawi (RQ6), care would need to be taken to consider the context of the research (RQ3).

Importantly, in each workshop, both researchers and participants had to navigate different expectations, knowledges, and practicalities. According to Phillips, Christensen-Strynø et al. (2022), arts-based research “*furtheres the heightened negotiation of knowledge across voices, and thus carries the promise of radically destabilising traditional knowledge hierarchies and generating knowledge that can contribute to research and social and practice transformation*” (p.17). Thus, it could be argued that despite complexities and tensions around academic and artistic legitimacy, the TABPA workshops supported a research structure, while promoting flexibility, humility, and responsiveness (RQ2/3). Through this process, researchers and participants were able to negotiate and exchange knowledge on the risk factors and prevention of diabetes and hypertension.

## **7.4 Ethical Considerations: Navigating Informed Consent**

As in Phase 1, there were several ethical considerations, particularly in relation to navigating a formal consent process within creative arts-based participatory research. The following section will consider these challenges in more detail and suggest possible refinements for future work.

Challenges with time-management were an issue in both Scotland and Malawi, however, there were different reasons for this. The TABPA workshops were designed to last three hours including a break. In Scotland, the date and time of the women’s pilot TABPA workshop was largely determined by the availability of the venue, a vibrant community space in Glasgow city-centre designed to support marginalised communities’ access to creativity, which was easily accessible by public transport and already known to some of the participants. The TABPA workshop took place from 11am-2pm. To make the consent process more efficient than in Phase 1, all participants were given the participant information sheet in advance of the workshop and the media consent form was integrated into the general consent form to reduce the amount of paperwork.

We then planned to go through the consent process as a group. I would read out each form and participants could tick the Yes/No boxes as they heard each statement of consent, rather than providing individuals with the forms as they arrived. Having experienced challenges with latecomers in Phase 1, it was also decided to allocate a 15-minute window for latecomers before starting the consent process and to bring an additional researcher, Anna, to provide support, including helping participants who were late. Therefore, as I would read the forms out, Anna and Christiana would be able to go round each participant and help where needed. Despite all of this planning, the consent process was still complex, over half of the participants arrived after the 15-minute window, and the majority needed one-on-one support, as noted in my fieldnotes:

11:15am: We only had four participants out of an expected thirteen. However, I had confirmed all participants attendance the Thursday before and was confident at least another three would definitely turn up given their enthusiasm over message. One participant messaged to say she was stuck in traffic; another unfortunately could no longer make it as their child was unwell. I decide that we should get started. The four people are sitting in our circle of plastic chairs, and I begin to explain what the project is again, summarise the information sheet and start to give a brief description of the difference between type 1 and type 2 diabetes. A few people come in as I am going through this information, Anna welcomes the latecomers and shows them to a seat. I then begin to go through the consent form, encouraging everyone to tick as we go along. At the beginning this appears to go well, however, I pause when I notice some people are reading more slowly and are a few boxes behind and others who are reading more quickly begin asking questions- specifically about media consent. At this point another few participants arrive, and the process is generally disrupted. Anna and Christiana brief the people who just arrive, and I decide to go round and help the people who were already here as it was clear the tick-together process was not working. It was a complicated process- further complicated by asking for consent for photographs and videos and explaining how they will/will not be shared. I do think it went as smooth as it could have given the circumstances. We collect in the consent forms for Anna to check they are all filled out correctly. By the end of this process 11 participants have arrived- we are running about 15-20 mins behind.

[Fieldnotes\_Scotland\_Women's TABPA\_Reflections Activity 0]

Despite our best efforts, the consent process meant that we started late and had to make up time later in the workshop. It is important to acknowledge that some factors (e.g. staggered arrivals) will always be out of the researcher's control. However, again there is a disconnect between the creativity and flexibility required of arts-based participatory methods and the formal and rigid structure

of academic consent processes. While these processes are integral to supporting the ethical conduct of research and participants' understanding of their involvement, there might be alternative ways to gain consent. While steps were taken to simplify the language in the participant information sheet, it was still a long document, which many participants may not have been able to read (or comprehend) ahead of the workshop. There were also valid concerns over how photographs and videos of the participants might be used, as many were comfortable with images being taken for the purpose of data analysis but did not want the images to be shared in any way. I intended to clarify how images would be used in the group explanation, however, as some participants read at different speeds and had different English literacies, the explanation was disjointed.

Moralli (2023) reflected on similar challenges in their qualitative research on migration. Cultural and language barriers, as well as inaccessible, Eurocentric models of informed consent meant they had to balance two fundamental ethical principles, "*avoidance of harm*" and "*respect for autonomy*" (Moralli 2023: p.763). In addition to informed consent forms, the authors used procedural consent, where they continually assessed the "*voluntariness of participants' involvement and exposure*" at several points throughout the research to ensure participants understood the nature of their participation (Moralli 2023: p.763). By using both forms of consent, they sought to acknowledge the complexity of the process and reflect on how participation may be influenced by participants' past experiences (Giorgi, Pizzolati et al. 2021, Moralli 2023). For example, the use of formal paperwork may reflect the proceduralism of the asylum-process for many (Giorgi, Pizzolati et al. 2021, Moralli 2023). In the Scotland women's pilot TABPA workshop, I felt it was important to sacrifice time to make sure that community members were fully informed and that any concerns were addressed. However, there may be alternative strategies that would be more effective and more responsive to the communities' experiences: for example, a phone consultation with participants ahead of the workshop or a detailed video explanation of the project ahead of time, perhaps in different languages, might be more engaging ways to ethically communicate information about the research. However, steps would need to be taken to determine whether participants have the phone or digital access required to make this feasible. The

introduction of oral or procedural consent processes that embrace the flexibility of the broader arts-based participatory research process should also be explored.

In the Malawi men's pilot TABPA workshop, the consent process was also longer than anticipated. The workshop was scheduled from 9am to 12pm and, unlike the women's pilot TABPA workshop in Scotland, the majority of the men had arrived on time. We started with a prayer by 9:05am before Rhoda began to explain the workshop in detail, with myself and Trust, a second Malawian facilitator available to support the process. As I could not speak Chichewa, I was unsure at what point in Rhoda's introduction I should provide participants with the consent forms. This resulted in a substantial delay to the workshop beginning and meant that much of the information was repeated as the groups filled out the forms together. On reflection, I should have spent more time with Rhoda ahead of the workshop to explore the best way this information could be conveyed in a short space of time. Ahead of the Malawi women's refined TABPA workshop, we clarified this between ourselves, and the process was much smoother. However, as Rhoda later highlighted, "*in the Malawian context, if we were to do it in a traditional or local way of obtaining consent, we would not have taken much time*" [Rhoda\_Comments on Analysis]. This was something that I should have explored thoroughly before writing my ethics proposals. Like other postgraduate participatory researchers, it is likely that my inexperience, in combination with my outsider status, meant that I was ill-prepared to challenge dominant institutional ethics procedures (Southby 2017). This is an important learning experience for me and something I hope to gain confidence with as I continue in my career. Thus, future work should explore how the research process can be better communicated ahead of the workshop in culturally-relevant ways, as well as exploring alternative ways to gain informed consent, as noted above.

## **7.5 Practical Considerations: A Note on the use of Warm-up games**

As discussed in the previous chapter, warm-up games were an important way to build relationships at the beginning of the workshop; however, they were also an important way of moving from the rigid consent process to a more creative

approach. As in Phase 1, all the TABPA workshops began by asking community members if they knew a game we could play to get to know one another. Again, participants in the Scotland women's pilot TABPA workshop did not have any suggestions, so Christiana and I introduced two games ourselves:

Game 1: Christiana decided to lead a gentle warm-up game where everyone had to count to 10 as a team. We would count the numbers one at a time, however, only one person could say a number at any one time. If multiple people said the same number at the same time, we would need to start again. We would win the game if, as a team, we had counted to 10 without any interruptions.

Game 2: I led a dance game. We all had to stand in a line, whoever was at the front had to do a dance move and everyone had to copy, we would circle the room. When we got back to the beginning the next person would take over. [Fieldnotes\_Scotland\_Women's TABPA\_Pilot\_Reflections on Activity 1]

The games helped to change the atmosphere from *'a bit noisy and disorganised, to more focussed, although relaxed and friendly'* [Fieldnotes\_Scotland\_Women's Pilot\_TABPA\_Reflections on Activity 1]. In Malawi, the warm-up games had a similar impact, although we realised that including a more active game, was particularly useful. In the Malawi men's pilot TABPA workshop, one man suggested a game where he would ask everyone their name. Once everyone had said their name, each person would have to name one other person in the group. Notably, as an observer and non-Chichewa speaker, I had not realised that this was the game, I incorrectly assumed the group had just completed introductions and that due to time-constraints, Rhoda had moved on to Activity 2. This interaction is described in my fieldnotes below:

'Everyone was still just standing in a line, it didn't feel like the atmosphere shifted in the way they usually did when we played a game. I asked Rhoda if there was something that she could do to get everybody moving like a dancing game or song to bring more energy to the group. Rhoda asked the group if they had a song we could sing. When one man introduced a song, Trust then thought to combine it with the naming activity. One participant came into the centre and started singing a phrase, that we all started to copy; as he did it, he danced and clapped. Everybody else joined in slowly, but by the end everyone was singing and dancing. This helped to shift the atmosphere from that when we were doing the paperwork'.  
[Fieldnotes\_Malawi\_Men's TABPA\_Pilot\_Reflections on Activity 1].

This extract reinforces the idea that encouraging creativity can help to create a more fun and playful atmosphere (Abdulla 2021), as well as the challenges of being an outside observer amidst language barriers. Nonetheless, we learned from this interaction and in the Malawi Women’s Refined TABPA workshop, played two games, one to get to know one another and a second to get everyone moving. In doing so, we successfully *‘changed the tone of the workshop and moved from everyone sitting on the benches to being on their feet, smiling, laughing, and dancing’* [Fieldnotes\_Malawi\_Women’s TABPA\_Refined\_A1]. It should be acknowledged here that as Rhoda had already started Activity 2 before I interrupted, the men in Malawi had heard the initial prompt for the visualisation and had longer than intended to think of their response. Therefore, we also decided to reduce the time given to the visualisation activity in the refined TABPA to generate more underlying perspectives on the NCD (see Table 9). This will be discussed further in Chapter 8.2.

Furthermore, the Scotland men’s refined TABPA workshop highlighted that the need for a game could be influenced by the number of participants. As there were only three participants, Christiana and I debated whether a game would be appropriate and decided to try the numbers game we had used in the Scotland Women’s Pilot TABPA workshop. However, this did not achieve what we hoped.

We successfully count to 10 as a group on the first go. The small group appeared to intuitively count in a circle so there was no overlap. After a few failed attempts we decide to move on.  
[Fieldnotes\_Scotland\_Men’s TABPA\_Refined\_Reflections on Activity 1]

While it is likely a different game might have been more successful, Christiana and I reflected that *‘with a small group, the game was less important. It felt really easy to have group cohesion with people, possibly supported by the informal, paced introduction’* [Fieldnotes\_Scotland\_Men’s TABPA\_Refined\_Reflections on Activity 1]. Again, this highlights that the TABPA structure is a helpful starting point but the should be readily adapted as required (RQ5).

## 7.6 A Brief Reflection on Facilitator Knowledge and Experience

As highlighted in Chapters 3.1.3 and 5.7.2, I am an outsider to the communities in Scotland and Malawi and therefore, to undertake this research it was essential that I understood the contexts in which I was working. This required the Phase 1 familiarisation process to ensure the approach could be culturally-situated within each community. I believe this process also supported me to facilitate the TABPA workshops, particularly when I was the primary facilitator in Scotland. However, it was noticeable that Rhoda and Trust, as new facilitators in Phase 3, and as experienced Malawian arts-practitioners, were confident and highly capable of facilitating the TABPA workshops without participating in Phase 1. Thus, for those who are completely new to the communities they intend to work with, a preparatory step such as the Phase 1 walkalong interviews form a necessary component of the TABPA framework. However, this stage may be less intensive, or not required at all, depending on how embedded practitioners are into the community.

## 7.7 Summary

This chapter explored the findings from the pilot and refinement of the TABPA with communities in Scotland and Malawi with focus on the methodological development of the approach. The open, flexible nature of the TABPA workshop scaffolding structure and the encouragement of facilitators appeared to foster a safe and supportive environment where participants could share personal narratives and experiences of diabetes and hypertension. By creating space for participant choice over the art form and the risk factors they focussed on, community members in Malawi felt “*free*” and overcame initial fears that accompanied their participation in the workshop.

However, the TABPA workshops also revealed challenges when navigating power in the co-production of knowledge. Despite efforts to centre community knowledge, community members in both Scotland and Malawi still had expectations that the TABPA workshops should be a space for health education. Furthermore, the open nature of the TABPA workshops could inadvertently contribute to the spread of partial or misinformation about health. The TABPA

workshops also highlighted diverging perceptions of academic and artistic legitimacy where researchers and arts-practitioners had different expectations of the quality of artistic outputs.

Finally, the chapter explored ethical and practical considerations that emerged from the pilot and refinement of the TABPA workshops. It highlighted the challenges with traditional ways of gaining informed consent and suggested alternative strategies to ethically communicate information about the research in an engaging way. The use of games was also particularly useful at promoting creativity within the workshop although they should be readily adapted to the requirements of different groups.

## **7.8 Conclusions and Implications for the Transcultural Arts-Based Participatory Approach Framework**

In this chapter, I have explored the use of TABPA workshops as a means to explore the risk factors for diabetes and hypertension among African communities in Scotland and Malawi. The findings from the pilot and refined TABPA workshops informed the development of the final TABPA framework in five ways:

1. The TABPA process can be messy, therefore workshops need to be open, flexible and adaptable to the unique requirements and expectations of each community (e.g. group size, participant confidence, time).
2. The TABPA workshop should include a strategy to clarify health information (e.g. a debrief session).
3. Differing perceptions of artistic legitimacy need to be negotiated and clarified with facilitators from the outset to determine how both artistic and academic modes of knowledge production can complement one another, and structure and flexibility can be balanced.
4. The acceptability of TABPA workshops may be improved by emphasising the focus on the process of developing artistic outputs rather than the product and exploring how to improve initial confidence in Scotland.

5. The use of a warm-up game is particularly important in bigger groups and works best when it gets the group physically active.

## 8 Culturally-Situated Understandings of Noncommunicable Disease Risk Factors

### 8.1 Introduction

Having explored the development and implementation of the TABPA as a methodology in the previous chapter, this chapter will explore the utility of TABPA workshops as a means to generate culturally-situated understandings of the communities' lived experiences, beliefs, and attitudes towards hypertension and diabetes risk factors (RQ4).

The chapter will first explore perspectives gained through the use of narrative, imagery and metaphor during the visualisation activity. It will then explore how knowledge was created through creative processes of discussion, artistic development and reflection throughout the workshop. The following six themes will be examined: diet, food and cultural identities; social prestige; physical activity; financial and family stress; migration, discrimination and a hostile system; and individual mindset and 'ignoring' advice.

### 8.2 Visualisation Activity: Narrative, Imagery and Metaphor

The visualisation activity (Activity 2) asked participants to close their eyes and consider the first thing that came to mind when they thought about diabetes [Women's TABPA workshops] or hypertension [Men's TABPA workshops]. As part of the TABPA's scaffolding structure, this activity was designed to be kept broad to ease participants into the workshop and build towards a focus on risk factors in Activities 3 and 4. As described in the previous chapter, this activity brought out several personal and experiential narratives about diabetes and hypertension (Chapter 7.2). It also appeared to be an effective way to delve into underlying knowledge and perspectives on the drivers, symptoms and treatment of each condition through participant narratives, imagery and metaphor. In the Scotland women's pilot TABPA workshop, responses highlighted how diabetes is conceptualised as a condition that is strongly related to lifestyle. This was poetically captured by Participant 7 who used metaphor to describe the "*journey*" of diabetes.

“When I close my eyes and with the word diabetes, I drew a person walking. We are on a journey. When we are walking, we walk on different surfaces. I always take it when I’m in the village, back home [in Malawi], that is what came into me. We are walking with different surfaces, you go somewhere it’s hilly, you go somewhere, it’s rocky. And when you’re walking on a rocky surface, you walk minding the stones that may prick my foot so it’s the same. You walk with diabetes in your head. How do I get...what are the things that will make me get diabetes. You think of the causes of diabetes. You think of your lifestyle. You think of what you can do, what you cannot do. So, it’s the same way as we walk. What is going to harm me? What is going to break my skin? What is going to make my journey difficult? So, it is the same way when we think of our diabetes. What is going to make me have this...make me suffer this diabetes. What is going to help me avoid diabetes? What is going to help me control diabetes? That is what came into my mind.” [Participant 7\_Scotland\_Women’s TABPA\_Pilot\_Activity 2]

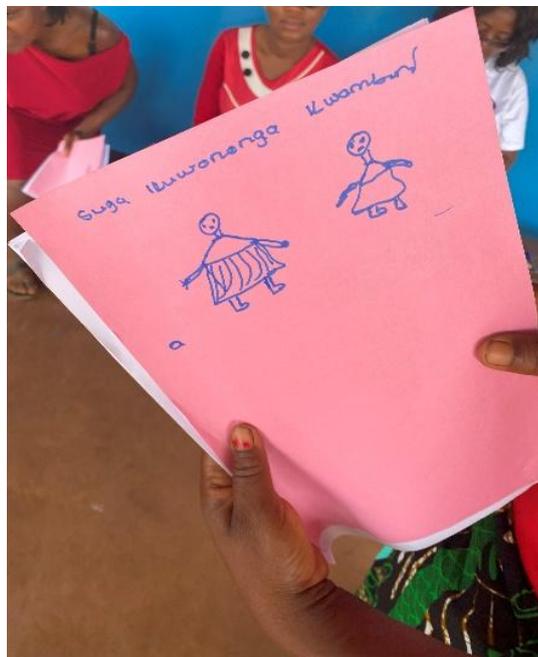
This is a powerful metaphor that highlights how diabetes can impact even those without the condition. There is a sense that the “stones” or risk factors for diabetes are all around, yet individuals still maintain a level of control if they move with caution. It could be argued that the example shows the time, thought and energy given to the prevention and control of the condition, while also generating a sense of individual empowerment. By exploring what she “*can do*” and what she “*cannot do*”, the participant suggests that she has power to engage in behaviours to support her own health, while recognising the constraints of wider, structural barriers. Another woman provided a similar narrative; however, she highlighted that the decisions made on this journey are also driven by worry and concern.

“When I close my eyes, when I think about diabetes, I feel shock. Because I have to do more exercise, I have to think about what I’m going to eat, I have to look after myself. Also, I have to find more about it. I have to find more information about diabetes. I have to find out more about how I can get it. Yes. Also, I can see many people. I can see photo from people who already got their diabetes, I feel scared and shock.” [Participant 9\_Scotland\_Women’s TABPA\_Refined\_Activity 2]

Thus, the visualisation activity appeared to create a space for participants to reflect on their own beliefs and worries about diabetes, as well as their capacity to prevent the disease through lifestyle modification.

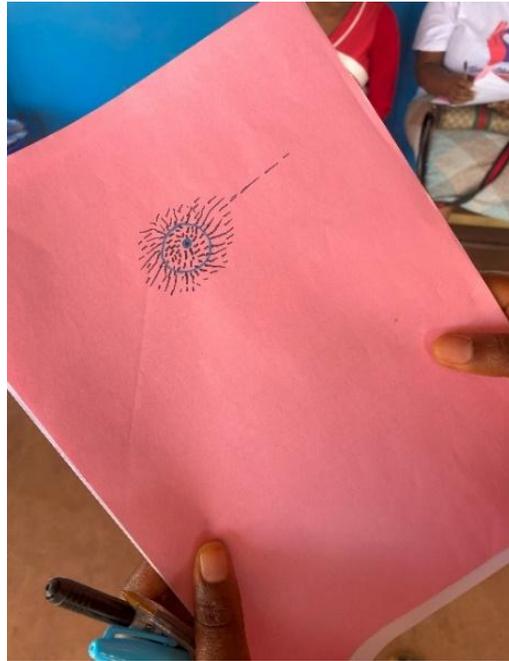
In the Malawi women’s refined TABPA workshop, the visualisation activity primarily brought out narratives relating to the symptoms and the impact of diabetes. Participants mentioned symptoms including weight loss, frequent urination, frequent hunger, appetite loss, fainting from low sugar, weakness, swollen legs and feet, wounds, burning in the legs, a dry throat and mood swings. A number of these symptoms were effectively conveyed through visual imagery as can be seen below.

“When you said the word diabetes, I thought of the damage that it causes. My aunt is diabetic. She used to be fat but is now lean.”  
[Participant 5\_Malawi\_Women’s TABPA\_Pilot\_Activity 2] [Figure 8-1]



**Figure 8-1:** Image from Malawi women's refined TABPA workshop visualisation activity (Activity 2). The participant's description of the image is described above (p.217).

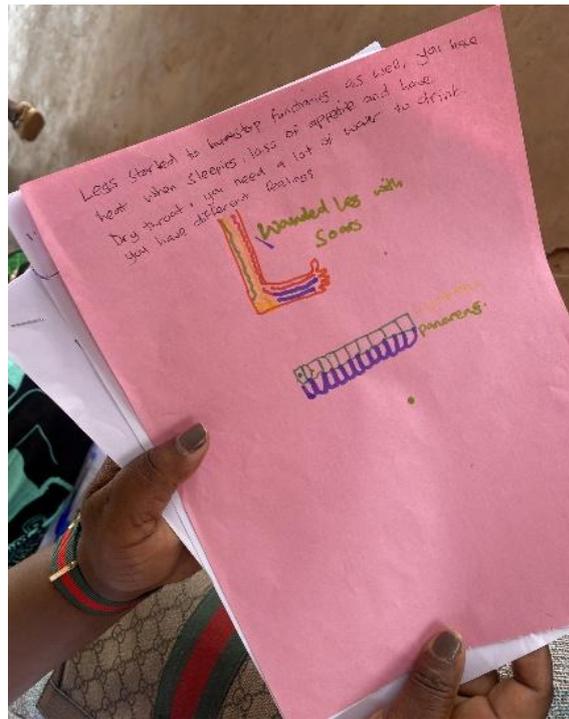
“When I closed my eyes, I saw darkness. Diabetic people are often hungry. They need to eat frequently...I drew this and there is a dot in the middle to represent hunger [Rhoda-it is believed that when a person is hungry, their eyes experience some kind of darkness (chidima)]” [Participant 7\_Malawi\_Women’s TABPA\_Refined\_Activity 2] [Figure 8-2]



**Figure 8-2: Image from Malawi women's refined TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.217).**

One participant highlighted a range of diabetes symptoms as described through their response to the activity below. She later revealed that her mum had diabetes, which likely informed her response.

“I thought about how people are affected by diabetes. They are some whose legs get amputated. Like in this picture, I have drawn a swollen leg. There are swollen veins and wounds inside the leg. Some have even had both their legs amputated because of diabetes. I have also drawn a pancreas, I don't know what it's called in Chichewa.....it works in coordination with the liver, the liver also gets affected. For some people, diabetes turns into cancer. It causes a lot of problems. These are the common problems that are related diabetes. When people's legs get amputated, their movement is limited. They are usually on a wheelchair, and they fail to work normally. When sleeping, they feel a burning sensation in their legs. I wrote that here. You also lose appetite. Food doesn't taste as good as before. You are given a specific diet to follow. Sometimes they tell you not to eat meals with fat. Sometimes they tell you to lose weight. Usually, throat gets dry, and you need water frequently. Sometimes you also get varying feelings, you get moody. For example, you don't want to meet people or chat with them. You just isolate yourself. I also heard that when you are diabetic, you need to have balanced emotions. Not too happy nor too sad. So, I just wrote some of the things that a diabetic person feels/experiences.” [Participant 10\_Malawi\_Women's TABPA\_Refined\_Activity 2] [Figure 8-3]



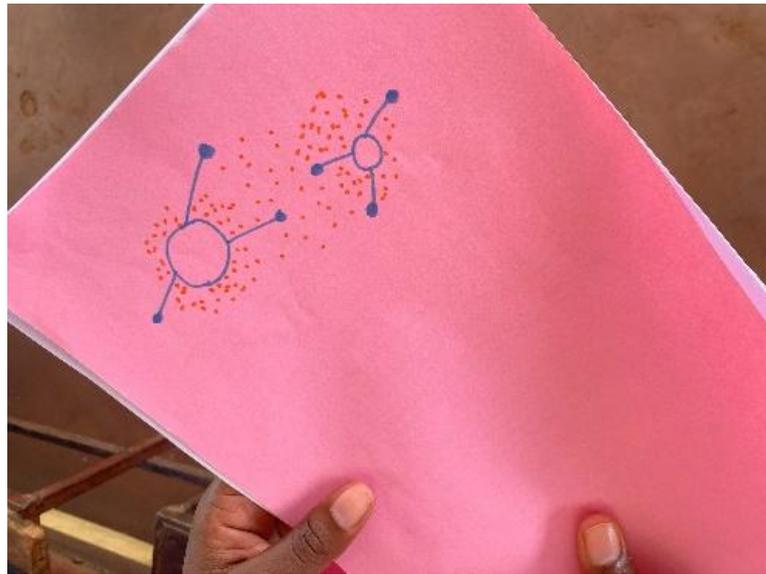
**Figure 8-3: Image from Malawi women's refined TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.218).**

While participants in Scotland also discussed symptoms in the visualisation activity, they were generally less severe than those discussed in Malawi. Symptoms mentioned in the Scotland women's pilot TABPA workshop included fainting, tiredness, dizziness and headache. While one woman highlighted that people with diabetes could fall into a coma if their sugar level became too high, only Participant 4 described symptoms of diabetes in depth. Her personal experiences of diabetes are presented in Chapter 7.2; however, it is important to note that she had struggled to gain a diagnosis of gestational diabetes when they were in Africa. Alloh, Hemingway et al. (2021) found that experiences of the healthcare system at home in Africa were linked to how West African migrants with type 2 diabetes situate themselves as patients in the UK. These experiences were predominantly negative and linked to late diagnosis. Thus, given the difference between NCD healthcare access between Malawi and Scotland, as described in Chapters 4.5.2.4 and 5.5.2.5, the visualisation activity was particularly revealing of how access (or lack of) to diagnosis and treatment can shape community conceptualisations of diabetes. In Malawi, the focus becomes on the profound physical impact of the disease, while in Scotland narratives are related to lifestyle and control.

The differences between the conceptualisations in Scotland and Malawi may also be linked to national health promotion strategies. In the UK, NCD-related public health messaging tends to prioritise individualised lifestyle change (Piggin 2012, Talbot and Branley-Bell 2021, Limb 2022). One example is the ‘Better Health’ weight-management campaign launched by the UK government and designed to support individuals to improve their health through weight loss, physical activity and quitting smoking (Public Health England 2020, Talbot and Branley-Bell 2021). The campaign was viewed positively by some as a way to support community, exercise and motivation; however, both public and professional bodies criticised the approach and the language used as superficial and fat-shaming, and as failing to account for broader structural influences and mental health (Talbot and Branley-Bell 2021). In Malawi, education at healthcare facilities has been the primary strategy to share information about NCDs. However, financial barriers and inadequate resources mean that community outreach for NCD awareness, prevention and service provision is limited and that clinical services and the management of NCDs are prioritised over prevention (Lupafya, Mwangomba et al. 2016). Additionally, although NCD management is prioritised, access to treatment and medication is still limited (NCDI Poverty Commission 2018). This suggests that in Malawi, community members’ conceptualisation of diabetes as a disease with a stark physical impact is shaped by insufficient access to diagnosis and treatment, and is compounded by a lack of community outreach and education on prevention (Lupafya, Mwangomba et al. 2016, NCDI Poverty Commission 2018). In Scotland, on the other hand, it appears that swift access to care and exposure to lifestyle-related messaging through healthcare professionals and widespread campaigns could influence why community members perceive NCDs as preventable and controllable with behaviour change.

The visualisation activity also appeared to bring out underlying and more abstract knowledge. For example, as discussed in Chapter 7.3.1, one woman in Malawi suggested there could be an association between diabetes and sugar blocking the function white blood cells.

“When I heard the word diabetes, I drew this. I imagined white blood cells, which I believe, are the ones that fight against diseases. I pictured them surrounded with a lot of sugar and they are failing to fight against diabetes.” [Participant 9\_Malawi\_Women’s TABPA\_Refined\_Activity 2] [Figure 8-4]

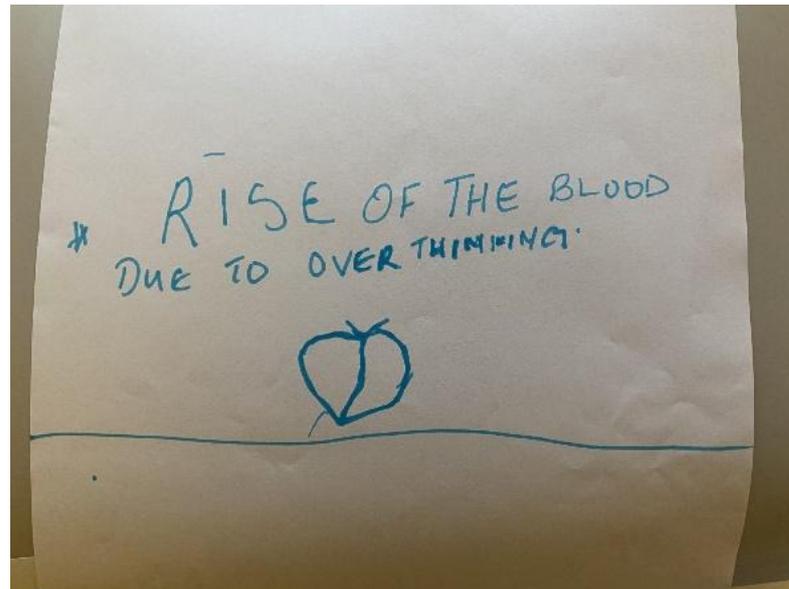


**Figure 8-4: Image from Malawi women's refined TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.220).**

Type 2 diabetes is recognised as an inflammatory disease, and research has reported that an increased white blood cell count can predict the incidence of type 2 diabetes (Zhang, Yang et al. 2017). While Participant 9 may have had some knowledge of this, it is possible that she was also applying knowledge associated with infectious diseases and was trying to make sense of whether white blood cells (i.e. an immune response) are responsible for preventing diabetes. It could be argued that this nuanced detail is too specific to have emerged through traditional forms of data collection.

Interestingly in both men's TABPA workshops, most of the visualisations related to the causes of hypertension, including overthinking and stress, as shown by one participant in Scotland.

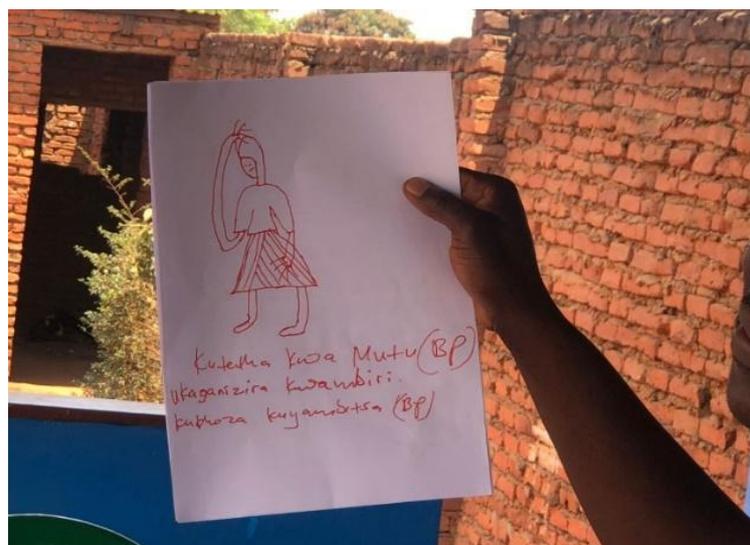
“What first came to my mind is like the rise of the blood like due to bad thinking.” [Participant 2\_Scotland\_Men's TABPA\_Refined\_Activity 2] [Figure 8-5]



**Figure 8-5: Image from Scotland men's refined TABPA workshop visualisation activity (Activity 2): The participant's description of the image is described above (p.221).**

In Malawi, several men highlighted that overthinking and stress were caused by financial demands and responsibilities. This is shown in one man's description of his drawing during the visualisation activity.

“Although this person is lean, she still has BP because of stress. Financial demands e.g. farm products; school fees etc cause stress and headaches because of overthinking. This is why this person is holding her head to show that she is stressed, it's like she is saying “aaah, what am I going to do?” [Participant 7\_Malawi\_Men's TABPA\_Pilot\_Activity 2] [Figure 8-6]

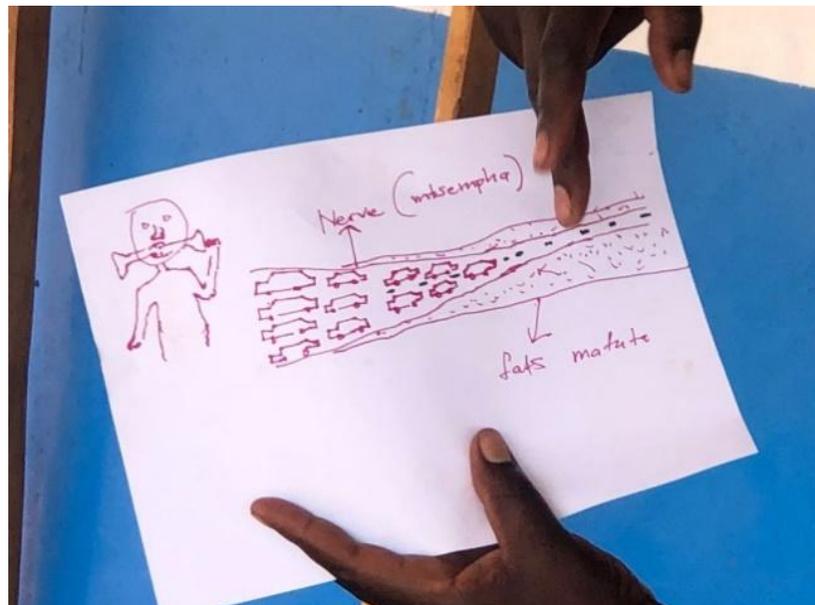


**Figure 8-6: Image from Malawi Men's TABPA Visualisation Activity (Activity 2): The participant's description of the image is described above (p.222).**

By acknowledging the “*person is lean*” but “*still has BP*”, the participant appears to suggest that stress as a risk factor is independent of other drivers like weight. The image conveys a familiar depiction of stress whereby the person is holding their head in their hands, trying to hold the weight of their thoughts, arguably promoting a more empathetic and emotional understanding of the risk factor than might be observed through narrative alone.

Notably, in both Malawi and Scotland, men also used the visualisation activity to highlight that hypertension was associated with how blood travels through blood vessels. For example, one man in Malawi drew an image to show how consumption of fats can obstruct the blood flow through veins. The image is described by the participant below.

“I have drawn a vein. This is a vein. I have drawn cars in the vein, as if they are on the road. Here they are moving smoothly but at the end, the road has narrowed. This is because the vein is full of fats. These symbolize fats. It means that this person has been eating a lot of fats, for example, chicken meat like broilers. That’s why I have drawn a chicken bone to show that. So, the fats are in the vein, blocking the movement of the blood, which is presented here in form of cars.” [Participant 4\_Malawi\_Men’s TABPA\_Pilot\_Activity 2] [Figure 8-7]



**Figure 8-7: Image from Malawi men's pilot TABPA workshop visualisation activity (Activity 2): The participant’s description of the image is described above (p.223).**

This example demonstrates a detailed understanding of both fats as a cause of hypertension and the physiological response. It is also possible that this image stems from an attempt to conceptualise what a ‘symptomless’ disease looks like in the body. As highlighted in Chapter 7.5, the men in Malawi were given longer than intended for Activity 2; therefore the detail of this response may reflect the longer time that they had to think about the prompt ‘What comes to mind when you hear the words high blood pressure?’ and how they would choose to answer it. Thus, while the visualisations from the Malawi men’s pilot TABPA workshop may have highlighted community knowledge, they may have been less effective at generating more hidden, underlying perspectives on the disease.

### 8.3 Building Knowledge Through Creative Processes

Overall, the visualisation activity appeared to be an effective way of understanding how communities conceptualise diabetes and hypertension, generating personal, emotive and underlying beliefs about the diseases. The remaining TABPA activities (Activities 3, 4 and 5: Table 9) sought to expand on these narratives and to use a combination of discussion, creative processes and reflection to explore community perspectives on the drivers of diabetes and hypertension. The following section will examine how these processes interacted to generate knowledge through an exploration of six emergent themes.

#### 8.3.1 Diet, Food and Cultural Identities

In the Scotland women’s pilot TABPA workshop Activity 3, Group 1 decided to explore diet by drawing a dining table of ‘healthy’ and ‘unhealthy’ behaviours on two scrolls of paper (see Figure 8-8). Unfortunately, the beginning of the audio was not captured, but according to Christiana *‘the conversation started with a woman describing the ratio of a very small cup of tea, to many spoonfuls of sugar. She discussed it with humour and used the absurdity of the image to demonstrate how unbalanced diets become normalised. The group then tried to come up with more images of things they considered to increase risk factors in diabetes. They decided to draw the images on a large scroll as though we were depicting a dinner table to scale’* [Christiana\_Fieldnotes\_Scotland\_Group 1\_Drawing\_Women’s TABPA\_Pilot\_Reflections on Activity 3]. The combined process of discussion and drawing brought out a range of perspectives on food

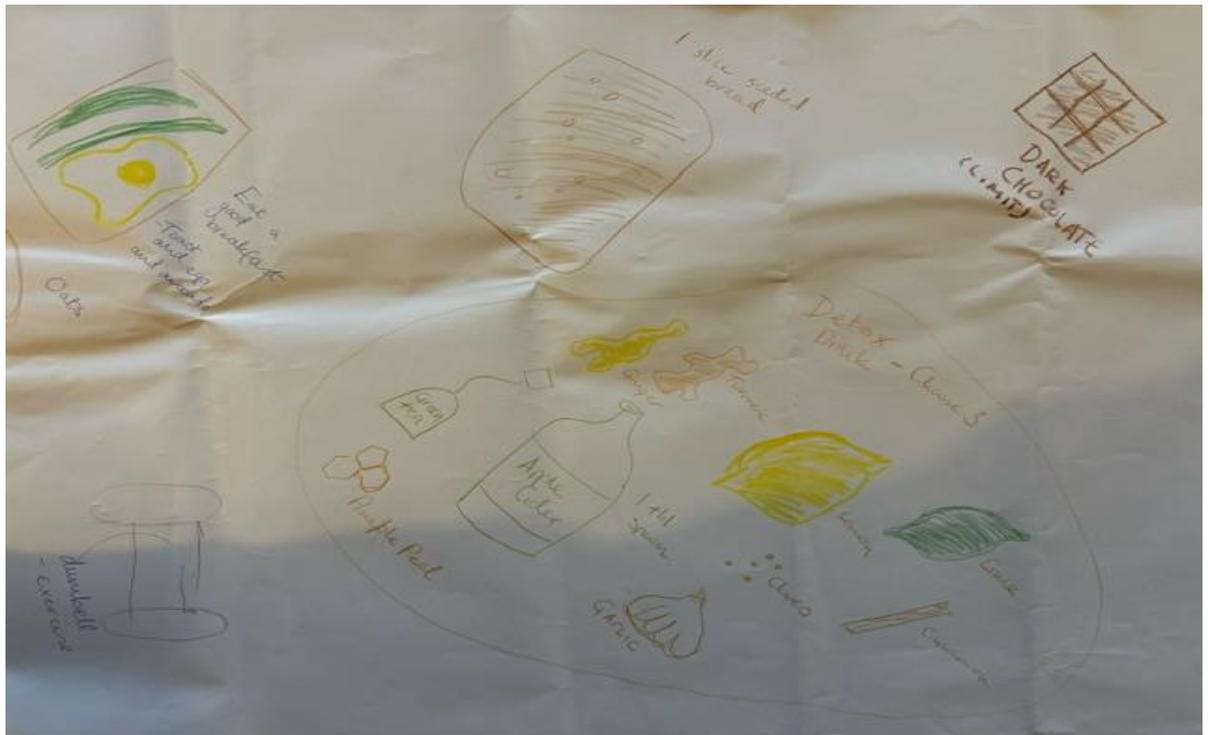
and diet. These included taste preferences and cultural identities related to food, particularly as a source of comfort, the availability of and access to certain foods and strategies to support a healthier diet.



**Figure 8-8:** Image from Scotland women's pilot TABPA workshop. Group 1's drawing of 'unhealthy' (above) and 'healthy' foods (below) and behaviours from Activity 3 and 4 respectively.



**Figure 8-9:** Image from Scotland women's pilot TABPA workshop. Close up of Group 1's Drawing of 'unhealthy' foods and behaviours from Activity 3.



**Figure 8-10: Image from Scotland women's pilot TABPA workshop. Close up of Group 1's Drawing of 'healthier' foods or behaviours from Activity 4.**

Group 1 discussed a range of foods, including biscuits, sweets, different fruits and cultural staples, such as rice and African bread (see Figure 8-8, Figure 8-9 and Figure 8-10). There was also some debate over the sugar content of fruit. For example, Participant 2 indicated that 'natural' sugar was better than processed sugar, although it should be consumed in moderation. This sparked a debate over the consumption of specific fruits.

Participant 2: [Dates] are natural, when you think it's, it's natural. It's very normal. It's not like sugar. When you take it, it's natural sugar when you take it, it's not almost to stay in your body, you understand?

[...]

Participant 2: 20 minutes digest, 10 minutes fruits...natural ones, all the fruit, don't take too much, like banana you can take one a day. One for one day...

[...]

Participant 4: No, no. They...[bananas] have limit on it. You can't take one a day, one tomorrow, you will be taking about seven in a week, in a week. [Group 1\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

Alloh, Hemingway et al. (2019) found that there was little knowledge about natural sugar among West Africans diagnosed with diabetes in the UK and highlighted that, in general, West African discourse on sugar focusses on processed forms. The extract above highlights that participants do hold some knowledge about natural sugars; however, it also demonstrates the need for more clarity when communicating healthy quantities. Furthermore, although many participants knew they should try to avoid overconsuming certain foods, it was difficult to cut staple foods like rice out of their diet completely.

“Going back to something that you do, OK, when it does, you have diabetes, but that some things have the limit, but we don't control our eating. It happens to everybody. We don't control it. You know, sometimes you say I will not eat this thing, then I will not eat this thing for this week. I will not eat rice for one week or once a week. Then some, you know, rice, nobody can do without rice. I try it. I say I will not eat rice every week. I always avoid rice all week, so I make it twice a week. But I did it with bread, I didn't take bread for one month, two months and it really worked. I can feel that in my body, but later I still go back.” [Participant 4\_Group 1\_Scotland \_Women's TABPA\_Pilot\_Activity 3]

As discussed in Section 5.5.2.1, African foods, taste preferences, large portion sizes, and social norms around eating are strongly tied to cultural identity (Alloh, Hemingway et al. 2019, Asamane, Greig et al. 2019, Henry Osokpo, James et al. 2021). This means that trying to completely cut out staples like rice is unlikely to be sustainable (Ochieng 2013, Henry Osokpo, James et al. 2021). Qualitative studies have highlighted that reducing or adapting cultural staples within diets is a common challenge among sub-Saharan African migrants living in high income countries (Kindarara, McEwen et al. 2017, Alloh, Hemingway et al. 2019, Alloh, Hemingway et al. 2019, Asamane, Greig et al. 2019). When asked, in Activity 4, why people go back to eating foods that they know they should reduce, one woman suggested that it was because they missed them.

Facilitator 2: So, when you were saying, for one month, it's easy to not drink...eh, to not eat too much bread. Why do we go back to that?

[...]

Participant 2: Because you miss something.

Several Participants: mhmm

Facilitator 2: You're homesick...yeah

P2: You miss something, you miss it. [Group 1\_Scotland \_ Women's TABPA\_Pilot\_Activity 4]

This is consistent with research with African migrants in the UK and the United States (Kindarara, McEwen et al. 2017, Asamane, Greig et al. 2019). For example, ethnically diverse older adults in Birmingham, including those from African-Caribbean communities, reported that traditional food practices could create a sense of comfort and closeness to home (Asamane, Greig et al. 2019). Additionally, the familiarity of large portion sizes in African cooking can also make it challenging for some African migrants to adjust their appetites to follow health guidance that advises a reduced portion (Alloh, Hemingway et al. 2019).

Furthermore, women in Scotland recognised that their eating habits were linked to the availability of and access to certain foods. In Activity 4, one woman in Group 1 emphasised that even though she would not buy certain foods, she would eat them at community meetings.

“There's some stuff I don't buy, and I go to a meeting, like you have it here, don't buy this, I don't need this, but I eat it, it happens. Most of the things, I don't buy, I don't have it in the house, but when I come for a meeting, they have it, I take, I eat some of it.” [Participant 4\_Group 1\_Scotland\_Women's TABPA\_Pilot\_Activity 4]

While the participant is knowledgeable about her own food consumption, the physical availability of snacks at community meetings makes it harder to resist. Eating out of the home has been associated with higher total-energy and fat intake (Lachat, Nago et al. 2012). The participant may also feel more compelled to eat at community gatherings due to the cultural importance of food. In many African cultures, food is shared as group and associated with strengthening relationships and cultural belonging (Jakub, Turk et al. 2018, Henry Osokpo, James et al. 2021). As noted in Chapter 5.3.2, many of the participants in Scotland regularly attended meetings as part of community groups, often several times a week. Nonetheless, eating because snacks are available was a problem reinforced within the workshop. We had provided a range of snacks, which included fruit, but also crisps and cereal bars that contained chocolate. Participant 4 highlighted this at the end of the workshop, emphasising that it was important to put our discussions into practice.

“I want to say something for today. Yes, it was OK, but I want to, I want to say we talk about diabetes, all these things. Maybe next time we try to avoid for to have biscuits on the table. ...You have to put it in practice. Don't just talk, talk, when you have to put in practice.”  
[Participant 4\_Group 1\_Scotland\_Women's TABPA\_Pilot\_A5]

Through the processes of discussing and drawing different foods, participants in Group 1 of the Scotland women's pilot TABPA workshop also came up with strategies to support healthier eating, like the example above. When explaining their drawing the women suggested that not buying sugary foods, eating lower sugar alternatives (e.g. dark vs milk chocolate) and consuming healthy snacks, like chia porridge, can help reduce the temptation of unhealthy choices. Importantly, the women emphasised that “*everything has a limit*”, a perspective which reflects current health messaging to make healthier food choices rather than cutting certain foods out of the diet completely. Finally, in Activity 4, Participant 4 discussed the use of African herbal remedies that she understood could be used to help control blood sugar.

Participant 4: And a leaf, we use a bitter leaf. There is a leaf, but I don't know...maybe you know bitter leaf. There is a leaf, when you touch it like this, it is so bitter, [...] you blend it, you try the water [and it] is very bitter. So, it control's the sugar, like in the sugar [...] you takes [eat] something and your sugar levels are high. So, when you start taking that [bitter leaf], by the time you go back to test, you're not taking something sweet like that, you take that [bitter leaf] and you went back for your test. You will notice, you will notice that the test, the test is normal. There's nothing like that. So, I do that sometime[s] and I go to African shop. I buy [bitter leaf] and blend it. I take the water out, I put it in a bottle, for something in the morning, when you take it, you feel it in your body that you [have] taken something. So, I'll take it in the morning. Drink it. I take it. So that's I've been doing that. Even here, back home. But so, that's something you can use, it doesn't mean... that we know there is diabetes, but there are some things we can do to help us to control to, to...I believe they say they kill, but there are some herbs they use to kill it. But I don't know. Yeah, maybe your doctor might not believe in that. In the culture, we are talking about creativities, all these herbs, all this nature, nature...

Participant 8: Back home, back home...mostly back home. [Group 1\_Scotland\_Women's TABPA\_Pilot\_Activity 4]

While Participant 4 said she takes bitter leaf in the UK, Participant 8 indicated that herbal ‘cures’ are more common back home. The suggestion that Western doctors “*might not believe in*” herbal remedies also highlight the disconnect and

tensions between biomedical and natural forms of healing. Complementary and alternative medicines, including herbal remedies like bitter leaf, are commonplace across sub-Saharan Africa and have been shown to be used for type-2 diabetes management both on the continent and among African migrants in high income countries (Abo, Fred-Jaiyesimi et al. 2008, Alloh, Hemingway et al. 2019, Henry Osokpo, James et al. 2021, Chetty, Govender et al. 2022). Research has suggested that African migrants use herbal remedies as they perceive them to be natural, harmless and curative (Alloh, Hemingway et al. 2019, Henry Osokpo, James et al. 2021).

As in Scotland, the participants in Activity 3 in the Malawi women's refined TABPA workshop used a combination of discussion and creative processes to explore the dietary drivers of diabetes. Group 1 chose to create a drama. They began by taking turns to highlight some of the causes, symptoms and ways to prevent the condition they knew about, before deciding what characters should be in the play. One participant suggested that the play will start, *“like we are at home. Let's say the patient went somewhere and is coming back home but is very weak and failing to walk”* [Participant\_Group1\_Malawi\_Women's TABPA\_Refined\_Activity 3]. This suggestion offered a starting point from which Trust (second facilitator in Malawi) could probe more into what had caused the woman's weakness. This prompted the participants to create a backstory for the character, and the following narrative was created.

*“She attended a wedding, and she couldn't resist, she just ate rice, meat, drank Fanta.”* [Participant\_Group 1\_Malawi\_Women's TABPA\_Refined\_Activity 3]

The idea that the character, *“couldn't resist”*, creates a sense of the temptation offered at a wedding, where 'special' food and drinks were available that might not be so easily accessible day to day. A qualitative study with adults with type 2 diabetes in Malawi, also found that patients found the food at weddings delicious and hard to resist (Mphwanthe, Carolan et al. 2021). As discussed in Chapter 4.3.5, weddings and celebrations form a significant part of social life in the community in Sector A and are therefore an important space to share and consume food. Rhoda also pointed out that sharing food is a sign of shared celebration and that *“when you refuse to eat at a celebration, it is like you are not celebrating with them, others may take offence”* [Rhoda\_ Comments on

Analysis], highlighting the importance of eating as a form of cultural belonging in Malawi. One woman later suggested that there has been a notable change in Malawian lifestyles which means that these events, and therefore dietary patterns, are becoming more common.

“It’s because of the way we live nowadays. There are frequent celebrations or parties.” [Participant\_Malawi\_Women’s TABPA\_Refined\_Activity 5]

The rise in celebrations may reflect lifestyle change associated with urbanisation, although more research would be needed to understand this fully.

Further insight into participants’ knowledge of diet as a cause of diabetes was provided during and after the performance of Group 1’s drama in the Malawi women’s refined TABPA workshop. During the drama, the patient was diagnosed with diabetes by a doctor who revealed more of the causes of the condition, as well as how to control it.

Doctor: Ooh. It’s possible that you inherited it. It could have also been caused by the food that you eat. Either way, I will just give you some advice for you to manage the disease. Food like rice, don’t eat white rice. Instead, eat brown rice.

Mother: Which one is brown rice?

Doctor: There is a type of rice that looks red. That rice does not have starch. You can eat that being a diabetic person. Also, eat foods that do not have starch. For example, potatoes (not specified sweet/Irish). I don’t know if that can work for you because it varies from person to person. Some other diabetic people find it problematic. Eat brown bread. Drink tea without sugar or use natural honey in tea. Also, don’t take fizzy drinks or soda like Fanta. Don’t go to weddings and drink Fanta because you have seen it, instead drink water. Or else, take 100% juice, which is not too sweet. Eat small amounts, frequently. Do you get hungry? [Group 1\_Drama\_Malawi\_Women’s TABPA\_Refined\_Activity 4]

This extract not only highlights mixed knowledge about foods that contain sugar and starch, but also prompted an interesting debate about the differentiation of foods that need to be reduced to *prevent* vs *control* diabetes. Following the performance, all workshop participants reflected on the play, particularly on the doctor’s advice. While several participants agreed that *mgaiwa* [whole-grain maize flour] and reducing white rice are the preferred choice for those with

diabetes, there was some confusion over whether this applied to those without the condition. In Activity 5, one woman argued that the substituting *nsima* for *mgaiwa* was not worth it for those without the condition.

Participant:[In Group 1's play] the doctor said she should eat mgaiwa (flour made without removing husks)

Facilitator 1: She told her to eat mgaiwa

Facilitator 2: Did she say that?

Participant: No

Participant: That was for a person who already had the condition. But we are talking about preventing diabetes if it is not hereditary. The mgaiwa issue doesn't apply here

Facilitator 1: Okay

Participant: We should eat white flour or gran-meal....mmh [did not sound very certain]

Facilitator 1: What exactly are we saying on the flour, which one should we eat?

Participant: It depends, sometimes diabetic people react to mgaiwa but they eat grand-meal

Participant: But that's for a person who already has the condition. We are talking about prevention

Participant: For a person who already has it, they should eat mgaiwa. But those of us who don't have the condition, why should we eat mgaiwa? No, we should eat white flour

[Participants laugh]

Facilitator 1: For prevention?

Participant: Most people cannot resist white flour just to prevent diabetes.

Facilitator 1: Ooh, they can't?

Participant: No, everyone has preferences. When you already have the disease, you don't have an option because you want to maintain your

health. When you don't have the disease, you feel that there's no need to punish yourself. You tell yourself that I will do that when they diagnose me with it but for now, let me eat white flour.  
[Malawi\_Women's TABPA\_Refined\_Activity 5]

This extract highlights that some participants hold a misconception of when starchy foods should be avoided. It also reveals that regardless of this understanding, taste can still act as a deterrent. By emphasising that there is '*no need to punish yourself*' if you do not have diabetes, the woman implies that the trade-off between taste and health is not sufficient to change her behaviour. The importance of taste preferences was supported again when participants were asked who would struggle to follow dietary guidance. One woman emphasised that young people would likely reject the advice because of their fondness for sweet foods like cake.

Facilitator 1: So, about all this advice we have given through the song and play, whether preventive measures or solutions, do you think there is anyone who can find it hard to follow them?...

Participant: I think the youths. They can just ignore and say they can't do that. For example, telling them that they should not eat food with a lot of sugar. We love cakes; so, to eat a cake that is not sweet we would think it is not a cake at all [Malawi\_Women's TABPA\_Refined\_Activity 5]

This example is consistent with the findings from a scoping review of dietary patterns among women of reproductive age in sub-Saharan Africa (Yiga, Seghers et al. 2020). The study found positive attitudes towards the overconsumption of foods high in sugar, which many perceived to have better taste. Furthermore, many young people perceived that dietary-related health risks are only present in old age, which may reinforce the participant's justification that young people would "*ignore*" the advice (Yiga, Seghers et al. 2020).

### 8.3.2 Social Prestige

In Malawi, 'eating well' and sedentary behaviour were viewed by many as a sign of social prestige. This was most common in the men's pilot TABPA workshop, where participants highlighted that those in the community often valued the consumption of fatty foods and weight gain as a sign of prosperity. This narrative first appeared during the development of Group 2's drama in Activity 3. The men

started their discussion by suggesting, “*one person should shout at another. Then this person should faint, and he will be taken to the hospital where he would be diagnosed with BP [high blood pressure]*” [Participant\_Group 2\_Malawi\_Men’s TABPA\_Pilot\_Activity 3]. However, after some prompting from Rhoda to consider the causes in more detail (see Chapter 7.3.2), one man emphasised the link between eating well, physical inactivity and wealth.

“But mostly it is about what people eat that cause BP. Most people think oily or high fat content foods are a symbol of eating well, not knowing we are destroying ourselves. These simple local foods without oil - sometimes we just cook with soda - are the type of foods that just give us energy and we don’t gain much weight. The thing is when someone is eating fats and gaining weight; we commend them that they are eating well. They feel good that it is well with them, not knowing that they are sitting on a ticking bomb. Another thing is that here in urban cities, we do not exercise. Here in town, we do not have time to do exercises and we do not... the body is usually dormant. In rural communities, many people rely on farming, and while on it, they exercise. Here you find that we use bicycle [taxis] for transportation even in short distances instead of just walking [and] taking it as an opportunity to exercise. We think when people see us [walking], they will say we are broke. So, we emulate such behaviours and suffer the consequences”. [Participant\_Group 2\_Malawi Men’s TABPA\_Pilot\_Activity 3]

Similar perceptions about weight gain as a sign of good health and affluence have been well-documented across sub-Saharan Africa, and are often linked to historic undernutrition (Manyara, Mwaniki et al. 2024). Research has also shown that urbanisation has contributed to a rise in physical inactivity in sub-Saharan Africa (Msyamboza, Ngwira et al. 2011), partly due to changes in types of work and the increased availability of motorised transport (Banda, Bunn et al. 2023). However, social perceptions around wealth in Malawi have also meant that residents in both urban and rural areas prefer to travel by alternative means than walking (Banda, Bunn et al. 2023).

Group 2 decided to incorporate the participant’s perspectives directly into their drama, focussing on a character who had moved from the village to the city and benefited socially from his weight gain.

“Maybe when the play is starting, the person with high blood pressure should be saying that he doesn’t eat simple foods, and that he doesn’t like them. He should be demanding that someone should buy him

meat, saying that he needs more fats in his body. Then he should be proud of himself, praising himself saying he is in the city where sometimes people shame others for their poverty, but it is well with him. There should be another person to whom he will be boasting. The person should agree with him that he is looking well and gaining weight... this way the play will start very well. Because it will show that this person wanted to eat well [fats and oils].”

[Participant\_Group 2\_Malawi\_Men’s TABPA\_Pilot\_Activity 3]

The extract highlights how identity, positive reinforcement from others and social stigma towards poverty can interact to reinforce the association between “*looking well and gaining weight*”. The character not only values his own personal development in the city, but this development appears to influence his tastes as he “*doesn’t like*” simple foods, alluding to the more traditional diets eaten in rural areas. A study in Malawi found that there was a higher prevalence of overweight/obesity, hypertension and diabetes in rural-to-urban migrants than in urban or rural residents (Chilunga, Musicha et al. 2019). There was also greater risk of cardiometabolic diseases among rural-to-urban migrants with higher socioeconomic status compared to those of a lower socioeconomic status (Chilunga, Musicha et al. 2019).

When creating their drama in Activity 3, Group 2 also highlighted that women’s perspectives on food and weight could also be related to social and gender norms.

Facilitator 1: What of foods? Do people know that there are foods that need reduced intake, but they don’t, what exactly is the problem?

Participant: Women. They want their friends to know that they put onion in food.

Participant: They want to be associated with eating well.

Participant: They also admire other women who are fat

Participant: “I also want to look like that”

Facilitator 1- So they want to look like others?

Participant: They fear that their marriage would end. They say men like fat women

Facilitator 1- So men want fat women and women want to save their marriages

Participant: Yes not thin women [Group 2\_Malawi\_Men's TABPA\_Pilot\_Activity 3]

The men suggest that women also associate weight gain and eating well with prestige. The indication that women “*want their friends to know that they put onion in food*” is also an interesting point that suggests that onions are a luxury. However, the discussion also appears to be framed by a gendered perspective that women wish to gain weight to appeal to men. Notably, in the Malawi women's refined TABPA workshop, although one woman briefly linked the consumption of sugary drinks to financial prestige, social and gender norms around weight gain were not discussed. However, Ndambo, Nyondo-Mipando et al. (2022) found similar perceptions among women in their qualitative work in Lilongwe. Women associated weight gain with health, beauty, and family (e.g. childbearing) and highlighted social expectations that weight gain was associated with a successful marriage (Ndambo, Nyondo-Mipando et al. 2022).

### 8.3.3 Physical Activity

Like participants in the Malawi men's pilot TABPA workshop, participants in the Scotland women's pilot TABPA workshop also discussed barriers to physical activity. During the preparation of their drama in Activity 3 in the Scotland women's pilot TABPA workshop, Group 2 introduced a character “*who, when they are advised him or her to go exercise, they don't want to*” [Participant 10\_Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]. When the same group considered why someone might not exercise, there was a debate over whether it was due to a lack of time or a lack of interest among members of the African community.

Facilitator 1: Why might somebody not want to do exercise or why would they eat everything?

Participant 5: You should ask us! [Gestures around the group]

[All laugh]

Facilitator: [laughs] well why do you not like to do [exercise]?

Participant 6: No. Some people, they, they want to do exercise, but if some people go to work if they go to work, if they go to work, they'll just come back, they'll just sit down and eat then after dinner, the next thing, sleep, the following morning there is no time to even I want to go and I want. Let me just maybe press up two or let me just jump up. Let me just do this. No, the only thing work, cook, eat and sleep. There is no time for 10-minutes for exercise, 15 minutes. That 15 minutes is calculate that 15 minutes, ah one hour.

[sparks a debate, everyone starts talking over one another]

Participant 5: But depending on your workplace you can have a little exercise...for someone who is used to exercise you can do it anywhere...it's not everybody that love exercise...

Participant: Uh uh that's it

Participant 3: It's not everybody...

Participant 10: I think the issue here, time it can be, but I think... I think, I think the issue here, it is not, many of us it is not our culture. We don't love it.

Participant 5: That's it. It's not you're not having the time, you're...

Participant 10: If you love it, you'll find even 5 minutes to do it, it's because it's not in ours, we don't like, we don't love doing it.

[everybody conversing at once- debating and agreeing]

[Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

Qualitative research in the north of England found several barriers to physical activity among African Caribbean adults, including ethnicity, socioeconomic status and a lack of motivation, particularly among women (Ochieng 2011). Barriers relating to ethnicity were linked to unappealing Eurocentric ideas of physical activity, where gyms were viewed as predominantly white, male spaces (Ochieng 2011). More recent research also indicated that structured forms of exercise, like visiting the gym, do not fit into social norms among African communities and reinforced the idea that walking and dance offer more culturally-appealing forms of exercise (Moore, Rivas et al. 2019). As highlighted by Rhoda, the lack of appeal for Eurocentric forms of exercise could be linked to the high prevalence of physical activity as part of everyday life in Africa (e.g. farming, as described by a participant in the Malawi men's pilot workshop in

Section 8.3.2). Indeed, Moore, Rivas et al. (2019) found that motivation for moderate-vigorous physical activity among African Caribbean women was limited by self-perceptions of living an active lifestyle. Following the debate above, one participant in Group 2 reasoned that the problem was not exercise per se, rather it was the type of exercise, and if you find something you enjoy, you will do it, even if others try to put you off.

“And if you...if you love it, likewise me now, I don't go out to jog, to do, or to go gym. Do you understand me? But always, at least I time myself, that OK, I will dance for 10 minutes. Do you understand? I will dance for 15 minutes. That 15 minutes, I can, I can increase it to 30 minutes. Do you understand? But one day somebody just come to my house to come and visit me. And that time is the time for my exercise. I say OK, don't worry. Just sit down with me. I'm going to... I want to do something. So, I just play... I'm playing music and dancing in my just my.. ah... What if you, if you are in shame, some people will say something that will just... It will just make you realise, ah what am I doing? So. But if you don't care, any anywhere, if I just feel like now, if I just feel like I go out and I'm free, I'm in your house. I just come to your house to come and visit you. You will just see me that I just stand up, I'll just dance, you say what's happening? I will not listen to you. Do you understand? So, there is some, some people like that...” [Participant 3\_Group 1\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

As discussed in Chapters 4.4 and 5.4, music and dance are embedded within many African cultural identities. As Participant 3 highlights, dance can be an easy, accessible and enjoyable form of exercise that can be done anywhere. Integrating dance into future health promotion initiatives could help to move away from Eurocentric ideas of physical activity (Ochieng 2013, Moore, Rivas et al. 2019). However, as other participants remained unconvinced that they would find a sustainable form of exercise (that they enjoyed), it remains important to consider how individual motivations may interact with cultural beliefs.

### **8.3.4 Financial and Family Stress**

As described previously, participants in the Malawi men's pilot TABPA workshop used the visualisation activity (Activity 2) to highlight financial stress as a cause of hypertension. In Activity 4, Group 1 incorporated this understanding into their play. This is illustrated through the following extract, where the character faints following exposure to multiple stressors, including the arrival of 'loaner' (informal lender) to collect borrowed money.

[Another man enters the arena. He comes to fetch his money. The owner of the house attempts to give him a handshake, but he declines]

Man: You should have told him that I am not here

Wife: I already told him to come in

Loaner: Now I have found you. I want my money today. Last time you ran away from me, and you cut the line when I call you. I have followed you home today. I need my money today. 60,000 kwacha.

Man: I told you that I was waiting for my bonus. They told us at work that we would receive bonuses yesterday, but we never did

Loaner: No no no. It's been a while since you promised to give me back my money. I need my money today. If not.....

Wife: Your relatives came, they were saying someone wants to sell your land and your livestock

Man: So, what did you tell them?

Loaner: As for me, I need my money now

Man: [Directed to wife] What did you say are the school needs for the child?

Wife: She needs money

[The man holds his head and faints. The people present at the scene carry him and leave for the hospital. They arrive at the hospital and are in the doctor's office.]

[Group 1\_Drama\_Malawi\_Men's TABPA\_Pilot\_Activity 4]

The above extract emphasises how financial stress and familial responsibility can interact to cause or exacerbate hypertension, resulting in the character's collapse. The interaction also suggests that the man has been avoiding his problems. In the same TABPA workshop, Group 2 also explored the idea of financial stress as a driver of hypertension. When developing their drama, one man said because "*people don't want to share their [financial] worries*" their high blood pressure "*shoots*" or in worse cases they commit suicide [Participant\_Group 2\_Malawi\_Men's TABPA\_Pilot\_Activity 3]. Studies have indicated that Malawi has a high burden of mental health disorders, which is

made worse by a high prevalence of multimorbidity and insufficient mental healthcare infrastructure (Kim, Mazenga et al. 2014, Lilford 2020, Nkoka, Munthali-Mkandawire et al. 2024). Qualitative research with young people in Malawi has also indicated that mental health literacy is low and that struggles generally go unspoken (Jumbe, Nyali et al. 2022).

Group 1's drama in the Malawi men's pilot TABPA workshop also highlighted how financial stress can interact with traditional gender roles. When Group 1 were preparing their drama, they specifically chose for one of the characters to portray the main character's wife.

Participant: So, the doctor will be saying this to the wife, as a guardian

Participant: Yes, this one is the guardian

Participant: Then on stress, [the doctor] will say that loans also cause stress. Tell him not to take too many loans. [Group 1\_Malawi\_Men's TABPA\_Pilot\_Activity 3]

Acting as the character's guardian, it appeared that the wife became primarily responsible for the man's health and the lifestyle change recommended by the doctor. This narrative was brought out further when the entire workshop reflected on Group 1's performance together in Activity 5.

“[In Group 1's drama, the character] fell down because his wife came to demand school fees for children and the loaner came as well, demanding for his money. He was stressed because of this, and he fainted. So, on this issue, if it's the man that is suffering, the woman should buy the right food for him to prevent such occurrences and vice versa. The man may be stubborn and may want to continue with non-recommended eating habits.” [Participant\_Malawi\_Men's TABPA\_Pilot\_Activity 5]

This extract suggests that the man's wife directly contributed to the character's stress by “*demanding*” financial support for their family. The participant also reinforces the idea of the wife as the man's “*guardian*” who should support their husband's health, although he does acknowledge that this responsibility goes both ways. Another participant in the same activity reinforced the idea that some men feel pressure to provide financially for their wives and families.

“I also want to add that three-quarters of high blood pressure cases are in men, 75%. Women are the least affected. It’s possible I have underestimated... could be 90% of cases are men. This is because the wives give their husbands a lot of financial pressure. Sometimes men are already stressed with the need to provide; you find that women come with more demands, so the BP rises faster. Men and women should cooperate, although it’s difficult sometimes. Men also cause stress in their wives, maybe because of promiscuity, excessive drinking [alcohol] without considering the needs at home [to provide food]. You find that sometimes women leave the whole financial responsibility on the man.” [Participant\_Malawi\_Men’s TABPA\_Pilot\_Activity 5]

Although the participant believes there is a higher prevalence of hypertension among men in Malawi compared to women, in reality, the difference is much smaller. A population-based study in Malawi indicated that the prevalence of hypertension was 16% among urban men and 14% among urban women (Price, Crampin et al. 2018). Although the participant does acknowledge that marital stress can be experienced by both men and women, his perspective reinforces gendered ideas about responsibility. This finding is consistent with research in sub-Saharan Africa where ideas of masculinity are linked to a sense of male responsibility to keep their families happy and healthy (Chikovore, Hart et al. 2014, Watson, Chatio et al. 2023). However, this expectation is often in conflict with economic reality, and can compound the issue and cause further distress (Chikovore, Hart et al. 2014).

Finally, through these reflexive processes, the participants in the Malawi men’s pilot TABPA workshop explored how they might prevent stress. One man highlighted that it was important to “*avoid loans*” and “*sharpen [their financial] planning skills*” [Participant\_Malawi\_Men’s TABPA\_Pilot\_Activity 5]. This suggestion mirrors recommendations from the Financial Literacy Baseline Survey (Chirwa and Mvula 2014), which indicated that comprehensive financial education programmes are needed to address widespread financial illiteracy in Malawi. One man emphasised that reducing financial stress and tackling hypertension required everyone’s involvement.

“Just thoughts. We have said it is everyone’s responsibility to support in coming up with solutions to HBP starting with family, community and even the government. I was thinking the government should economically empower people so that they are financially independent. Adults and youths should be economically independent

to avoid stress. Also, the way we approach each other, we should be calm so that we understand their problem [hear their side]. We should not rush to judge others. So, it's everyone's responsibility. The community, the government, and even as individuals, we have a role to play." [Participant\_Malawi\_Men's TABPA\_Pilot\_Activity 5]

Community members in Scotland discussed similar family and financial pressures as drivers of stress and hypertension. As in Malawi, it appeared that gender roles also played a role in men's perceptions of stress. Two participants in the Scotland men's refined TABPA workshop chose to create stories which revealed these nuances in Activity 4. One man told a story about a man named Sam who experienced financial challenges when trying to support his business and family.

"Yes, so my story is about a man called Sam and he has a family of five kids and a wife. He has a business which he sells food stuff, and a patty shop and stuff. But he doesn't have a lot of money like. He's a little bit poor, he's average, like middle class. He's from a middle-class family. He couldn't afford to pay for the shop and stuff he had, so he had to relocate to another place, to another country away from where he lives, and his kids are still in school. Like they went to public school, which he could only afford because it's free. And so, then when he went. Before he went, he had some health issues which he couldn't afford to pay, like to take care of himself...while at home his wife and his kids, they take care of the shop and stuff, and whenever he's alone, abroad, he thinks about like paying for, the money and for the rent and stuff...

But unfortunately there was a day, his wife was in the shop, his kids were still in school and stuff, the owner came like, they [paid him rent], then like three or four months later, the owner came again, [Sam's family] asked [Sam] for the money, [but he didn't have it] so the owner of the shop took the keys away from [Sam's] wife, and sent them away from the shop, and the wife called Sam and Sam was in a big shock, like, oh, no, like why is it [happening to] me and like that. Why, the ending, he fell into a coma... Sam fell into the coma by hearing the news and being rushed to the hospital, and while at the hospital he got diagnosed with high blood pressure because of thinking of pain of mourning for the shop, while - and his wife and kids were also worried about what was going on. And he was being sent over back home, he had to get back home and stuff. So that's the story." [Participant 2\_Story\_Scotland\_Men's TABPA\_Refined\_Activity 4]

As in Malawi, this story suggests that male responsibility as the breadwinner can lead to financial challenges, however, Sam's story also brings in migration as an additional stressor. Far from his family, Sam appeared to face additional barriers where he was "*alone*" with a lack of support, and arguably a lack of control,

over the situation when the owner of the shop arrived to collect rent. Participants in the Scotland women's pilot TABPA workshop discussed a similar sense of helplessness when trying to help family "*back home*", as noted by the following discussion during Group 2's creation of their drama in Activity 3:

Participant 1: And family problems can make you stress.

Participant 8: That is it... that is it.

Participant 1: We are back home here. You know, you're always worried back home, how they are and how our relatives are. And sometimes they, in the phone, they will, they will tell that they have some problems. So that makes you more worried how they are going to solve it and how we are going to help them like... [Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

In Activity 4 of the Scotland men's refined TABPA workshop, one man used storytelling to show how emotional stress could contribute to hypertension in several ways. Participant 1 told the story of Mr Jack who, after giving his wife his new phone in exchange for her old one, discovered his wife had been unfaithful and fell ill.

"Trying to set up [his wife's] phone, Jack discovered on the phone that the wife has been having emotional discussion with the family doctor recommended by the wife, okay? This lead to this shock. So, sorry- This lead to shock and once happily married man, Mr Jack, becomes moody and keep thinking, skipping meals, become aggressive and suddenly fell sick. Why? Because of the news. Because of the information. This information, and not yet confirmed, but he discover that on the phone when he was trying to set up the phone he loved, he exchanged it for another phone and that brought the sad news.

What happened? Okay, the wife broke the news to him that the doctor was her ex-boyfriend. This lead to increase in Mr Jack's BP [blood pressure], and the BP was from 125/80 to 200/110. That is very, very high. The BP refused to come down. Why? Because of the emotional situation and ongoing imagination." [Participant 1\_Story\_Scotland\_Men's TABPA\_Refined\_Activity 4]

These narratives suggest that while the men might be aware that there are underlying and longer-term causes of stress and hypertension, there is still an association in both countries between a defining emotional event and the manifestation of the disease. This may be due to the fact that hypertension is a 'silent killer' commonly presenting without symptoms. When continuing the

story of Mr Jack, the same participant in Scotland demonstrated how the impact of stress was exacerbated by the consumption of his favourite salty foods.

“Even after apology from the wife. The wife apologised but the rift, the BP refused to come down from 200, he usually goes above 200/110. And the wife keep feeding him with high salty food as a way to apologise, a special delicacy but very salty food. Why? Because the wife felt she’s responsible for the health situation of Mr Jack. So, the wife feel that the best way is to cook a special meal loved by Mr Jack, which is salty food. That is ignorance.” [Participant 1\_Story\_Scotland\_Men’s TABPA\_Refined\_Activity 4]

The participant emphasises that the food prepared by his wife was a “*special delicacy*”, again demonstrating how taste preferences and cultural foods can provide comfort. However, the story of Mr Jack, also shows the additional, and complex, interaction between comfort eating, stress and hypertension (Dalmazo, Fetter et al. 2019, Hill, Conner et al. 2022). As described by the participant in the final reflections, presenting the information as a story revealed more about how “*positive*” and “*negative*” activities interact.

“I think it’s more informative when it comes with a story and, you know, life situation that explains, you know, life situation and story reinforce the information more, you know, like if we are this story now, we know that okay the man has- If someone goes beyond the limit, you know, having the number of children you cannot cater for, or not doing due diligence in your business or business appraisal, it can end up and come back and hurt you in your health and it can, each story is sort of a positive relationship or positive correlation between your health, specifically your blood pressure and your activities. The more negative activities you have, the more, you know, higher the reading of your blood pressure. So, while your problem is going up, your blood pressure will go along with it. So that’s what it miss. So, with the story, we can say that it has a positive correlation from his own story and my own story, they seem to be similar way, you know? Mine goes in the area of marriage, family affairs, and his also goes in family affairs, which means families are an important factor when it comes to blood pressure. If you are able to have a stable family, then definitely you are going to have a stable blood pressure. If you are going to have a volatile family then your blood pressure will also be volatile, from what we have seen, so far, because it’s a story but there are some elements of truth in the story. And without knowing what each other is writing, we came up with the same thing.” [Participant 1\_Scotland\_Men’s TABPA\_Refined\_Activity 5]

The participant reflects on how family was a common theme between the stories in the Scotland men's refined TABPA workshop and therefore an important influence on health. He emphasises how the stability of family can be both a disruptive and protective factor in managing blood pressure and reasons that the 'volatility' of the relationships in both stories have "*elements of truth*". The similarities in the stories likely reflect the realities of some families and family-related stress as a driver of hypertension. However, the suggestion that "*if you are going to have stable family, then definitely you are going to have a stable blood pressure*" could oversimplify the relationship and minimise the impact of other drivers including diet and exercise.

### **8.3.5 Migration, Discrimination and a Hostile System**

While the previous section highlighted issues related to migration and stress, participants in the Scotland women's pilot TABPA workshop described the links more directly. When reflecting on the drivers of stress in Activity 3, Group 2 highlighted the impact of UK Home Office immigration policies and processes.

Facilitator 1: What do you think might contribute to stress or overworking?

Participant 12: Home Office [quietly]

Facilitator: Sorry?

A few participants: Home Office! [all laugh loudly and make noises of agreement]

Participant: Yes

Facilitator 1: That's a really good point.

Participant 10: That's a good point!

Participant 1: Yes, that is killing one.

Participant 12: Even when I was Nigeria, I don't have that kind of stress... the one I have here

Participant 3: Home Office...

Participant 10: And MEARs [Government contracted organisation for housing and support for asylum seekers]! That is killing us. [Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

As highlighted by Participant 12, the stress she has experienced post-migration rivals that from the country she sought refuge from. The emphasis that the system is “*killing*” people demonstrates lived experiences of the UK government’s ‘hostile environment’ policies designed to deter illegal migration (Qureshi, Morris et al. 2020). There is little evidence that this strategy has been successful and instead the policies have been found to have perpetuated inequalities and fostered racism (Qureshi, Morris et al. 2020). Several women emphasised that their stress worsened, and their health had declined when they arrived in the UK. In Activity 3, another woman in the same group generously shared her own experience, where she had faced both a lack of support and an interrogative immigration process.

Participant 3: By the time they come here, they face Home Office. Different sickness. Likewise, me. I have more than three [health conditions] and I didn't have it before because if I just see ringing, my phone is ringing. When I came here, if my phone is just ringing...my my I would just be breathing [makes a heavy panting sound] at the end of the day, hypertension.

Participant 10: [Knowing laugh]

Participant 3: And I didn't have it before. I can fear in my country ah I will see that thing like this [...] when I came here, in hotel, when I just came here, in hotel, you know, I don't know anything about this thing, I don't know anybody to encourage me. I don't... do you understand me? In hotel, on one day like this, you know, I'll just put my phone like this [puts phone on table]. If the phone just ringing private number, I'll just be breathing like this [heavy panting]. Different question, different question on Fridays like this, I will be happy that Saturday, Sunday, no call. I will rest. On Monday, Oh, my God. I just... my, my son will mum say calm down. If, if I receive callers I will be crying. When I come to this country, I cry for a month.

Participant 10: Are you serious? [sympathetically]

Participant 3: I cry for a month and now say God, if I want to die, then let me just go, I cry [participant's emphasis]. My daughter is crying. If I just say, just take my case. [Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

The woman's personal and emotive narrative of her experience of the immigration system emphasises the isolation and trauma that can occur without necessary support. She also alludes to 'fear' in her home country, highlighting the multiple and complex stressors associated with both pre and post migration (Agyemang, van der Linden et al. 2021). In the same activity, another woman went on to emphasise that even equipped with the knowledge and behavioural discipline to prevent diseases like diabetes, the stress and structural barriers associated with a hostile and discriminative system means that attempts can often be futile.

Participant 8: I was thinking, as much as we're trying to prevent diabetes and what brings this? You may watch your diet. You may be very disciplined. But according, I shall say the Home Office and its effects on us. There are so many people who already strained of [facing challenges with] eating in Africa, but because of so many requirements and needs, they get diabetes. To us also here it has happened that you may not have it genetically, may not have it to spread everything, but because of the pressure, stress, suffocation, home office, that person you find they are developing diseases. It is expected to get diabetes, and the worst of it that you cannot even [muffled] because the system is tightening day by day, that increase, they don't mind any body, how it may affect them at all. And a lot of discrimination...

Participant 10: Even it's, it's very difficult for us to afford health food. The amount of money we're getting, how can we afford to buy health food? You're getting only £45 a week. How can you afford to buy health food, £45? For that amount of money? [Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

These perspectives are consistent with evidence of how the UK immigration system negatively impacts the mental and physical health of asylum seekers through direct and indirect structural means (Isaacs, Burns et al. 2022). The all-encompassing stress of the process can inhibit individual agency to engage in health behaviours, and this is compounded by systems that reinforce poverty, racism and 'otherness' (Isaacs, Burns et al. 2022). In the above extract, Participant 10 also highlights how their ability to afford healthy food was constrained by the inadequacy of the financial support provided by the UK government. In the UK, the majority of asylum-seekers do not have the right to work, and are therefore entitled to Section 95 welfare support, a government allowance to cover essential living costs (food, clothing, and toiletries). This allowance has been widely criticised as being insufficient and third-sector

organisations have had to step in to meet essential needs amidst growing dietary inequalities (Mayblin and James 2019). These experiences are exacerbated further by rising food costs following COVID-19 and the Cost-of-Living crisis (Hoenink, Garrott et al. 2024).

The women's experiences of the asylum system were primarily brought out by discussions when creating their drama in Activity 3. Group 2 decided that they wanted to include some of these perspectives in the play itself in Activity 4. This can be seen in the extract below:

[Character 3 sits down, and Character 4 enters]

Character 2: Oh Oh, how are you sis?

Character 4: I am stressed

Character 2: Oh my god, have a seat

Character 2: What happened? What happened?

Character 4: Very stressed. I've come from hospital, they checked my blood pressure, I can't ...I'm so stressed. My sugar level is too high, as much as I've tried to maintain myself and keep everything, prevent diabetes. I find myself, the stress of Home Office, has killed me.

[All: Ohhh]

Character 2: Oh noo

Character 1: You know I told you, I told you, don't allow Home Office...I told you...you have to

Character 2: You have to be strong, you are not alone!

Character 4: I first ignored it, when my friend was talking about her daughter who is very disabled, can I even sit?

Character 2: you can sit

Character 4: Great, I mean I don't want to sit? When my friend was talking about the issue of Home Office not giving her daughter who is disabled, support, she has to take to hospital, to school, everywhere with her daughter, I thought maybe... Another friend of mine tells me, she has stayed here for two years, Home Office is calling, phoning her, not giving her any good news apart from stress. Now she has

developed diabetes and blood pressure. I thought maybe it is far from me, but look at me, very stressed with Home Office, even now, I'm now trying to get medication that can't even work on me because I'm resistant, resistant because of Home Office stress. When I came to this country, I thought maybe I would be better, but the Home Office is not acting anywhere on our problems, their delay and their denial of their justice, it has made me get diabetes and [unclear] and now, even when I'm here, I cannot communicate with my family. My children when I left them, my cousin was keeping them, now he is dead, they are stranded. The wife is working in the village where they buried her husband. The Home Office, when I came here, they gave me a card with a photograph with a man and my name. Since then, they have never given me back my card, so I don't have anything, so I cannot even go to hospital because I can't afford transport...

Character 2: [stands up and goes to put arms around C4 as C4 sits down] It is okay, you will be fine. [Group 2\_Drama\_Scotland\_Women's TABPA\_Pilot\_Activity 4]

The extract creates an emotional and personal testimony about the multiple intersecting impacts of the asylum system on the character's physical and mental health. As an observer, the play also presented as a powerful moment of resistance and community support against the hostile system. While the TABPA workshops used theatre in a very informal way, its use appears similar to other scholars' experiences of the art form. As highlighted by Erel, Reynolds et al. (2017) participatory theatre "*allows participants to voice and embody their own versions of their experiences which are not prompted by researchers' questions, but rather by a collective process of reacting to other participants' stories and experiences*" (p.310). The authors further argue that participatory theatre can be used for social transformation, particularly for those who are systemically marginalised, where they can make "*visible experiences of oppression, thereby becoming more conscious of the power relations at work*" (p.310). It could be argued that the processes in the TABPA workshops also supported this in some way, creating space where participants could explore their experiences together and show their power within systems of oppression.

### **8.3.6 Individual Mindset and 'Ignoring' Advice**

Interestingly, theatre was used in both Scotland and Malawi to show that it was common for people to "*ignore*" the health advice of their family and friends. When Group 2 were creating their drama in Activity 3 of the Scotland women's pilot TABPA workshop, they suggested that one of the characters should be

someone who did not care about what they ate and would not listen to health advice.

Participant 5: Someone who eats whatever they come across, they don't care about...

Participant 10: And when they are advised him or her to go exercise they don't want...

Participant 5: Yeah...they just eat anything [echoed by other participants]

Participant 1: They don't listen, especially the, you know, the older group, they don't listen [laughs]

Participant 3: And they don't even bother to leave for check-up at all. They don't even bother to...just eat, drink. [Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 3]

As in Chapter 6.2.2, through the creation of their drama, women in Scotland revealed an individualised perception of health issues and lifestyle choices, where it could be argued that blame is projected onto the imaginary character for their behaviour. When considering what might help the character to change their lifestyle in Activity 4, Group 2 decided to introduce another character to tell them that a mutual friend had recently been diagnosed with diabetes.

Participant 5: Another friend comes in to say, to talk about, someone has a mutual friend they know saying the person has just been diagnosed of diabetes. And this is me. I'm scared. I'm like really? But she looks so healthy. That means I have to see a doctor and probably check, you know.

Facilitator 1: So, knowing somebody would help you change your behaviour, yeah?

Participant 10: Yeah, yeah! Who has who has the same behaviour like yours. [Group 2\_Scotland\_Women's TABPA\_Pilot\_Activity 4]

The women highlight how knowing someone with diabetes who had a similar lifestyle could encourage others to change their behaviour. This suggests that providing health messaging with patient testimonials from people with similar backgrounds and behaviours could be a promising way to support community

members in Scotland to engage in preventative behaviours, although this would need to be supported with further research.

In Malawi, the community members in both TABPA workshops also highlighted how individual motivation may shape engagement with health behaviours. During the reflections in Activity 5, one man in the Malawi men's pilot TABPA workshop, said that the drama performances had shown "*main issue [with high blood pressure] is about ignoring or invalidating the advice that other people give us, that we should reduce fat intake and also do exercises*"

[Participant\_Malawi\_Men's TABPA\_Pilot\_Activity 5]. In the women's refined TABPA workshops, community members suggested that many would not change their behaviours until they actually had a health condition.

"It's difficult because change is a choice. People do things according to how they feel or how they want things to be. You cannot tell someone to change when they have not yet made that decision to change. Most people wait for a problem to come, that is when they change. So, if you have reached out to them with information and they are not changing, you just let them be until they encounter a problem." [Participant\_Malawi\_Women's TABPA\_Refined\_Activity 5]

When considering what might help people who do not respond to lifestyle-related health guidance, community members in the Malawi men's pilot TABPA workshop also suggested that learning from other's experiences might reinforce the message. This was highlighted by one man below.

"On the same note, to help those who ignore advices, I think we can involve people who were in the same position to be an example. These are people who also ignored advices at first and had to suffer the consequences." [Participant\_Malawi\_Men's TABPA\_Pilot\_Activity 5].

## 8.4 Conclusions

Overall, the TABPA workshops appear to be useful as a means of generating culturally-situated understandings of the communities' lived experiences, beliefs, and attitudes towards risk factors for hypertension and diabetes. The visualisation activity created space for community members to present a range of knowledge and conceptualisations of diabetes and hypertension more broadly through alternative visual, emotive and metaphor formats. This was particularly

interesting as it highlighted women's conceptualisations of diabetes as a disease associated with lifestyle in Scotland compared to one that causes a great physical impact, as described in Malawi. The creative processes involved in developing artistic outputs also allowed participants to build knowledge through a process of suggestions, debate, artistic refinement and reflection. It could be argued that, through these processes, the approach drew out nuanced and detailed community perspectives on a range of risk factors, including culturally-situated understandings of diet, physical activity and stress in both Scotland and Malawi. This included similar knowledge and perspectives on 'healthy' and 'unhealthy' eating, taste preferences, culturally important foods and challenges with the availability of certain foods at community events in both contexts. However, it also brought out more contextual knowledge, including the relationship between 'eating well', weight gain and social prestige in Malawi, and the influence of migration and immigration systems as a cause of multiple stressors in Scotland.

Overall, despite the challenges and the need for flexibility and refinement required within each TABPA workshop (Chapter 7), the creative activities and scaffolding structure appeared to support the generation of in-depth knowledge on the risk factors of diabetes and hypertension that could be used to inform culturally-situated health promotion interventions.

## 9 The Transcultural Arts-Based Participatory Approach: A Methodological Reflection

### 9.1 Introduction

This research explored the development of a transcultural arts-based participatory approach (TABPA) to explore the drivers of diabetes and hypertension among African communities in Scotland and Malawi. The previous chapters examined the findings from the Phase 1 familiarisation processes (Chapters 4-6) and the pilot and refinement of the TABPA workshops in Phases 2 and 3 (Chapters 7 and 8). The study sought to address the five research questions below:

- RQ1. How do the perspectives and experiences of community members and stakeholders inform the methodological development of the TABPA?
- RQ2. To what extent can the TABPA minimise researcher-participant hierarchies and encourage inclusivity among participants in practice?
- RQ3. What factors influence the feasibility and acceptability of the TABPA for use with African communities in Scotland and Malawi?
- RQ4. Can the TABPA be used to generate culturally-situated understandings of the target communities lived experiences, beliefs, and attitudes towards hypertension and diabetes risk factors?
- RQ5. What skills, knowledge and resources are necessary to support wider implementation of the TABPA?

In this chapter I will summarise the findings in relation to each of these research questions in turn before reflecting on the sixth and final research question: How does TABPA development compare between African communities in Scotland and Malawi and what does this mean for a transcultural approach in practice? In doing so, this chapter aims to bring the comparative threads of the thesis together to reflect on the transcultural methodological processes and discuss to

what extent they reflect the transcultural community-based participatory research model presented in Chapter 2.4.5 (Figure 2-2)

## **9.2 A Summary of Research Questions 1-5**

### **9.2.1 How do the perspectives and experiences of community members and stakeholders inform the development and implementation of the TABPA methodology (RQ1)?**

The perspectives and experiences of community members and stakeholders informed the methodological development of the TABPA in several ways.

1. Firstly, perspectives on community, arts and health generated by walkalong interviews, community and stakeholder workshops in Malawi and Scotland provided an in-depth understanding of the different contexts that would shape the research. These will be described in more detail in Section 9.3.1. However, they were particularly important as outsider research, to familiarise me with the context. The knowledge gained through this process, supported me in facilitating the Phase 2 and 3 TABPA workshops, with greater cultural sensitivity (e.g. navigating sensitive topics like the immigration system in Scotland (Chapter 8.3.5). However, as discussed in Chapter 5.7.2, this stage may only be necessary to facilitators, like me, who are not already situated within the communities they are working.
2. The walkalong interviews, and Phase 1 community and stakeholder arts-based workshops revealed that participating in arts was often viewed positively in Scotland and Malawi and linked to cultural meaning, particularly music and dance. In the Phase 1 workshops, community members and stakeholders highlighted a range of art forms that could be compatible with community interests, including music, dance, drawing, theatre and poetry; however, choice, flexibility and language were important factors. Therefore, the TABPA protocol was modelled on the flexibility of Phase 1 community workshops where community members could use any art form they liked to create a creative response about the risk factors for diabetes or hypertension.

3. Phase 1 walkalong interviews and stakeholder workshops revealed that there are several barriers that may limit community participation in art, including financial barriers to accessing arts activities (e.g. time and travel costs) in both contexts and to accessing arts resources (e.g. pens for drawing) in Malawi. Thus, in Phases 2 (Scotland) and 3 (Malawi), all TABPA workshops were organised at local and easily accessible venues, travel and financial compensation were provided and the workshop date/time was, as far as possible, negotiated around participants' commitments, particularly in Scotland. Childcare was also arranged for the Scotland women's pilot TABPA workshop.
4. Phase 1 stakeholder perspectives also highlighted the importance of facilitators in creating a safe, supportive environment to reduce harm from potentially stigmatising topics. The TABPA was designed to centre participant voices and not ask for any personal experiences of diabetes or hypertension directly. In the Phases 2 and 3 TABPA workshops, each group would have one facilitator who could be present to provide reassurance and support participant discussions.
5. Finally, due to challenges with time-management in the Phase 1 community workshops, more time was allocated for latecomers and the consent process in the TABPA protocol. I also arranged for an additional facilitator to be present at all TABPA workshops in Phases 2 and 3 to support practical needs (e.g. consent processes).

### **9.2.2 To what extent can the TABPA minimise researcher-participant hierarchies and encourage inclusivity among participants in practice (RQ2)?**

While the TABPA workshops showed several strengths as a means to minimise researcher-participant hierarchies and encourage inclusivity, there were still challenges with persisting power dynamics. Community members in both contexts shared personal, emotive, and detailed narratives about the causes of diabetes and hypertension and reflected positively on the TABPA process as a space for co-learning where they felt '*comfortable*' and '*free*' to express their views. Thus, it appears that the TABPA workshops did successfully redistribute

power by promoting a safe, supportive environment and participant autonomy through flexible research processes, choice and facilitator support. However, there were issues around navigating power and participant expectations that the workshops should be used for health education in addition to health enquiry, by correcting participants' misunderstandings of the diseases and/or by educating the community directly.

There were also interdisciplinary challenges in navigating the expectations of researchers and arts-based workshop facilitators. Researchers and facilitators may have different expectations about the final artistic output and how the process is communicated to participants. TABPA workshops are designed to focus on the process of creating the art form, and facilitators should avoid imposing any expectations of quality onto participant creative outputs, which could reinforce hierarchies. Thus, while the TABPA shows promise, challenging both researcher-participants and researcher-researcher power relations is an ongoing process.

### **9.2.3 What factors influence the feasibility and acceptability of the TABPA for use with African communities in Scotland and Malawi (RQ3)?**

Overall, the TABPA workshops appeared feasible and acceptable for use with African communities in both Scotland and Malawi. There are the three key findings that reflect the feasibility (F) of the TABPA:

F1: As discussed in Chapter 7.3.1, the open, flexible nature of TABPA workshops could encourage the spread of partial or misinformation about health issues. Thus, to be feasible, and prevent harm, the TABPA needs to integrate a process that clarifies health knowledge.

F2: The feasibility of TABPA workshops is influenced by how the creative process is negotiated by community members and facilitators. It is important to provide participants with as much choice as much as possible; however, facilitators are required to support participants to focus on the activity prompt (e.g. the risk factors of the NCD).

F3: The feasibility will also be shaped by diverging expectations of artistic legitimacy between researchers and facilitators, particularly over the quality of the artistic outputs (Chapter 7.3.2).

The acceptability (A) of the TABPA also appeared to be influenced by three main and related factors.

A1: Participants in both Scotland and Malawi appeared to value that the TABPA workshops offered a safe and supportive environment.

A2: Related to F1, community members in Scotland and Malawi had expectations that the TABPA workshops were a form of health education and/or wanted their perspectives clarified.

A3: Related to F3, the acceptability of TABPA workshops is supported by providing community members with choice over the art form they use; however, this is also shaped the wider context. This is explored further in Section 9.3.1.1.

#### **9.2.4 Can the TABPA be used to generate culturally-situated understandings of the target communities lived experiences, beliefs, and attitudes towards hypertension and diabetes risk factors (RQ4)?**

Through creative processes of visualisation, discussion, artistic development and reflection, community members in Malawi and Scotland shared in-depth understanding of the drivers of both diseases and the facilitators and barriers to health behaviours (diet, physical activity) and stress. For example, through visual explorations of ‘healthy’ and ‘unhealthy’ eating, women in the Scotland TABPA workshop revealed a range of cultural and environmental barriers to following dietary advice, while also recognising practices that could support them. Women in Scotland also used drama to highlight the stress and structural challenges that come with migration and discriminative immigration policies. In Malawi, the processes of creating drama highlighted that women thought that taste preferences and an increase in celebrations may have led to greater consumption of unhealthy food and that men believed that social prestige led to an unhealthy diet and sedentary behaviour. Finally, men in both Scotland and

Malawi revealed that challenges with financial stress related to male familial responsibility and financial management can contribute to hypertension. Thus overall, the TABPA appears to be useful as a means to generate culturally-situated understandings of the communities' lived experiences, beliefs, and attitudes towards hypertension and diabetes risk factors.

### **9.2.5 What skills, knowledge and resources are necessary to support wider implementation of the TABPA (RQ5)?**

This research showed that a range of skills, knowledge and resources are needed to support wider implementation of the TABPA.

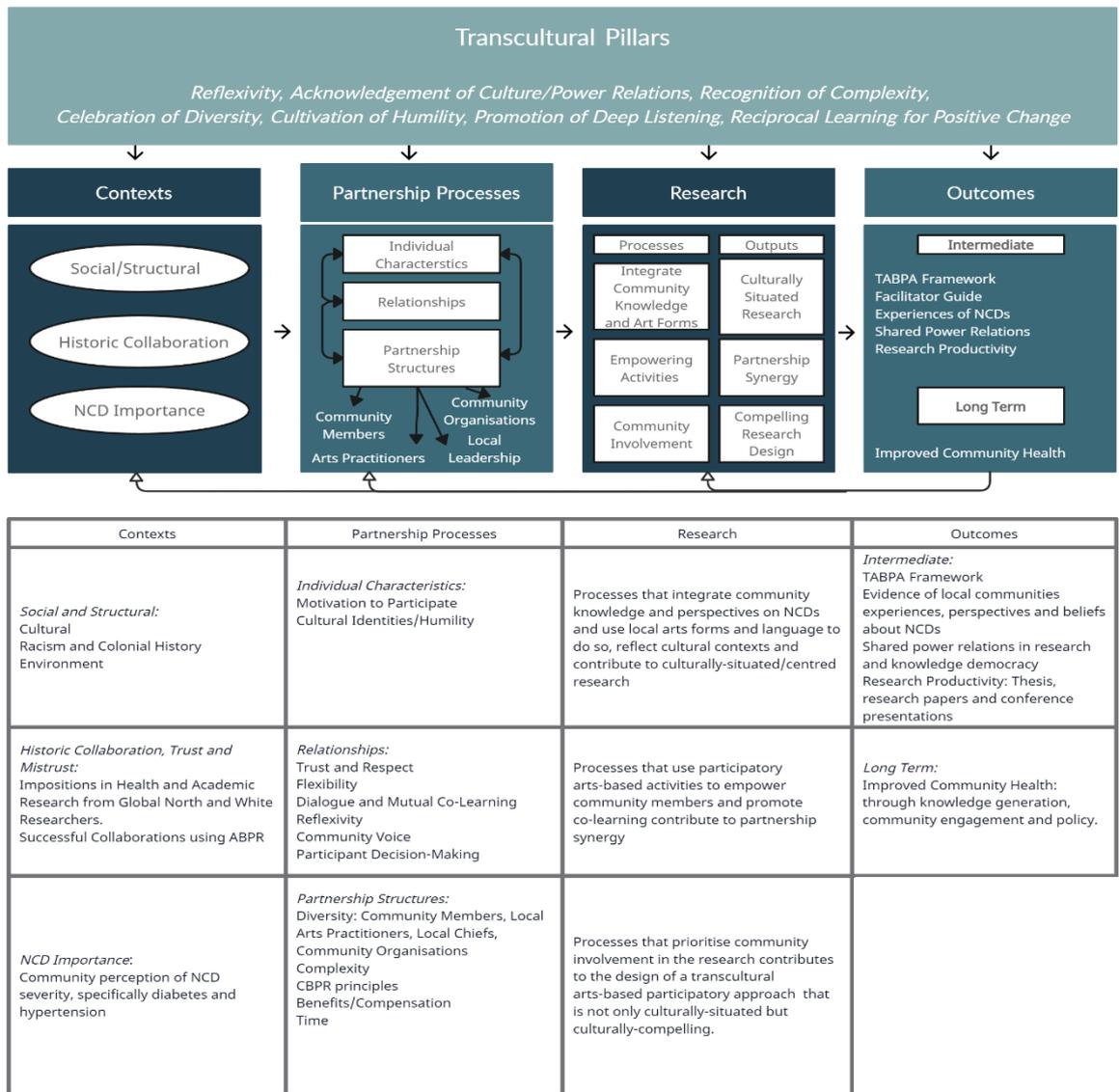
**Skills:** Researchers and, importantly, facilitators should be supportive, flexible and responsive to community concerns. Through processes of communication, listening and reflection, researchers/facilitators should be prepared to adapt the TABPA workshop activities when required.

**Knowledge:** Phase 1 was a fundamental process to understand the contexts that might shape community engagement in TABPA workshops. However, this process was less important in Malawi, as the facilitators were already familiar with the local context, including use of art and common perceptions of research and health. In Scotland, I was an outsider and therefore needed additional knowledge to be prepared to facilitate the TABPA effectively. Thus, the need for Phase 1 activities (walkalongs, community and stakeholder workshops) will depend on the practitioner's prior experience and knowledge of the local community.

**Resources:** There should be sufficient budget to provide payment, travel, snacks and childcare for participants and venue hire. There should also be a range of creative resources (e.g. pens, pencils etc.) to encourage participant choice over the art form. For researchers or organisations who require external arts-practitioners to facilitate the TABPA, it is also important to adequately budget for their support.

### **9.3 How does TABPA development compare between African communities in Scotland and Malawi and what does this mean for a transcultural approach in practice? (RQ6)**

Having summarised the general findings from the research, I now return to the transcultural community-based participatory conceptual model I presented in Chapter 2.4.5. The model shows four domains: context, partnership processes, research and outcomes. These domains interact iteratively with one another and are each shaped by the seven guiding transcultural pillars (Scholte 2014). In this concluding section, I will use each domain to reflect on my experiences of developing a transcultural approach with African communities in Scotland and Malawi and the implications for future practice.



**Figure 2-2 Transcultural Community-Based Participatory Research Conceptual Model for TABPA development. Adapted from Ortiz, Nash et al., (2020), Wallerstein, Oetzel et al. (2008), Wallerstein, Duran et al. (2017) and Scholte (2014).**

### 9.3.1 Transcultural Contexts

Community-based research requires careful understanding of the diverse and multiple contexts within which the research is situated (Ortiz, Nash et al. 2020). This becomes even more important and complex when navigating two discrete communities and settings. The transcultural community-based participatory research model introduced three context-related themes that should be engaged with: Social and Structural; Noncommunicable Disease Importance; and Community Historic Collaboration. However, it should also be recognised that these contexts are dynamic and are shaped before, during, after and sometimes,

by, the research (Ortiz, Nash et al. 2020). The following section will reflect on these contexts and how they shaped the research in Scotland and Malawi.

### **9.3.1.1 Social and Structural: Cultural, Environmental and Social Contexts**

Firstly, the research procedures needed to be responsive to the different cultural and environmental contexts of Scotland and Malawi. One of the clearest examples was the difference between how *time* is conceptualised and structured, and how this shaped recruitment and participation in walkalong interviews (Chapters 3.4.2.2 and 5.2). As discussed in Chapter 4.2, in many African cultures, time is conceptualised in a slower, more cyclical way than Western linear conceptions, therefore participants' availability for a walkalong interview in Malawi appeared to be responsive to their present, rather than future, commitments (Ong 1982, Abdi 2009). This flexibility allowed for a more informal method of recruitment in Malawi than in Scotland. Miguel and I could spontaneously arrange interviews within Sector A, and these could be readily adapted to accommodate participants' everyday routines. This meant that the walking element of the interviews was directly shaped by socio-cultural (e.g. status, presentability), economic (work) and environmental (heat) factors, which in some cases meant that community members chose not to go for a walk at all. In Scotland, recruitment followed a more formalised procedure, where the walks were prescheduled to begin at a set time and location, more in line with Westernised forms of recruitment and concepts of time. Participants could negotiate a time to fit with their other responsibilities, a location with consideration of the weather (e.g. shopping centres) and, in many cases, were actively interested in going for a walk. Thus, it could be argued that the flexibility written into the walkalong interviews meant that we were able to be adapt the method to be responsive to the socio-cultural and environmental contexts in both Scotland and Malawi.

Secondly, this research highlighted the interactions between historic, cultural and social contexts that can shape participation in arts-based activities among African community members in Scotland and Malawi. As described throughout this thesis, music and dance were culturally-important art forms among both Malawians and African communities in Scotland. However, while the emotional and religious connection to music and dance was similar (see Chapters 4.4 and

5.4), there were some differences between the two contexts. In Malawi, music and dance are intertwined with cultural and spiritual meanings, yet folk media have been appropriated during and after the colonial period for political, health and development strategies (Lwanda 2003, Kamlongera 2005, Abdulla 2020, Abdulla 2021). These complex meanings and histories appear to still shape how communities view these art forms, particularly as ones that are popular, engaging and, notably, a way to spread messages (see Chapter 6.2.1). In Scotland, community members highlighted that music and dancing were popular art forms; however, as noted by Ay in Chapter 5.3.2, the differences in cultural and socioeconomic contexts of the United Kingdom and Africa meant that they are less accessible than they were at home. Indeed, while church and religious groups may support engagement in different art forms in Scotland, there may be several barriers to participation, including cost and lack of culturally-relevant opportunities (Netto 2008, Arts Council of England 2018) (see Chapter 5.4). Thus, during both the Phase 1 community workshops and the Phase 2/3 TABPA workshops, community engagement with music and dance in Malawi appeared to be more organic, whereas participants in Scotland were following instructions and were initially more hesitant to engage in creative activities.

### **9.3.1.2 Historic Collaboration, Trust and Mistrust**

As shown in Figure 2-2, historic research collaborations and their legacies of trust and, at times, mistrust, will shape how communities engage in participatory research (Ortiz, Nash et al. 2020). Community gatekeepers play an important role in protecting communities from exploitative and extractive research practices, and for these reasons are often hesitant to invite new, unknown researchers into their communities. In the current research, as a new researcher in this field, I was fortunate to have been able to build on networks of trusting collaborations in both contexts that began long before my involvement in this research. In Scotland, the research was supported by past relationships between academics at the University of Glasgow and organisations working with African communities in Glasgow. In Malawi, research was facilitated through the Malawi Epidemiology and Intervention Research Unit's existing relationships with Sector A Chiefs. Thus, while the gatekeepers differed in Scotland and Malawi, the processes of gaining their trust through known and trusted past collaborators was the same. Gaining the trust of gatekeepers at this

stage also had important implications for trust development throughout the research process, as will be described in Section 9.2.3 below.

### **9.3.1.3 Noncommunicable Disease Importance**

The research topic did not originate from the community members themselves, it emerged in response to the Culture and Bodies Project in Malawi and Tanzania (Bissett, Gray et al. 2022). Therefore, it was important to spend time to understand whether or not diabetes and hypertension were important to the communities in Scotland and Malawi. As shown in Chapters 4.5 and 5.5, community members in both contexts held concerns about the impact of diabetes and hypertension, perspectives that often stemmed from personal or familial experiences of the diseases. It was interesting to note that while community members in Scotland and Malawi both appeared to be worried about the conditions, the way they conceptualised the diseases were often quite different. In Malawi, diabetes and hypertension were conceptualised as ‘deadly’ diseases associated with long term complications and negative impacts (see Chapters 4.5.1 and 8.2). In Scotland on the other hand, community members conceptualised the conditions as diseases related to lifestyle, which although difficult, could be controlled with dietary moderation, exercise and medication (see Chapters 5.5.2 and 8.2). As highlighted in Chapter 8.2, the difference between community conceptualisations, was likely due to differences in health messaging and access to treatment in Malawi and Scotland. In the UK, health promotion campaigns and health messaging prioritise individual lifestyle change to prevent and control NCDs (Talbot and Branley-Bell 2021, Limb 2022). In Malawi, financial and access barriers to NCD prevention and control mean that people are provided with limited education on behavioural prevention strategies and may be more likely to experience long-term complications from NCDs (Lupafya, Mwangomba et al. 2016, NCDI Poverty Commission 2018).

### **9.3.2 Transcultural Partnership Processes**

As highlighted by Ortiz, Nash et al. (2020), partnership processes are shaped by the association between individual characteristics, reciprocal relationships and partnership structures, which should interact to produce a “*commitment to collective empowerment*” (p.186). The following section will reflect on each of

these elements within the context of the current research, with a focus on the transcultural comparison between Malawi and Scotland and to what extent collective empowerment was achieved through the TABPA.

### **9.3.2.1 Individual Characteristics: Motivations to Participate and Cultural Humility**

Individual characteristics are a fundamental component of partnership processes; however, they are also the least explored in the literature (Ortiz, Nash et al. 2020). They are shaped by factors including motivations to participate in the research, cultural identities and cultural humility. In the following section, I will reflect on some of these factors and how they may have overlapped or differed between community members in Scotland and Malawi. However, it is important to note that although I spent a considerable amount of time getting to know the communities in each context in Phase 1, I cannot claim to know or be able to represent all of the individual characteristics that shaped the research.

Reasons for participation in social and health research are complex and involve a process of balancing perceptions of individual benefits, community benefits and the potential risk (Sikweyiya and Jewkes 2013). A range of motivating factors were revealed during this research. The most common appeared to be the opportunity to learn about diabetes and hypertension, as described by one man in Malawi, *“still you are medical people, we should learn, that is why we are here”* (Chapter 7.3.1: p.175). Yet this expectation brought complex challenges when trying to prevent the spread of partial (or mis-) information. Personal and medical benefits appear to be a common motivator for participation in health research, with some evidence suggesting that participants disclose personal information to try to receive prompt intervention (Sikweyiya and Jewkes 2013). Many of the participants had been, or knew someone who had been, diagnosed with diabetes or hypertension. Research suggests that participants are unsurprisingly most interested in participating in research related to their own conditions and in engaging with researchers on the causes of their disease (Bradley, Braverman et al. 2016). In the women’s pilot TABPA workshop in Scotland, some community members used reflections on the visualisation activity to ask direct questions about diabetes, which were undoubtedly linked

to their personal experiences (see Chapter 7.2). It is likely that the recruitment strategies used also contributed to a number of participants having motivations to gain health knowledge. In Malawi, while there was no preference for participants beyond gender and varied age range, as highlighted by Rhoda, it is likely that the chiefs still recruited TABPA workshop participants whose experiences they felt would be the most 'useful' to the research.

Participant motivation for personal health benefits may also overlap with more altruistic motivations to promote better health or health services for others (Sikweyiya and Jewkes 2013, Geppert, Candilis et al. 2014, Bradley, Braverman et al. 2016). While this may not have been directly highlighted by participants themselves, the common desire to create artistic outputs that could share health messages to the community do suggest that altruistic motivations were present among community members in both Malawi and Scotland.

Financial incentives were undoubtedly another important motivator both in Scotland and Malawi. The ethics around payment for participation remains complex. Researchers have indicated that payment can over-incentivise and exploit vulnerable individuals who need financial support (Head 2009, Field and Johar 2021). On the other hand, payment can be a way to redistribute power within research through recognition that participants are giving up their time (Head 2009, Field and Johar 2021). Additionally, arts-based research methods demand significant time investments from communities, which, without compensation, can create inequalities and power hierarchies, particularly when led by white Western researchers (Bunn, Kalinga et al. 2020). Thus, the ethics of financial compensation was guided separately by stakeholders in both Scotland and Malawi. In the UK context, minoritised communities are systemically marginalised, and partners within community organisations emphasised early on that it would be unethical to invite members of the African community to participate in research without some form of financial compensation, particularly amidst the Cost-of-Living Crisis. Participants were, therefore, provided with both supermarket vouchers and travel reimbursement (see Chapter 3.4.2.5). However, in Malawi, payment for research has different connotations, as too high a rate could over-incentivise participation within a low-income setting or create further barriers to local researchers who are often already under-funded (Nyangulu, Mungwira et al. 2019). The Malawi National

Committee on Research in the Social Sciences therefore only approves payments in the form of reimbursement (e.g. for travel) rather than compensation for time. As a result, the participant's travel reimbursement was set a generous rate agreed with researchers at MEIRU and the ethics committee (see Chapter 3.4.1.5). Thus, financial compensation likely served as a motivating factor in both Scotland and Malawi, although the rates and provision of it were different. Lastly, it is important to note that while financial motivation is important, it also interacts with personal and altruistic motivations (Sikweyiya and Jewkes 2013, Geppert, Candilis et al. 2014, Bradley, Braverman et al. 2016). Overall, it appeared that community motivations for participation were similar in both settings. However, it appeared that my whiteness also served as an additional motivator in Malawi. As described in Chapter 4.2, it is likely that community members in Sector A were motivated to participate in the walkalong interviews because I was a young, white woman, and going for a walk with me could bring social prestige (Chapter 4.2). This brought important reflections on power which I will discuss in the following section.

Cultural identities also played an important role in partnership processes. Community members' diverse and heterogenous cultural identities came out in their definitions and descriptions of community, social relationships and religious identities, as well as relationships to food and art forms, particularly music and dance. Community members in Malawi appeared to have a shared cultural identity where ideas of 'community' were understood as being a part of 'one family' and were interlaced with ideas and practices relating to social belonging and responsibility within the geographically-situated space of Sector A (Chapter 4.3.3). In Scotland, cultural identities were more fluid, with participants identifying as members of specific and heterogenous African cultural communities, as well as members of the broader Glaswegian community (see Chapter 5.3.2). Despite the diverse and complex cultural identities of participants in Malawi and Scotland, the TABPA workshops appeared able to bring out culturally important behaviours linked to diabetes and hypertension in both settings: for example, eating well to maintain social prestige in Malawi (Chapter 8.3.2) and the practice of eating culturally-important foods for comfort and homesickness in Scotland (Chapter 8.3.1). These findings suggest that there

is scope to use the TABPA framework in a range of cultural contexts with appropriate adaptations.

While attention is often focused on the cultural identity of communities in CBPR, there is a need for a more inward focus that also recognises the intersectional identities of researchers (Muhammad, Wallerstein et al. 2014). Researchers have reflected on the insider-outsider dichotomy and, as described by Smith (2012), the “spaces between” (Kerstetter 2012, Muhammad, Wallerstein et al. 2014, Milligan 2016). There is now a growing recognition of the dynamic and often situational nature of researchers’ positionalities and identities which are formed and represented in many different ways within and outside a research project (Milligan 2016). My own identity was something that I continually reflected on throughout the research, from my Glaswegian identity when conducting walkalongs in Glasgow (Chapter 5), the multilayered influence of Whiteness when working with African communities in both Scotland and Malawi (Chapters 4, 5 and 6), to the complexities around my role as a “health expert” and how this was perceived among both communities (Chapter 7.3.2). Milligan (2016) reflected on her own shifting identity as a ‘cross-cultural researcher’ working with Kenyan youth, and argued that using participative research methods centred on building trusting relationships helped to shift her identity from an ‘outsider’, first towards a ‘knowledgeable outsider’, and then towards an ‘inbetweener’. The latter term is used to describe a researcher’s agency to build trust, relationships and knowledge with community participants through active decision making where the researcher is positioned somewhere between ‘outsider’ and ‘insider’. My own commitment to building trust arguably helped to shift my position towards an ‘inbetweener’ in some cases, particularly where community members in Scotland and Malawi appeared to earnestly want to be involved in multiple phases of the research, as well as future health enquiries (see Chapter 7.2). However, despite the dynamic nature of the research and the relationships I formed, my position was (and is still) that of a “*guest*” (p.1053) within communities in both Scotland and Malawi (Muhammad, Wallerstein et al. 2014). It is important that I am still reflexive of my positionality and recognise that my responsibility to contribute to more equitable research relationships is ongoing (Coultras 2022).

Finally, the reflection above only accounts for my own cultural identity and does not explore the identities of the facilitators involved in this research. While, I cannot claim to represent the distinct cultural identities and positionalities of Miguel, Luke, Rhoda, Trust, Christiana and Anna, I acknowledge that they too shaped, and were likely shaped by, the research in multiple ways. In future research, more time should be taken to explore these identities and positionalities with all members of the research team to reflect on how they might influence the research process.

### 9.3.2.2 Reciprocal Relationships

The second theme within the Partnership Processes domain is Reciprocal Relationships (Figure 2-2), which represent the social dynamics around participatory decision making, trust, conflict management, and dialogue (Ortiz, Nash et al. 2020). The following section will reflect on the diverse forms of trust and participatory decision making within this research.

Trust is a dynamic and complex process. Lucero (2013) developed a trust typology to support understanding of the process of trust development in CBPR partnerships, identifying six categories: critical reflexive trust, proxy trust, functional trust, neutral trust, unearned trust and trust deficit (suspicion) (Lucero 2013, Lucero, Wallerstein et al. 2016). While trust was not directly evaluated with the research partners, I argue that it was formed in several categories over the research. Partnerships in both Scotland and Malawi were framed strongly by *Proxy Trust: Partners are trusted because someone who is trusted invited them*. Partnerships in the current research were built through a chain of trusting relationships with, and connections between, community gatekeepers and community members, and connections between community members themselves (see Chapter 3.4). As previously mentioned, walkalong recruitment in Malawi (Chapter 4.2) and Scotland (Chapter 5.2) was directly supported by community members sharing the research with their friends and neighbours. Nonetheless, my outsider status and historic collaborations with health researchers may also have produced *Functional Trust: Partners are working together for a specific purpose and timeframe, but mistrust may still be present*, and *Unearned Trust: Trust is based on member's title or role with limited or no direct interaction*. The former is perhaps most evidenced by the

young woman in Malawi who shared that they had been scared ahead of the workshop, unsure of the “*kind of people*” (Chapter 7.2: p.171) they were going to meet, while the latter is revealed in the complexities around my role as ‘health expert’ (see Chapter 7.3.1).

However, through the Phase 1 walkalong interviews and workshops and the Phase 2 and 3 TABPA workshops, we (researcher, facilitators and community members) together formed *Critical Reflexive Trust: Trust that allows for mistakes and where differences can be talked about and resolved*. In the TABPA workshops, this form of trust was realised through community members’ open and personal contributions (Chapter 7.2), the generation of a safe and supportive environment where community contributions were valued (Chapter 7.2), as well as negotiation during the conflicts that emerged through a complex process of co-producing knowledge (Chapter 7.3). It also involved being responsive to community reflections and suggestions, from making small practical changes to future TABPA workshops (e.g. sharing further information and resources on diabetes and high hypertension) to my own responsibility to return to the communities to share the findings and explore the next steps. The transformation from proxy trust towards critical reflexive trust has been shown to be a common feature of CBPR partnerships (Lucero, Wallerstein et al. 2016). However, these trust-building processes may not be representative of every community member’s and partner’s experiences of the current research, nor be assumed as fixed. Future work should continue to explore how to define and evaluate trust in collaboration with all project partners.

In addition, this research held strengths and weaknesses when trying to centre community decision-making. As Chapters 4 and 5 highlight, I spent time with the communities in both Malawi and Scotland, learning about their perspectives and experiences of health and local art forms. I tried to make these encounters as flexible and open as possible to centre participant perspectives, redistribute power and build relationships. I believe that this process was integral to building informal partnerships with community members and that it was successful in many ways, as discussed in Section 9.3.3.3. However, it should also be recognised that despite the steps taken to involve the community throughout, there were several ways in which community involvement could have been strengthened. I wrote the initial topic guides, developed the broad TABPA

workshop protocols and was primarily responsible for the analysis. Although each of these steps was informed by participants' perspectives and was readily adapted and discussed with facilitators and stakeholders, community involvement could, and should, have been shaped more directly with the community themselves. This involvement would have likely helped to address challenges such as conflicting expectations of the research, as well as perhaps mitigating some of the hesitancies or initial awkwardness with the creation of art in Scotland, as discussed in Chapter 7.3.2.

Centring community participation throughout the research was more challenging than anticipated. Firstly, in both Scotland and Malawi, community partnerships with gatekeepers and facilitators had to be adapted and changed due to different partners' capacity and changing employment. For example, in Malawi, I worked with four different facilitators over the project. The time and effort required to develop new stakeholder partnership structures amidst the competing pressures within a doctoral degree programme meant that community partnerships formed an 'advisory role' providing input and guidance, without reaching a 'partnership role' involving shared decision-making (Morin, Maiorana et al. 2003, Newman, Andrews et al. 2011). While regular meetings and effective communication have been found to strengthen relationship building and co-decision making with project partners, studies have also indicated that long-standing CBPR partnerships should be readily adaptable to meet community needs over the changing requirements of the research (Brush, Mentz et al. 2020). Thus, I made sure to engage project partners where I could at different timepoints, seeking feedback on the topic guides and workshop protocols, analysis and written findings from facilitators in Malawi and from community organisations in Scotland.

Furthermore, the workshop protocols were designed to gain in-depth feedback from participants at the end of each workshop. To some extent this was successful. However, as highlighted in Chapters 6.3.4 and 7.4, the workshops often ran over time and participants were often tired or distracted by other commitments towards the end. It is also possible that having spent time building positive relationships over the workshops, participants were reluctant or cautious about providing negative feedback. Thus, if following the Transcultural CBPR model to adapt the TABPA in future, it may be useful to involve additional

sessions with community members to collectively reflect on the TABPA and co-analyse the outcomes. These sessions would continue the processes of relationship building and centre on the idea that it was a safe space to provide both positive and negative reflections. Unfortunately, these collaborative analysis sessions were not sufficiently considered at the outset of this research, and due to time and funding constraints were not added iteratively.

Other PhD students conducting participatory research have experienced similar challenges navigating their commitments or ideals of participation amidst a time and resource-limited degree that prioritises individualistic research milestones (Klocker 2012, Wray, Soukhaphon et al. 2020). Nonetheless, these are challenges common to all CBPR research and this perspective is not intended to be used as an ‘excuse’ nor an ‘apology’ that replaces the need for action (Janes 2016). As Klocker (2012) writes, there is large body of “*judgmental*” (p.9) literature that can reinforce a dichotomy between ‘good’ and ‘bad research’ and oversimplifies the complex pursuit of participation. The many strengths of participation throughout this research and the experience gained should also be celebrated.

### **9.3.2.3 Partnership Structures**

Finally, partnership processes are also shaped by partnership structures (Figure 2-2). According to Ortiz and colleagues (2020), “*partnership structures consist of complexity and diversity of relationships among the partnership stakeholders, time in partnership, existence (or not) of formal agreements, and shared resources, which facilitate alignment with CBPR principles*” (p.186). This research involved complex and diverse partnerships shaped by several factors, including the context, time and geography, skills and capacity, access to resources and ethical decision-making. This section will reflect on some of the key features of partnership structures in Scotland and Malawi.

This research involved formal partnerships with community gatekeepers and arts-practitioners/facilitators which were shaped by the cultural context and practical considerations. In Malawi, partnerships were formed and shaped by traditional cultural practices, where I sought approval and support from the local Chiefs and provided customary gifts in exchange (see Chapter 3.4.1.2) - an important practice when conducting research within African communities

(Appiah 2020). I also formed partnerships with Malawian arts practitioners who provided support for the additional cultural and language considerations that came with my outsider status in Malawi. This included reviewing topic guides and protocols, translation, reflecting and refining the methods, and providing feedback and reflections on the written findings. Each facilitator was paid for their time and contributions, and rates and days of work were negotiated at the beginning of each partnership and adapted when appropriate.

In Scotland, I formed partnerships with community organisations who fulfilled gatekeeping responsibilities and supported recruitment in a similar way to the chiefs in Malawi, while also providing cultural and contextual input to the topic guides, protocols, analysis and writing. I was the lead facilitator of the TABPA workshops in Scotland for two main reasons: i) I wanted to gain first-hand experience of TABPA facilitation; and ii) data collection was conducted in English. However, I recognised that I still needed practical support with workshop facilitation and recruited my sister, Christiana, an experienced participatory artist, to partner with me. One reason I chose to partner with Christiana was due to my low budget, as she agreed to support me at a low rate. An international and participatory research project is resource heavy. As a PhD student, I had access to limited research funds to support data collection, which I had to supplement through various small grants. I prioritised my limited budget to pay participants in both countries and support travel for data collection in Malawi.

Facilitators in Scotland and Malawi not only provided practical support, but also artistic expertise. Rhoda and Christiana played an important role in the development and refinement of the TABPA workshop protocol. I drafted an initial protocol before sitting with Christiana to negotiate the language used to reflect a more creative approach that was still situated within a research context (Chapters 3.6.1 and 7.1). I also refined the protocol with Rhoda and Trust between the men's pilot and women's refined TABPA workshops in Malawi (Chapter 3.6.1 and 7.1, 7.3.2 and 7.5). During the process of refinement, Rhoda and Trust helped to frame the workshop activities differently to create the time, reflection, and additional questions needed to develop the more open and creative responses observed in the findings (See Chapter 3.6.1 and Chapter 7.3.2). Thus, while the nature of the facilitator partnerships differed between

Scotland and Malawi, collaboration with artistic practitioners in both contexts strengthened the workshop protocol and therefore the TABPA in practice.

### **9.3.3 Transcultural Research Processes and Outputs**

#### **9.3.3.1 Did the integration of community knowledge and art forms support culturally-situated research?**

The Transcultural CBPR model (Figure 2-2) theorises that processes which integrated community knowledge and perspectives on diabetes and hypertension (and used local arts and languages to do so) would reflect cultural contexts and contribute to culturally-situated research in both Scotland and Malawi.

In the present research, the open, scaffolding structure of the TABPA workshops appeared to support an approach that centred community knowledge. The openness of the visualisation activity allowed individuals to explore their own initial understandings and beliefs about diabetes and hypertension, before exploring them with others. This brought out a range of responses, from personal and familial experiences to knowledge about the causes, symptoms, treatment and control of diabetes and hypertension. When brought together in Activities 3 and 4, community members could integrate their own knowledge with other participants to explore and negotiate the causes and prevention of the disease. Notably, the content that community members included in their artistic outputs from Activity 4 often depicted information that the participants wanted others in their community to know or thought others would find helpful to follow (see Chapter 7.3.1). Thus, it could be argued that framing the research with arts-based activities supported community members to identify and negotiate the information they deemed was most important and most achievable behaviour change for the wider community. Therefore, the TABPA workshops were an important starting point from which to co-develop intervention strategies in future.

The flexibility of the TABPA workshops enabled community members to use a range of art forms to explore their perspectives. In Scotland, community members used theatre, drawing and storytelling, while in Malawi, they used theatre and song. Interestingly, the artistic outputs, particularly theatre and storytelling, highlighted how relationships can shape health behaviours. For

example, men in Malawi created a drama that showed how positive feedback from others can reinforce perceptions of social prestige related to weight gain, while women in Scotland used their drama to show the importance of community support when trying to change other's health behaviours. The interactions between characters in the drama helped to frame the everyday encounters, and the relationships they are built on, that could facilitate the drivers of diabetes and hypertension which may be more difficult to bring out in a more structured/traditional methodology (Erel, Reynolds et al. 2017).

### **9.3.3.2 Did empowering activities support partnership synergy?**

The model also theorises that processes using participatory arts-based activities to empower community members and promote co-learning would contribute to partnership synergy in Scotland and Malawi.

As highlighted in Chapter 7, there was strong evidence that the TABPA workshop activities in both countries contributed to community reflection and co-learning. Community reflections were likely built through the series of scaffolding activities that supported trust building, openness, and flexibility. Firstly, the use of warmup games (Activity 1) helped to create a sense of play which began to: break down the initial formal research atmosphere; create a sense of group cohesion; and build relationships among and between community members and researchers/facilitators. Secondly, the visualisation activity (Activity 2) created an open space for individual and joint reflection, where community members could communicate their initial thoughts or beliefs about diabetes/hypertension without correction or judgement. Thirdly, working as a group to develop a creative response to the prompts about the causes and prevention of diabetes and hypertension (Activity 3 and 4) supported a sense of teamwork and openness. These strengths reflect the complementary nature of arts-based and participatory methods which in combination can offer *“a safe space for people to foster dialogue and express themselves”* (p. 41) (Coemans and Hannes 2017).

The benefits of co-learning as a driver of partnership synergy were most strongly realised in the Malawian context. Community members in Phase 3 TABPA workshops reflected positively on the mutual exchange of knowledge between each other and with facilitators/researchers (Chapter 7.2) Some participants

also revealed that the TABPA workshops had made them feel free to express themselves, and one woman even suggested that we return and explore other health issues in a similar way, so that researchers and community members could listen and learn from each other's knowledge (see Chapter 7.2). In Scotland, the co-learning process appeared to be more subtle, community members indicated that the workshop had been educational and provided 'helpful' insight (Chapter 7.3.1).

As also discussed in Chapter 7.3.1, co-learning could bring challenges, particularly where community members wanted their knowledge clarified by the researchers as 'health experts'. This was an important similarity between Scotland and Malawi, and highlights one of the weaknesses of the approach from a participatory perspective. An overt focus on centring community perspectives on diabetes and hypertension and avoiding the imposition of biomedical knowledge meant that the TABPA workshops failed to fulfil community expectations. This was exemplified when one woman in Malawi suggested that next time the workshop should include a debrief session where the health information could be clarified. This interaction was an important learning point, and I recognised that I should be responsive to community concerns, and as a result organised information sessions on diabetes and hypertension for community members and provided additional resources where I could. These encounters, while not embedded in the research from the beginning, demonstrate the importance of deep listening and responding to communities, without which we stand to reinforce tokenistic ideas of participatory research.

### **9.3.3.3 Did community involvement support the development of a culturally-compelling research design?**

Finally, it was theorised that processes that prioritise community involvement in the research contribute to the design of a transcultural arts-based participatory approach that is not only culturally-situated, but culturally-compelling in both Scotland and Malawi.

Panter-Brick and colleagues (2006) argue that community involvement in developing health interventions can create outcomes that are not only culturally acceptable but also culturally-compelling to the target community. This is done

by using forms of intervention that appeal to the community rather than just focusing on the content. In the current research, the TABPA workshops were designed to incorporate art forms that were compelling to the community. As Phase 1 highlighted, although many art forms (music and dance, theatre, drawing and poetry) may appear compelling at face value, each comes with their own benefits and challenges when used as means to communicate perspectives on health. I realised that it was not the art form per se that made the approach culturally-compelling, but the freedom and flexibility offered to participants to choose and adapt their use of art as they saw fit. Nonetheless, there were still some differences between Scotland and Malawi. Participants in Malawi appeared to need less support from the facilitators when creating their artwork and placed more value in the artistic output than the process (see Chapter 7.3.2). This difference likely reflects the diverse and dynamic contexts of the research (see Section 9.3.1).

Community involvement in Phase 1 highlighted important nuances that supported the development of the TABPA workshop protocol. The walking interviews provided a foundational understanding of what art forms were enjoyable to community members in general. Community and stakeholder workshops generated practical insights into how community members actively engage with different art forms in a more functional capacity (i.e. to communicate their knowledge on diabetes and hypertension). Understanding how communities would engage in creative activities in both theory and practice is particularly important when seeking to embed art forms that are culturally-situated without losing or imposing meaning (Abdulla 2020).

#### **9.3.4 Transcultural Research Outcomes: A TABPA Framework and Recommendations**

The outcomes domain seeks to outline the intermediate and long-term goals of the project with reflection on the principles and values of CBPR as a process, as well as on broad goals to improve health outcomes (Ortiz, Nash et al. 2020). In the current model I theorised that the process of TABPA development could contribute to four intermediate outcomes namely: 1. A TABPA framework; 2. Evidence of local communities' experiences, perspectives and beliefs about NCDs; 3. Shared power relations in research and knowledge democracy; and 4.

Research productivity. Finally, the long-term goal was to improve community health through knowledge generation, community engagement and policy. I will reflect on each of these goals below.

#### **9.3.4.1 Transcultural Arts-Based Participatory Approach Framework**

The primary intermediate goal of this research was to develop a TABPA framework, consisting of a familiarisation phase and TABPA workshops. As described above, the research highlighted that Phase 1 was fundamental to understand the diverse contexts that might shape community engagement in the TABPA workshops and the TABPA workshops were feasible and acceptable for use with African communities in two distinct contexts. Importantly, many of the activities were readily adapted and responsive to the different cultural, environmental, historical and social contexts in Scotland and Malawi, as well as to practical challenges and financial constraints. Despite these adaptations, the workshops contributed to similar outcomes in both Scotland and Malawi whereby community members could share their knowledge on diabetes and hypertension freely and expressively, use artistic forms of their choice, learn together with each other and the researcher/facilitators, and build relationships. Thus, the framework presents as a set of recommendations that reflect transcultural, arts-based participatory principles and should be readily adapted to the needs and expectations of different communities, different contexts and different settings.

I present my main recommendations for adapting and implementing the TABPA framework below. These are not intended to be new concepts, but rather reflect my specific experiences of developing the approach.

- I. Familiarisation Step: Depending on the researcher and/or practitioner's familiarity of the communities they are working with, there should be some process of contextualisation with the community on the wider contexts including local arts and health (e.g. walkalong interviews, community workshops, stakeholder interviews/workshops). This step may be modified or even omitted depending on the extent to which researcher/practitioners are already familiar with the community.

1. The TABPA workshop scaffolding structure is a fundamental element of the approach. By using games, individual visualisations, and group activities, community members can build culturally-situated knowledge on the causes and prevention of NCDs.
2. Flexibility is key. Community members in both Scotland and Malawi valued flexibility, choice and the inclusion of artistic forms that remove language barriers. It is likely that some participants will be hesitant about creating artistic outputs, and providing a safe and trusting environment is important to help them overcome this.
3. Facilitators play a fundamental role in providing a safe and supportive environment. They should be available to provide support, encouragement and reassurance throughout the TABPA workshop.
4. Facilitators and researchers should be ready to adapt the TABPA workshop protocol according to community expectations before, during and after the workshop.
5. It is important to negotiate how community members would like to receive health information, and when, to ensure that community voice is centred, but participants do not leave with knowledge or behaviours that could be harmful to their or other's health.
6. It is important that all practitioners/facilitators spend time prior to the TABPA workshop ensuring that everyone has the same expectations of the process, and the outcomes.
7. The flexibility of the arts-based activities mean that the TABPA workshops are an inherently messy process. Facilitators should be ready to embrace this and recognise where they might want to bring in other practitioners for additional support.
8. TABPA workshops demand time and energy from participants, and therefore contributions should be valued through financial compensation for time and travel, and childcare should be provided where required. The

form and value of compensation should be negotiated with community stakeholders, with consideration of community needs and the wider contexts.

#### **9.3.4.2 Evidence of local communities' experiences, perspectives and beliefs about NCDs**

This research generated in-depth evidence of experiences, beliefs and perspectives on diabetes and hypertension among African communities in Scotland and Malawi. The TABPA workshops generated culturally-situated understandings in Scotland and Malawi, as well as illuminating transcultural differences and similarities in how communities engage in health behaviours.

#### **9.3.4.3 Shared power relations in research and knowledge democracy**

As described throughout this chapter, power hierarchies were still present within this research in many ways due to my positionality as a white Western researcher and as a perceived 'health expert'. Nonetheless, the TABPA framework through both the Phase 1 familiarisation activities and Phases 2/3 workshops did appear to contribute to the redistribution of power through relationship building, fostering a safe and supportive environment and the co-production of knowledge. These processes were supported by a research approach that involved spending time with the community, building trust, playing games, flexibility, co-learning, and importantly being responsive to community concerns. It could be argued that this was most obvious in Malawi, particularly where the TABPA workshop activities alleviated the 'fear' described by community members. In both contexts I was also able to demonstrate my commitment to the community by providing an additional health information session. By being responsive to the community, I hope to contribute to research that sets a precedent for health researchers to deeply listen to community members and stakeholders and engage in a continual process of learning.

#### **9.3.4.4 Research Productivity: Thesis, research papers and conference papers**

While I have spent much of this thesis exploring the benefits of the TABPA framework for community members and partners, it is important to acknowledge my own benefit from this research. This project has contributed towards my own

pursuit of a PhD and an academic career. I have presented the initial findings at an International Health Humanities Conference and at research events at the University of Glasgow and to colleagues at the Malawi Epidemiology and Intervention Research Unit (MEIRU). Informed by my experiences, I have also co-founded a cross-institutional research network dedicated to arts-based participatory approaches to community-based research with minoritised communities. I will continue to present the methodological and health-related findings at national and international conferences and prepare written findings for publication in journals. For both conference and research papers, I will extend an invitation to project partners and facilitators to co-author in recognition of their invaluable involvement and address persisting institutional hierarchies (Coulter 2022).

#### **9.3.4.5 Long Term Outcomes**

The long-term outcome of this research was improved community health through knowledge generation, community engagement and policy. Sharing the culturally-situated knowledge generated in this study through publication and policy pathways could inform the co-design of culturally-compelling interventions to prevent diabetes and hypertension among African communities in Scotland and Malawi. In practice, this outcome will involve several other stages of development and evaluation. The next steps of this research could involve implementing the TABPA framework with additional groups in each context to identify common perspectives on diabetes and hypertension risk factors. More research would also be needed to determine what factors identified by communities would be the most feasible to target through co-designed interventions. For example, this research suggested that music and dance could be a culturally-compelling strategy to increase physical activity among African communities in Scotland, however, more research is needed to explore how to do this in practice. Additionally, there is a need to explore strategies to better communicate research information to participants in an engaging and ethical manner.

Finally, I recognise that this thesis does not end my responsibility to the communities I worked with. I am due to return to Malawi in October 2024 to hold a community dissemination event and to share the findings with stakeholders, and I am committed to doing the same in Scotland. I hope to maintain the

relationships I have built with community members and stakeholders beyond this project and explore with them how to translate the knowledge gained into meaningful next steps for research and practice to improve community health in relation to diabetes, hypertension and other NCDs.

## **Postscript**

### **A Final Reflection on Positionality, Transculturality and Ethical Dilemmas**

In this thesis, I presented the development of a framework for a transcultural arts-based participatory approach to explore the drivers of diabetes and hypertension among African communities in Scotland and Malawi. I demonstrated how through collaborative processes of familiarisation, development, pilot and refinement, I co-created a methodological approach that could be used and adapted to generate culturally-situated understandings of health behaviours in different contexts. However, this PhD was not just the development of a methodological approach, it was also a continual process of learning where I grappled with my positionality as a non-local scholar, the complexity of working across and between distinct geographic and cultural contexts, and associated ethical dilemmas. These challenges are closely connected and are difficult to untangle from one another. In this concluding section, I endeavour to reflect on my own journey through this research, what I learned, where I made mistakes and what the TABPA framework looks like moving forward.

### **Transcultural, Ethical and Relational Challenges of Being an Outside Researcher**

#### **Cross-Cultural Power Dynamics**

Being a non-local scholar shaped power dynamics with both facilitators and participants in many ways. In Malawi, the research was undoubtedly strengthened by the cultural skills, knowledge and competence of local facilitators and translators. I initially built partnerships with Miguel, Luke and Rhoda based on proxy-trust established between each facilitator and my supervisor [CB]. This proxy trust was then extended when Rhoda brought Trust onboard as a facilitator in Phase 3. Miguel, Luke and Rhoda all held both facilitation and translator roles. While I cannot speak for others, having pre-established connections meant we each appeared to feel a sense of responsibility (and accountability) to do the work well. Despite this proxy trust, I still held a position of power as an outside researcher with broadly pre-determined research goals and being responsible for payment to the facilitators.

The process of paying the Malawian facilitators brought more ethical and relational challenges than I had initially expected. I deferred to CB and MEIRU's guidance to agree an appropriate daily rate with each facilitator, however, always made space for discussion with facilitators to ensure that rates were fair. This also meant I had to pay careful attention to the local currency (kwacha), which devalued significantly over the duration of my fieldwork. After one period of fieldwork, I had travelled back to Scotland and left the remaining payment in kwacha at MEIRU for one of the facilitators to collect once they had completed translation and transcription. However, due to devaluation, the payment I had left fell substantially short of the rate we had agreed in GBP. I managed to resolve this and quickly provide appropriate payment; however, I felt some guilt I had not anticipated the problem before I had left Malawi. Similarly, when I was based in Glasgow, I reached out to Luke and Rhoda for support with translation, transcription and chapter reviews; however, I had to follow complex university protocols to provide invoice payments. While I faced similar challenges in relation to university protocols when paying facilitators in Scotland, I felt more discomfort when going through the process for Malawian facilitators as the finance system sits counter to the predominantly cash-based economy of Malawi and payments often took longer than anticipated to process. Thus, navigating payment, while an ethical imperative, brought relational challenges, that often relied on open communication and the trust that I had built with each facilitator to rectify different challenges, particularly while working at geographic distance.

Separate from issues of payment, power dynamics would often shift between myself and Malawian facilitators over the duration of the project. When I reviewed each of the relevant topic guides and protocols with Miguel, Luke, Rhoda and Trust ahead of data collection, generally they had little to add or change. This could have been due to power hierarchies where they may have been cautious to provide negative feedback. However, in practice, facilitators naturally adapted the workshops to the cultural context in subtle ways. This included introducing opening and closing prayers, suggesting games that would be familiar to the community and acknowledging local hierarchies (see Chapter 6.3.1). The most notable changes to the workshop protocols often occurred in-between workshops, where we worked together to reflect and refine the

activities. This process helped to redistribute power more equitably between myself and facilitators as they gained more experiential knowledge and therefore more control over the research process. However, it could also reveal conflicts in our expectations of the research process, particularly what the final TABPA workshop arts outputs should look like (see Chapter 7.3.2). In these encounters, I was once again reminded that knowledge production is a dynamic process that needs to be negotiated carefully between all partners.

Being a non-local scholar could also bring relational power-dynamics when working with participants. As described in Chapter 7.2, it appeared that it was more difficult for me to build trust with community members in Malawi, where some participants had initially been “scared” to attend the workshops, not knowing what to expect. I do not know if this fear was linked to my outsider status or the research itself, however, it might have been reduced had I been more embedded in the community. Participants’ concerns may also have been influenced by the recruitment strategies, where, because they were invited by the Chiefs, they had less direct contact with the research team to ask questions before arriving at the workshop. Furthermore, although Miguel provided a fluid live translation of walkalong interviews, going through a proxy created an additional layer of ‘otherness’ that I had not felt during walkalongs in Scotland. Thus, building meaningful connections with the Malawian community members I interviewed felt harder.

Similarly, during both Phase 1 and Phase 3 workshops in Malawi, although I tried to get involved where I could, playing the warmup games and actively listening and observing, I still felt more distant than I did during the workshops in Scotland. Due to the language barriers, I found it harder to get involved in the main activities without disrupting the flow of the workshop or imposing the use of English (even accidentally). Many participants did kindly share their experiences in English so that I could be involved, but I often wondered if my presence changed how they would have communicated their experiences had I not been there. Despite all of these challenges, I do believe that the trust-building processes and workshop activities did contribute to the redistribution of power hierarchies, even in small ways. My position as an outsider was not fixed, rather it shifted and changed as I got to know facilitators and participants.

## Working Across Languages

Language barriers were one of the biggest challenges of researching as a non-local scholar. Despite the skills of Miguel, Luke, Rhoda and Trust, in Malawi collecting and interpreting data generated in Chichewa was complex. However, working with participants in Scotland, also brought important language considerations. In this section I will explore some of the practical challenges of working across languages in more detail.

The first notable challenge of working across languages appeared during an arts-focussed walkalong in Sector A, Lilongwe. As described in Chapter 4.4, one participant had asked me whether I thought being an electrician was an art. I had thought this an interesting question, and returned to the participant asking whether he thought it was. It was only later that Miguel explained that the Chichewa word for art “*zaluso*” could also be translated as skill or talent, meaning I needed to be more specific in the walkalong interviews going forward to focus the discussion on more creative definitions.

I also needed to be cautious of how I interpreted the research transcripts which had been translated from Chichewa. For example, my interpretation of the poem created by participants in the Phase 1 Women’s Community Workshop in Chapter 6.2.4 was based on the English translation. Given the multitude of ways poetry can be understood, it was important that I also provided the original Chichewa version. In addition, I sense-checked the original translation and my interpretation of it with a Malawian friend who is experienced in arts-based participatory research. They made minor changes that improved the clarity of the English version but did not alter the meanings. Another example is provided by an extract from the Phase 3 Women’s TABPA workshop, which had originally been translated to say people “*cannot afford to not eat white flour...*”. I had incorrectly interpreted this as a financial barrier to healthy foods, however my supervisor [CB] and Rhoda highlighted that the whole grain flour is actually a relatively affordable staple and the alternative translation might be “*most people cannot resist white flour just to prevent diabetes*” (p. 232). Thus, I reanalysed the extract from the perspective of taste preferences rather than financial need. While it is possible that some misinterpretations remain in my analysis, by having Luke and Rhoda read and reflect on my written findings from

the workshops they facilitated, and therefore had contextual knowledge of, I hope to have mitigated this where possible. Regrettably, I did not leave enough time and did not have enough resources to have Miguel review the walkalong findings in Chapter 4 nor the funding to have all of the translation reviewed by a second party, ultimately a limitation of this research.

Similarly, as touched on in Chapter 6.2.4, as I could not follow discussions in Chichewa, I would often miss opportunities where I could have probed for more detail on Malawian participants' responses. This was particularly noticeable during Phase 1 workshops, where Luke was the sole Malawian facilitator. The facilitation of arts-based participatory workshops requires significant attention and focus, and it is easy to miss key points to follow up on when trying to navigate the practical and relational elements of different activities. This was something I learned firsthand in the Phase 1 workshops in Scotland, where I was grateful to have Christiana there to probe participants for details I missed. As I could not speak Chichewa and Luke did not have capacity to translate, I was often of little help during the Phase 1 workshops in Malawi, and the workshop protocol I had developed lacked detail on how and when to ask for more information. This was an important learning point for working with external facilitators both in Malawi and Scotland, where I realised that the protocol needed to cover the 'in-between' moments, not just the key activities. When writing the protocol for the pilot TABPA workshop I made sure to write in as much detail for the in-between moments as possible, trying to think about what others (less familiar with the research) would need to guide them through the process and discussions. I emphasised these details with Christiana and Anna (Phase 2) and Rhoda and Trust (Phase 3), asking for feedback on the protocol and if anything was still unclear. Upon reflection, this focus likely contributed to richer findings from the Phase 2 and Phase 3 TABPA workshops.

Additionally, as highlighted in Chapters 7.4 and 7.5, not speaking Chichewa also brought several awkward moments where I had misinterpreted the facilitation and interrupted to check we were following the protocol. These moments likely reinforced some of the power dynamics between myself and facilitators and likely influenced how I was perceived by participants. I often struggled with interruptions as I did not want it to appear to facilitators that I did not trust them or was moderating their facilitation, yet I was also aware that I had to

balance this worry with the quality of the data being generated. In-workshop dynamics with facilitators (and community members) would have been much easier to navigate if I had been able to speak Chichewa. In practice, these interruptions also shaped the data collected. For example, as mentioned in Chapters 7.5 and 8.2, the Phase 3 men's TABPA visualisations were more developed than those in the women's workshop, likely because my interruption meant the group had a longer time to process their thoughts.

Finally, it is important to reflect on how language influenced the research process in Scotland. While all data collection was done in English, the majority of participants were first-generation migrants with a range of English proficiencies. This could sometimes bring challenges in communication. This was more noticeable in walkalong interviews likely because the workshops created space for other (e.g., visual) forms of communication. When transcribing walkalong interviews I noticed small miscommunications or where I should have asked simpler questions. I often had to listen to the audio several times to ensure that I understood the participant's intended meaning. It also brought challenges with the communication of participant information which I will return to below. Upon reflection, it is likely that I was so aware of the challenges of researching in Chichewa in Malawi, I neglected to give the same attention to working in Scotland. This is big learning point for me and something I hope to address going forward to ensure that I take every step possible to make the research as inclusive as possible.

### **Cultural Adaptation of Arts-Based Participatory Research Methods**

One of the main questions this research addressed was how I could use and adapt arts-based methods to develop a transcultural method. In order to do this, I needed to understand how arts-based participatory approaches might be understood by communities in Malawi and Scotland. In the following section, I reflect on how understandings in the two countries may have differed or overlapped.

I began the research by seeking to understand the different ways in which art could be understood in Malawi and among African communities in Scotland. This appeared more straightforward for the former. While I had never visited Malawi,

I found that through the Culture and Bodies project that I had been involved with during my MSc (see Chapter 1.2), and through my supervisors and their Malawian connections, I had a larger toolkit of resources to draw upon and orientate myself within the cultural context in Malawi than in Scotland. I drew on the work and guidance of colleagues and mentors situated in Malawi including Dr Sharifa Abdulla, Dr John Luanda and my supervisor (CB) to guide my understanding of the complexities of health and art (and folk media) in Malawi, and how their meanings and implications have shifted and evolved through the history of colonialism and ongoing international development projects (see Chapter 6). In Scotland, 'getting started' felt more challenging, particularly having to find a new project partner so early in the study (Chapter 3.5.1) and due to scarcity of literature on African communities' engagement with art and experiences of health in Scotland. I responded to this challenge by seeking out local cultural events and activities where I could broaden my understandings, many curated as part of Black History Month or international festivals. For example, I visited museum exhibitions and went on a walking tour focused on Glasgow's involvement in slavery and colonialism, challenging perceptions of the city I had grown up in. I visited visual arts exhibitions by African and other indigenous artists, attended dance performances exploring Black cultural identities and racism, and music events celebrating the fusion of African and Celtic lyrics and sounds. By attending these events, I grappled with my privilege and discomfort, but I also experienced the power of art to convey meaning and celebrate cultural identities.

Despite building a foundational understanding both through the processes described above and through the walkalong interviews, I was still unsure of what the TABPA framework might look like, and how it might embrace diverse cultural identities and art forms in both contexts. I was cautious not to impose the Western art forms I was familiar with onto each community, while simultaneously recognising that my positionality meant I was ill-equipped to be able to integrate or adapt traditional art forms without undermining their meanings. Similarly, I was careful not to assume that an art form that worked in Malawi would work the same way in Scotland, and vice-versa. The initial conflict between how to create, but not impose or appropriate, art shaped the design of Phase 1, especially, the Phase 1 Community Workshops. I reasoned if, like

Abdulla (2021), I could keep the structure of the workshops as open and flexible as possible, then the community could use the activities to negotiate and play with their own understandings of art. Yet, this structure was still informed by my wider knowledge and experiences, both with participatory theatre and the workshop structure developed in the Culture and Bodies project (Chapter 3.1.2). Thus, I saw the method, not as a standalone protocol, but as something that could be moulded and adapted with participants. In this way, I hoped that it would embrace both my own culture and that of each community. In practice, I was surprised by how well the Phase 1 workshops worked in both Scotland and Malawi, with limited adaptation to the actual activities. I had intended to use the Phase 1 Community Workshops as a means to inform the development of the TABPA, however, I had not anticipated that the Phase 2 and 3 TABPA workshops would follow such a similar structure.

As evidenced throughout this thesis, community members in Scotland and Malawi chose broadly similar art forms, including drama, music, dance and drawing. While it could be argued that this similarity emerged from the way the questions were framed in the workshops, the way that each community used art suggested that their motivations for each art form were more nuanced. In Malawi, it appeared that community members understood arts-based participatory methods as a way they could adapt traditional forms of expression to communicate health messages. As discussed in Chapter 6, this use reflects a history of adaptation and appropriation of folk media and traditional art for alternative purposes including health messaging. Furthermore, the participants' choice of art forms in both Phase 1 and Phase 3 are notably comparable to Abdulla's (2021) work where community members in Malawi played with different forms of folk media to share their perspectives on HIV/AIDs. The similarities to Abdulla's work and participants' confidence to use the art forms (Chapter 7.3.2) suggest that the methods used did manage to capture culturally-appealing forms of creative expression. This may have been supported by the facilitators' subtle adaptations to the protocol. For example, Rhoda called on participants to suggest art forms rather than providing examples herself.

In Scotland, community members also appeared to understand the use of arts-based participatory methods as a way they could share health messages with others. However, the use of art was less spontaneous than in Malawi. As I write

in Chapter 6.2.1, Chapter 7.3.2 and Chapter 9.3.1.1, it appeared that the diversity of cultural experiences and access barriers to cultural art forms in Scotland made it more difficult to find a shared reference point from which to create or adapt art traditional art forms. However, participants still drew on the local cultural context. For example, women in the Phase 1 Community Workshop in Scotland created a drawing because: 1) it would be accessible to those with a range of English language capabilities; and 2) they reasoned that drawings were commonly used to convey information in the UK. Thus, it could be argued that they chose drawing as an art form because it could account for both their own experiences with language barriers following migration to the UK but also their knowledge of UK health promotion, acknowledging the complexity of their own experiences of the local context.

In summary, it appeared that participatory arts-based approaches were similarly understood in Malawi and Scotland, primarily as a means to communicate health information to others in the community rather than for the purposes of creative expression. However, the way that art was used in each setting did appear to be shaped by the cultural contexts in which they were applied.

### **An Outsider: An Opportunity to Learn and Reflect**

Although being a non-local scholar was often challenging, it also brought many benefits. Firstly, I believe that being aware of the power associated with my outsider status led me to be more reflexive of my interpretations and my use of art. I felt a responsibility to ensure that I did not misrepresent the communities or cultural contexts that I was working in, often spending an extended period reading literature, seeking guidance from project partners and revising my interpretations. For example, the walkalong chapters took the longest to write as I saw every piece of data and literature as helpful in my understanding of the wider context, even those that did not appear directly relevant to this research. Being reflexive of my outsider status also helped me to identify actions and encounters that I might have handled differently, including those described in the preceding sections. Reflecting on these interactions often made me feel uncomfortable, however, over the course of this research, I made peace with my discomfort. I reasoned that if I was not at least a little uncomfortable with my role and the associated power hierarchies, then I was not learning and was more

likely to become complacent and reinforce harms. While it was not easy, I believe that learning to sit in the uncomfortable will make me a better researcher going forward.

I started this PhD as an outsider to both communities, in that my unfamiliarity with the cultural norms in Malawi and among African communities in Scotland was undeniable. As a white, Western researcher, my positionality cannot be disentangled from racialised and colonial hierarchies that have shaped health research and practice with Black communities in both Malawi and Scotland (see Chapter 3.1 and Chapter 2.3.3). This reality is not something I have tried to shy away from, rather I used my discomfort at my complicity (see Coultas 2022 and Chapter 3.1.3) to reflect on my positionality deeply, question my decisions and interpretations throughout the research, and listen and learn from project partners. However, as I moved through each phase of data collection in Scotland and Malawi, I also saw myself embody the situational and dynamic nature of positionality that is now so often being recognised in participatory and transcultural discourse (Kerstetter 2012, Muhammad, Wallerstein et al. 2014, Milligan 2016, Smith 2021). I could simultaneously be an outsider, acting (and being perceived) as a white, Western academic and/or ‘health expert’ (see Chapter 7.3.1), while also building trust and relationships with each community through the use of participatory methods (Chapter 7.2). As I write in Chapter 9.3.2.1, like Milligan (2016), I became an “inbetweener” and learned how to embrace the fluidity of my positionality as something I have the autonomy to change through a commitment to authentic participatory research practices.

## **A Final Reflection on Ethics in Practice**

This research was my first experience of primary data collection. I had a theoretical understanding of ethical principles and the rules and regulations of institutional ethics boards. However, ethics in practice can be complicated. As described throughout this thesis, the research brought many complex ethical questions, from gaining informed consent in a culturally-appropriate way, managing health disclosures, exploring how and when to clarify health information, and ultimately the take and give of research participation. In this section, I seek to reflect on these dilemmas and highlight what I learned.

As I discussed in Chapter 3.9, I sought and gained ethical approval for each phase of this study both through UK and Malawian institutional ethics boards and sought and gained written informed consent from all participants, something I understood to be the best and ideal practice for my participant groups. As I highlighted in Chapter 3.9 and 7.4, I dedicated a substantial amount of time to making sure that everyone understood what was involved in participation, verbally communicating the information to both individuals and the wider group, and brought in extra support to make sure not to start any data collection until I was confident that everyone was comfortable in their involvement. However, these processes could have been much smoother had I spent more time with project partners to discuss the best way to gain informed consent in each context. For example, in Scotland I had not considered how the amount of paperwork that accompanied gaining consent would work with a group who had a range of English language and literacy capabilities, or the connotations of paperwork among people subject to the asylum system (see Chapter 7.4). In Malawi, while I did take care to get consent from both the local authority and individual participants (Chapter 3.9), I imposed my own westernised view of best practice by seeking written consent rather than exploring traditional oral ways of gaining informed consent (see Chapter 7.4). In both cases, I contributed to the colonial and biomedical structures that I was seeking to challenge. I view this as one of the key learning points of this research, and going forward I will seek more guidance on, and argue for, culturally appropriate ethics procedures.

A second ethical dilemma was how to navigate health disclosures and the potential spread of health misinformation. Participants were informed verbally and on written study information sheets that they did not need to disclose any personal health issues as part of the research, but that, if they did so, we would listen empathetically and supportively. In practice, many participants did choose to share personal and sensitive experiences in the workshops (see Chapters 6.3.1 and 7.2). In both Scotland and Malawi, we tried to respond sensitively, listening to them and thanking them for sharing, careful not to probe into, or discredit, their experiences. Additionally, at the end of each workshop (and walkalong) we either verbally communicated or provided participants with physical copies of resources describing diabetes and hypertension risk, and signposting participants to speak to health professionals if they had any concerns. However, as discussed

in Chapter 7.3.1, many participants either perceived us as medical professionals, or had expectations that we would share health knowledge as part of the workshops. This was another key learning point, as I had been so focused on centring community perspectives that I had failed to account for the idea that community members would want to learn from us as researchers, forgetting that the co-production of knowledge should be a mutual process. I tried to respond to participant concerns as best I could by returning to each community after data collection to host a dedicated question and answer session on diabetes and hypertension (Chapter 7.3.1) where participants could clarify their misunderstandings. I have since embedded the importance of clarifying health information into my recommendations for using and adapting the TABPA framework. I have also integrated this into my dissemination activities in each context.

Finally, a fundamental ethical question is how to navigate the ‘take and give’ in research, particularly in participatory paradigms which emphasise benefits for all parties. While the research was complex, demanded a significant time investment from each community and was often messy, I believe it held value for many of those who took part. Not only did participants receive payment for their involvement, but many formed friendships with one another (see Chapter 6.3.1), and said they learned something and wanted to share their knowledge with others. In many cases it also appeared that participants simply had fun. Additionally, community members in both countries expressed an interest in participating in future workshops and exploring other health issues. Therefore, while I cannot claim that this research is going to have a direct impact on the health of either community, I argue it is a step in the right direction to more equitable research practices and intervention design.

## **Going Forward**

The research was not an easy journey. The labour involved in transcultural and participatory research was not just time-intensive, but often emotional and uncomfortable. Nonetheless, the knowledge and skills that I have gained have only furthered my commitment to authentic community engagement and I hope to continue learning as I move through my academic career. The next stage of this research will involve implementing the TABPA framework again, with focus

on its capabilities as means to generate specific culturally-situated findings on noncommunicable diseases rather than focusing on the method itself. In the meantime, I will work to maintain the trust and relationships I have built with community members and project partners. Finally, I will share the findings of this thesis as two publications, co-authored with project partners. The first will centre the process of methodological development, the second will focus on community perspectives on diabetes and hypertension. In doing so, I hope to contribute to a growing discourse on more equitable health research practices and inform culturally-situated strategies towards the prevention of noncommunicable diseases.

## List of References

- Abdi, A. A. (2009). Oral societies and colonial experiences: Sub-Saharan Africa and the de-facto power of the written word. Education, decolonization and development, Brill: 39-56.
- Abdulla, S. (2020). The Art of Inclusion: Contradictions Affecting Theatre for Development Interventions in Malawi. Handbook on Promoting Social Justice in Education. R. Papa. Cham, Springer International Publishing: 999-1020.
- Abdulla, S. (2021). Culture, play and health: A folk media approach to HIV and AIDS research in rural Malawi, University of Glasgow.
- Abdulla, S. (2024). "Decolonising research and folk media: a methodology for Exploring narratives of HIV and AIDS in rural Malawi." Arts & Health: 1-17.
- Abo, K. A., A. A. Fred-Jaiyesimi and A. E. A. Jaiyesimi (2008). "Ethnobotanical studies of medicinal plants used in the management of diabetes mellitus in South Western Nigeria." Journal of Ethnopharmacology **115**(1): 67-71.
- Adelman, C. (1993). "Kurt Lewin and the origins of action research." Educational action research **1**(1): 7-24.
- Agyemang, C. and R. Bhopal (2003). "Is the blood pressure of people from African origin adults in the UK higher or lower than that in European origin white people? A review of cross-sectional data." Journal of Human Hypertension **17**(8): 523-534.
- Agyemang, C., R. W. Humphry and R. Bhopal (2012). "Divergence With Age in Blood Pressure in African-Caribbean and White Populations in England: Implications for Screening for Hypertension." American Journal of Hypertension **25**(1): 89-96.
- Agyemang, C., et al. (2018). "Variations in hypertension awareness, treatment, and control among Ghanaian migrants living in Amsterdam, Berlin, London, and nonmigrant Ghanaians living in rural and urban Ghana - the RODAM study." Journal of Hypertension **36**(1).
- Agyemang, C. and B.-J. van den Born (2022). "Cardiovascular health and disease in migrant populations: a call to action." Nature Reviews Cardiology **19**(1): 1-2.
- Agyemang, C. and B. J. van den Born (2019). "Non-communicable diseases in migrants: an expert review." J Travel Med **26**(2).
- Agyemang, C., E. L. van der Linden and L. Bennet (2021). "Type 2 diabetes burden among migrants in Europe: unravelling the causal pathways." Diabetologia **64**(12): 2665-2675.
- Alexander, V. D. and A. E. Bowler (2014). "Art at the crossroads: The arts in society and the sociology of art." Poetics **43**: 1-19.
- Alloh, F., A. Hemingway and A. Turner-Wilson (2019). "Exploring the Experiences of West African Immigrants Living with Type 2 Diabetes in the UK." International journal of environmental research and public health **16**(19): 3516.
- Alloh, F., A. Hemingway and A. Turner-Wilson (2021). "The Role of Finding Out in Type 2 Diabetes Management among West-African Immigrants Living in the UK." Int J Environ Res Public Health **18**(11).

- Alloh, F., A. Hemingway and A. L. Turner-Wilson (2019). "Systematic review of diabetes management among black African immigrants, white and South Asian populations." Journal of Global Health Reports **3**.
- Amberbir, A., et al. (2019). "Systematic review of hypertension and diabetes burden, risk factors, and interventions for prevention and control in Malawi: The NCD BRITE Consortium." Global heart **14**(2): 109-118.
- Amster, E. J. (2022). "The past, present and future of race and colonialism in medicine." Cmaj **194**(20): E708-e710.
- Antabe, R., et al. (2023). "Determinants of HIV-related stigma and discrimination in Malawi: evidence from the demographic and health survey." African Geographical Review **42**(5): 594-606.
- Appiah, R. (2020). "Community-based participatory research in rural African contexts: Ethico-cultural considerations and lessons from Ghana." Public Health Reviews **41**(1): 27.
- Appiah, R. (2021). "Gurus and Griots: Revisiting the research informed consent process in rural African contexts." BMC Med Ethics **22**(1): 98.
- Appiah, R., G. Raviola and B. Weobong (2024). "Balancing Ethics and Culture: A Scoping Review of Ethico-Cultural and Implementation Challenges of the Individual-Based Consent Model in African Research." J Empir Res Hum Res Ethics **19**(3): 143-172.
- Arts Council of England (2018). Equality and diversity within the arts and cultural sector in England: Report. Manchester.
- Asamane, E. A., et al. (2019). "Perceptions and Factors Influencing Eating Behaviours and Physical Function in Community-Dwelling Ethnically Diverse Older Adults: A Longitudinal Qualitative Study." Nutrients **11**(6): 1224.
- Bagcchi, S. (2022). "Malawi takes on cholera outbreak amid cyclone devastation." The Lancet Microbe **3**(7): e480.
- Banda, J., et al. (2023). "Qualitative study of practices and attitudes towards physical activity among prediabetic men and women in urban and rural Malawi." BMJ Open **13**(1): e058261.
- Bécares, L., et al. (2022). "Racism as the fundamental cause of ethnic inequities in COVID-19 vaccine hesitancy: A theoretical framework and empirical exploration using the UK Household Longitudinal Study." SSM - Population Health **19**: 101150.
- Becker, H. S. (1974). "Art As Collective Action." American sociological review **39**(6): 767-776.
- Benavides, J. A., et al. (2021). "The Power of Music to Prevent and Control Emerging Infectious Diseases." Frontiers in Medicine **8**.
- Beune, E. J. A. J., et al. (2010). "Inhibitors and enablers of physical activity in multiethnic hypertensive patients: qualitative study." Journal of Human Hypertension **24**(4): 280-290.
- Bhat, K., et al. (2022). "Identifying and understanding the factors that influence the functioning of integrated healthcare systems in the NHS: a systematic literature review." BMJ Open **12**(4): e049296.
- Biggs, H., et al. (2023). Evaluation of the New Scots Refugee Integration Strategy 2018-2022. Edinburgh

- Bird, J. (2022). Arts-Based Research as a Radical Methodology Within Healthcare. Arts Based Health Care Research: A Multidisciplinary Perspective. K. Hinsliff-Smith, J. McGarry and P. Ali. Cham, Springer International Publishing: 1-14.
- Birkinshaw, A., R. Nel and C. Walsh (2018). "Adherence of patients with type 2 diabetes mellitus with the SEMDSA lifestyle guidelines." Journal of Endocrinology, Metabolism and Diabetes of South Africa **23**(2): 39-45.
- Bissett, M., et al. (2022). "'I see salt everywhere': A qualitative examination of the utility of arts-based participatory workshops to study noncommunicable diseases in Tanzania and Malawi." PLOS Global Public Health **2**(12): e0000927.
- Blumenthal, D. S. (2011). "Is community-based participatory research possible?" Am J Prev Med **40**(3): 386-389.
- Boneh, G. and D. Jaganath (2011). "Performance as a Component of HIV/AIDS Education: Process and Collaboration for Empowerment and Discussion." American Journal of Public Health **101**(3): 455-464.
- Booker, N. A., A. N. Miller and P. Ngure (2016). "Heavy Sexual Content Versus Safer Sex Content: A Content Analysis of the Entertainment Education Drama Shuga." Health Communication **31**(12): 1437-1446.
- Bourdieu, P. (1991). Sociology in question. London, Sage.
- Bourdieu, P. (1996). The rules of art: genesis and structure of the literary field. Cambridge, Polity Press.
- Bourdieu, P. (2017). Habitus. Habitus: A sense of place, Routledge: 59-66.
- Bourdieu, P. and R. Johnson (1993). The field of cultural production: essays on art and literature. Cambridge, Polity Press.
- Boydell, K., et al. (2012). "The Production and Dissemination of Knowledge: A Scoping Review of Arts-Based Health Research." Forum Qualitative Sozialforschung / Forum: Qualitative Social Research **13**(1).
- Boydell, K. M., et al. (2016). "Arts-based health research and academic legitimacy: transcending hegemonic conventions." Qualitative Research **16**(6): 681-700.
- Boyle, A. (2023). "Unprecedented? The NHS crisis in emergency care was entirely predictable." BMJ **380**: p46.
- Bradley, M., et al. (2016). "Patients' motivations and interest in research: characteristics of volunteers for patient-led projects on PatientsLikeMe." Research Involvement and Engagement **2**(1): 33.
- Braun, V. and V. Clarke (2006). "Using thematic analysis in psychology." Qualitative Research in Psychology **3**(2): 77-101.
- Braun, V. and V. Clarke (2021). "Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches." Counselling and psychotherapy research **21**(1): 37-47.
- Braun, V. and V. Clarke (2023). "Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher." International Journal of Transgender Health **24**(1): 1-6.
- Braun, V., et al. (2018). Thematic Analysis. Handbook of Research Methods in Health Social Sciences. P. Liamputtong. Singapore, Springer Singapore: 1-18.

- Brown, K., M. Avis and M. Hubbard (2007). "Health beliefs of African-Caribbean people with type 2 diabetes: a qualitative study." Br J Gen Pract **57**(539): 461-469.
- Brush, B. L., et al. (2020). "Success in Long-Standing Community-Based Participatory Research (CBPR) Partnerships: A Scoping Literature Review." Health Education & Behavior **47**(4): 556-568.
- Bunn, C., et al. (2020). "Arts-based approaches to promoting health in sub-Saharan Africa: a scoping review." BMJ Global Health **5**(5): e001987.
- Byrne, B., et al. (2020). Ethnicity, Race and Inequality in the UK: State of the Nation, Policy press.
- Cammack, D., E. Kanyongolo and T. O'Neil (2009). "'Town chiefs' in Malawi." London: Africa Power and Politics Programme (APPP) of the Overseas Development Institute.
- Carpiano, R. M. (2009). "Come take a walk with me: The "Go-Along" interview as a novel method for studying the implications of place for health and well-being." Health & Place **15**(1): 263-272.
- Chetty, L., N. Govender and P. Reddy (2022). "Traditional Medicine Use among Type 2 Diabetes Patients in KZN." Advances in Public Health **2022**(1): 7334080.
- Chikovore, J., et al. (2014). "Control, struggle, and emergent masculinities: a qualitative study of men's care-seeking determinants for chronic cough and tuberculosis symptoms in Blantyre, Malawi." BMC Public Health **14**(1): 1053.
- Chikumbu, E. F., et al. (2022). "Experiences of multimorbidity in urban and rural Malawi: An interview study of burdens of treatment and lack of treatment." PLOS Global Public Health **2**(3): e0000139.
- Chilanga, E., et al. (2017). Food Insecurity in Informal Settlements in Lilongwe Malawi, Southern African Migration Programme.
- Chilton, G., N. Gerber and V. Scotti (2015). "Towards an aesthetic intersubjective paradigm for arts-based research: An art therapy perspective." UNESCO Observatory Multi-Disciplinary Journal in the Arts **5**(1): 1-27.
- Chilunga, F. P., et al. (2019). "Investigating associations between rural-to-urban migration and cardiometabolic disease in Malawi: a population-level study." International Journal of Epidemiology **48**(6): 1850-1862.
- Chilunga, F. P., et al. (2023). "Associations of psychosocial stress with type 2 diabetes and glycaemic control among Ghanaians: The RODAM study." Diabet Med **40**(1): e15006.
- Chimberengwa, P. T. and M. Naidoo (2019). "A description of community-based participatory research of hypertension awareness, prevention and treatment in a district of Matabeleland South Province, Zimbabwe." Afr J Prim Health Care Fam Med **11**(1): e1-e9.
- Chinyowa, K. C. (2005). Manifestations of play as aesthetic in African Theatre for Development. Unpublished M. Phil. dissertation., Harare University of Zimbabwe, Harare
- Chinyowa, K. C. (2015). "Participation as 'repressive myth': a case study of the Interactive Themba Theatre Organisation in South Africa." Research in Drama Education: The Journal of Applied Theatre and Performance **20**(1): 12-23.

- Chirwa, E. W. and P. M. Mvula (2014). Malawi: Baseline financial literacy and consumer protection household survey. Report for Reserve Bank of Malawi, Lilongwe unpublished.
- Coemans, S. and K. Hannes (2017). "Researchers under the spell of the arts: Two decades of using arts-based methods in community-based inquiry with vulnerable populations." Educational Research Review **22**: 34-49.
- Cole, M., H. Peek and D. Cowen (2019). "UK consumer perceptions of a novel till-receipt 'traffic-light' nutrition system." Health Promotion International **34**(4): 640-647.
- Cooke, B. and U. Kothari (2001). Participation: The new tyranny?, Zed books.
- Cooksley, T., et al. (2023). "NHS crisis: rebuilding the NHS needs urgent action." BMJ **380**: p1.
- Coultas, C. (2022). "Accounting for colonial complicities through Refusals in researching agency across borders." Journal of Social Issues **78**(2): 413-433.
- Crampin, A. C., et al. (2016). "Hypertension and diabetes in Africa: design and implementation of a large population-based study of burden and risk factors in rural and urban Malawi." Emerg Themes Epidemiol **13**: 3.
- Creamer, J., et al. (2016). "Culturally appropriate health education for Type 2 diabetes in ethnic minority groups: an updated Cochrane Review of randomized controlled trials." Diabetic Medicine **33**(2): 169-183.
- Dalmazo, A. L., et al. (2019). "Stress and Food Consumption Relationship in Hypertensive Patients." Arq Bras Cardiol **113**(3): 374-380.
- Daniels, D. (2003). "Learning about community leadership: Fusing methodology and pedagogy to learn about the lives of settlement women." Adult Education Quarterly **53**(3): 189-206.
- Di Cesare, M., et al. (2013). "Inequalities in non-communicable diseases and effective responses." Lancet **381**(9866): 585-597.
- Dinnie, E. and K. L. Holstead (2018). "The influence of public funding on community-based sustainability projects in Scotland." Environmental Innovation and Societal Transitions **29**: 25-33.
- Donaghy, E., et al. (2024). "Primary care transformation in Scotland: a qualitative study of GPs' and multidisciplinary team members' views." Br J Gen Pract **74**(738): e1-e8.
- Durkheim, E. (2016). The Elementary Forms of the Religious Life. Dinslaken, Germany, anboco.
- Eggen, Ø. (2011). "Chiefs and Everyday Governance: Parallel State Organisations in Malawi." Journal of Southern African Studies **37**(2): 313-331.
- Ekoru, K., et al. (2019). "Type 2 diabetes complications and comorbidity in Sub-Saharan Africans." EClinicalMedicine **16**: 30-41.
- Elliott, M. (2024). "Arts-based methods as a critical and decolonising process in global mental health: Reflections on popular discourse, artistic rigour and limitations." Methods in Psychology **10**: 100137.
- Epstein, M. (2009). "12. Transculture: A Broad Way Between Globalism and Multiculturalism." The American Journal of Economics and Sociology **68**(1): 327-351.

- Erel, U., T. Reynolds and E. Kaptani (2017). "Participatory theatre for transformative social research." Qualitative Research 17(3): 302-312.
- Escoffery, C., et al. (2018). "A systematic review of adaptations of evidence-based public health interventions globally." Implementation Science 13: 1-21.
- Fals-Borda, O. (1987). "The Application of Participatory Action-Research in Latin America." International Sociology 2(4): 329-347.
- Ferguson, L. D., et al. (2018). "Men across a range of ethnicities have a higher prevalence of diabetes: findings from a cross-sectional study of 500 000 UK Biobank participants." Diabetic Medicine 35(2): 270-276.
- Field, J. and A. Johar (2021). Perspectives on "Giving Back": A Conversation Between Researcher and Refugee. The Companion to Peace and Conflict Fieldwork. R. Mac Ginty, R. Brett and B. Vogel. Cham, Springer International Publishing: 471-484.
- Finlay, J. M. and J. A. Bowman (2017). "Geographies on the Move: A Practical and Theoretical Approach to the Mobile Interview." The Professional Geographer 69(2): 263-274.
- Flint, A., M. Günsche and M. Burns (2023). "We Are Still Here: Living with HIV in the UK." Medical Anthropology 42(1): 35-47.
- Freire, P. (1972). Pedagogy of the oppressed. Harmondsworth, Penguin.
- Frerichs, L., et al. (2017). "Stakeholder Perspectives on Creating and Maintaining Trust in Community-Academic Research Partnerships." Health Educ Behav 44(1): 182-191.
- Fuchs, F. D. and P. K. Whelton (2020). "High Blood Pressure and Cardiovascular Disease." Hypertension 75(2): 285-292.
- Furman, E., et al. (2019). "'A Space Where People Get It': A Methodological Reflection of Arts-Informed Community-Based Participatory Research With Nonbinary Youth." International Journal of Qualitative Methods 18: 1609406919858530.
- Furman, R., et al. (2006). "Inside a provider's perspective: Using practitioner poetry to explore the treatment of persons with mental illness." The Arts in Psychotherapy 33(4): 331-342.
- Garcia, C. M., et al. (2012). "Conducting Go-Along Interviews to Understand Context and Promote Health." Qualitative Health Research 22(10): 1395-1403.
- Geppert, C., et al. (2014). "Motivations of Patients With Diabetes to Participate in Research." AJOB Empirical Bioethics 5(4): 14-21.
- Gerber, N., et al. (2020). "Arts-based research in the social and health sciences: Pushing for change with an interdisciplinary global arts-based research initiative." Forum Qualitative Sozialforschung/Forum: Qualitative Social Research 21(2): 15.
- Gerber, N. and R. Siegesmund (2022). "Innovations in Arts-Based Research: ABR Provocations From the 16th International Congress of Qualitative Research." International Review of Qualitative Research 15(2): 147-167.
- Gilbert, P. A. and S. Khokhar (2008). "Changing dietary habits of ethnic groups in Europe and implications for health." Nutrition Reviews 66(4): 203-215.
- Giorgi, A., M. Pizzolati and E. Vacchelli (2021). Metodi creativi per la ricerca sociale. Contesto, pratiche e strumenti, il Mulino.

- Goff, L. M. (2019). "Ethnicity and Type 2 diabetes in the UK." Diabetic Medicine **36**(8): 927-938.
- Goff, L. M., et al. (2021). "Development of Healthy Eating and Active Lifestyles for Diabetes, a culturally tailored diabetes self-management education and support programme for Black-British adults: A participatory research approach." Diabetic Medicine **38**(11): e14594.
- Goff, L. M., et al. (2021). "Healthy Eating and Active Lifestyles for Diabetes (HEAL-D), a culturally tailored self-management education and support program for type 2 diabetes in black-British adults: a randomized controlled feasibility trial." BMJ Open Diabetes Research & Care **9**(1): e002438.
- Gouda, H. N., et al. (2019). "Burden of non-communicable diseases in sub-Saharan Africa, 1990-2017: results from the Global Burden of Disease Study 2017." The Lancet Global Health **7**(10): e1375-e1387.
- Government of Malawi (2019). 2018 Malawi Population and Housing Census: Main Report. Zomba.
- Gowshall, M. and S. D. Taylor-Robinson (2018). "The increasing prevalence of non-communicable diseases in low-middle income countries: the view from Malawi." International Journal of General Medicine **11**: 255-264.
- Grant, L., et al. (2011). "Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies." BMC Palliative Care **10**(1): 8.
- Greenaway, C., et al. (2020). "COVID-19: Exposing and addressing health disparities among ethnic minorities and migrants." Journal of Travel Medicine **27**(7).
- Grotowski, J., T. K. Wiewiorowski and K. Morris (1967). "Towards the Poor Theatre." Tulane Drama Review **11**(3): 60-65.
- Hackett, R. A. and A. Steptoe (2017). "Type 2 diabetes mellitus and psychological stress – a modifiable risk factor." Nature Reviews Endocrinology **13**(9): 547-560.
- Hawkins, M. M., et al. (2022). "The changing dynamics of community care and support in rural Malawi: The impact on Women's health and wellbeing at end of life." Social Science & Medicine **301**: 114934.
- Hayanga, B., M. Stafford and L. Bécares (2023). "Ethnic inequalities in multiple long-term health conditions in the United Kingdom: a systematic review and narrative synthesis." BMC Public Health **23**(1): 178.
- Head, E. (2009). "The ethics and implications of paying participants in qualitative research." International Journal of Social Research Methodology **12**(4): 335-344.
- Henry Osokpo, O., R. James and B. Riegel (2021). "Maintaining cultural identity: A systematic mixed studies review of cultural influences on the self-care of African immigrants living with non-communicable disease." Journal of Advanced Nursing **77**(9): 3600-3617.
- Higgins, V., J. Nazroo and M. Brown (2019). "Pathways to ethnic differences in obesity: The role of migration, culture and socio-economic position in the UK." SSM - Population Health **7**: 100394.

- Hill, D., et al. (2022). "Stress and eating behaviours in healthy adults: a systematic review and meta-analysis." Health Psychology Review **16**(2): 280-304.
- Hing, M., et al. (2019). "'Blood pressure can kill you tomorrow, but HIV gives you time': illness perceptions and treatment experiences among Malawian individuals living with HIV and hypertension." Health Policy and Planning **34**(Supplement\_2): ii36-ii44.
- Hoening, J. C., et al. (2024). "Changes in UK price disparities between healthy and less healthy foods over 10 years: An updated analysis with insights in the context of inflationary increases in the cost-of-living from 2021." Appetite **197**: 107290.
- Hoffman, R. M., et al. (2021). "High Rates of Uncontrolled Blood Pressure in Malawian Adults Living with HIV and Hypertension." Glob Heart **16**(1): 81.
- Holmwood, J. (2014). Sociology's past and futures: The impact of external structure, policy and financing. The Palgrave handbook of sociology in Britain, Springer: 588-610.
- Horne, F. (2011). "Conquering AIDS through narrative: LONGLIFE positive HIV stories." English Studies in Africa **54**(2): 71-87.
- Huebschmann, A. G., et al. (2019). "Sex differences in the burden of type 2 diabetes and cardiovascular risk across the life course." Diabetologia **62**(10): 1761-1772.
- Hussain, M., et al. (2023). "Colonization and decolonization of global health: which way forward?" Glob Health Action **16**(1): 2186575.
- Ibe-Lamberts, K., et al. (2018). "Dance and Hometown Associations are Promising Strategies to Improve Physical Activity Participation Among US Nigerian Transnational Immigrants." Journal of Racial and Ethnic Health Disparities **5**(2): 253-260.
- Ige-Elegbede, J., et al. (2019). "Barriers and facilitators of physical activity among adults and older adults from Black and Minority Ethnic groups in the UK: A systematic review of qualitative studies." Preventive Medicine Reports **15**: 100952.
- IPC (2023). Malawi: IPC Acute Food Insecurity Analysis JULY 2023 - MARCH 2024
- Isaacs, A., et al. (2022). "'I don't think there's anything I can do which can keep me healthy': how the UK immigration and asylum system shapes the health & wellbeing of refugees and asylum seekers in Scotland." Critical Public Health **32**(3): 422-432.
- Israel, B. A., et al. (1998). "Review of community-based research: assessing partnership approaches to improve public health." Annual review of public health **19**(1): 173-202.
- Issaka, A., Y. Paradies and C. Stevenson (2018). "Modifiable and emerging risk factors for type 2 diabetes in Africa: a systematic review and meta-analysis protocol." Syst Rev **7**(1): 139.
- Jackson, L. (2014). "The Multiple Voices of Belonging: Migrant Identities and Community Practice in South Wales." Environment and Planning A: Economy and Space **46**(7): 1666-1681.

- Jaiswal, J. (2019). "Whose Responsibility Is It to Dismantle Medical Mistrust? Future Directions for Researchers and Health Care Providers." Behavioral Medicine **45**(2): 188-196.
- Jakub, K. E., et al. (2018). "Cultural Beliefs, Perceptions, and Practices of Young Adult Offspring of African Immigrants Regarding Healthy Eating and Activity." Journal of Transcultural Nursing **29**(6): 548-554.
- James, P. B., et al. (2022). "The prevalence of anxiety, depression, and post-traumatic stress disorder among African migrants: A systematic review and meta-analysis." Psychiatry Research **317**: 114899.
- Janes, J. E. (2016). "Democratic encounters? Epistemic privilege, power, and community-based participatory action research." Action Research **14**(1): 72-87.
- Jumbe, S., et al. (2022). "'We do not talk about it': Engaging youth in Malawi to inform adaptation of a mental health literacy intervention." PLOS ONE **17**(3): e0265530.
- Kamlongera, C. (2005). Chapter 28. Theatre for Development in Africa. Media and Global Change: Rethinking Communication for Development C. L. d. C. S. CLACSO. Buenos Aires.
- Kamlongera, C. F. (1986). "An example of syncretic drama from Malawi: Malipenga." Research in African Literatures **17**(2): 197-210.
- Kapoor, I. (2005). "Participatory development, complicity and desire." Third World Quarterly **26**(8): 1203-1220.
- Kearns, A., et al. (2017). "Healthy Migrants in an Unhealthy City? The Effects of Time on the Health of Migrants Living in Deprived Areas of Glasgow." Journal of International Migration and Integration **18**(3): 675-698.
- Keough, S. B. (2024). Negotiating Time in a West African Context. Geography of Time, Place, Movement and Networks, Volume 1: Mapping Time Journey Experiences. S. D. Brunn. Cham, Springer Nature Switzerland: 91-104.
- Kerr, D. (1987). "Unmasking the Spirits: Theatre in Malawi." The Drama Review: TDR **31**(2): 115-125.
- Kerstetter, K. (2012). "Insider, outsider, or somewhere between: The impact of researchers' identities on the community-based research process." Journal of Rural Social Sciences **27**(2): 7.
- Kim, M. H., et al. (2014). "Prevalence of depression and validation of the Beck Depression Inventory-II and the Children's Depression Inventory-Short amongst HIV-positive adolescents in Malawi." J Int AIDS Soc **17**(1): 18965.
- Kindarara, D. M., et al. (2017). "Health-Illness Transition Experiences With Type 2 Diabetes Self-management of Sub-Saharan African Immigrants in the United States." The Diabetes Educator **43**(5): 506-518.
- Klocker, N. (2012). "Doing Participatory Action Research and Doing a PhD: Words of Encouragement for Prospective Students." Journal of Geography in Higher Education **36**(1): 149-163.
- Koekkoek, A., M. Van Ham and R. Kleinhans (2021). "Unraveling university-community engagement: A literature review." Journal of Higher Education Outreach and Engagement **25**(1).
- König, D. and K. Rakow (2017). "The Transcultural Approach Within a Disciplinary Framework: An Introduction." The Journal of Transcultural Studies **7**(2): 89-100.

- Kusenbach, M. (2003). "Street Phenomenology: The Go-Along as Ethnographic Research Tool." Ethnography 4(3): 455-485.
- Lachat, C., et al. (2012). "Eating out of home and its association with dietary intake: a systematic review of the evidence." Obesity Reviews 13(4): 329-346.
- Lane, D., D. G. Beevers and G. Y. Lip (2002). "Ethnic differences in blood pressure and the prevalence of hypertension in England." J Hum Hypertens 16(4): 267-273.
- Leininger, M. (1991). "Becoming Aware of Types of Health Practitioners and Cultural Imposition." Journal of Transcultural Nursing 2(2): 32-39.
- Leininger, M. (2002). "Culture Care Theory: A Major Contribution to Advance Transcultural Nursing Knowledge and Practices." Journal of Transcultural Nursing 13(3): 189-192.
- Lewin, K. (1946). "Action Research and Minority Problems." Journal of social issues 2(4): 34-46.
- Lilford, P. (2020). "Mental health in Malawi." BJPsych Int 17(2): 32-33.
- Limb, M. (2022). "Government's "feeble" food strategy fails to tackle health challenges, say experts." BMJ 377: o1460.
- Liu, J., et al. (2012). "Adapting health promotion interventions to meet the needs of ethnic minority groups: mixed-methods evidence synthesis." Health Technol Assess 16(44): 1-469.
- Lovell, C. C., et al. (2008). "'One Day I Might Find Myself HIV-Positive like Her': Audience Involvement and Identification with Role Models in an Entertainment-Education Radio Drama in Botswana." International Quarterly of Community Health Education 28(3): 181-200.
- Lucero, J., et al. (2016). "Development of a Mixed Methods Investigation of Process and Outcomes of Community-Based Participatory Research." Journal of Mixed Methods Research 12(1): 55-74.
- Lucero, J. E. (2013). Trust as an Ethical Construct in Community Based Participatory Research Partnerships.
- Lucero, J. E., et al. (2020). "Engage for Equity: The Role of Trust and Synergy in Community-Based Participatory Research." Health Education & Behavior 47(3): 372-379.
- Lucero, J. E. and N. Wallerstein (2013). "Trust in community-academic research partnerships: Increasing the consciousness of conflict and trust development." SAGE handbook of conflict communication 2: 537-563.
- Lupafya, P. C., et al. (2016). "Implementation of policies and strategies for control of noncommunicable diseases in Malawi: challenges and opportunities." Health Education & Behavior 43(1\_suppl): 64S-69S.
- Lwanda, J. (2003). "Mother's Songs: Male Appropriation of Women's Music in Malawi and Southern Africa." Journal of African Cultural Studies 16(2): 119-141.
- Mak, H. W., R. Coulter and D. Fancourt (2020). "Patterns of social inequality in arts and cultural participation: Findings from a nationally representative sample of adults living in the United Kingdom of Great Britain and Northern Ireland." Public Health Panor 6(1): 55-68.
- Mak, H. W., R. Coulter and D. Fancourt (2021). "Associations between neighbourhood deprivation and engagement in arts, culture and heritage:

- evidence from two nationally-representative samples." BMC Public Health **21**(1): 1685.
- Manyara, A. M., et al. (2024). "Knowledge, perceptions and practices towards diabetes risk in sub-Saharan Africa: a mixed-methods scoping review." Public Health Nutrition **27**(1): e104.
- Mathers, C. D. and D. Loncar (2006). "Projections of Global Mortality and Burden of Disease from 2002 to 2030." PLOS Medicine **3**(11): e442.
- Mayblin, L. and P. James (2019). "Asylum and refugee support in the UK: civil society filling the gaps?" Journal of Ethnic and Migration Studies **45**(3): 375-394.
- McFadden, P. (2001). Cultural practice as gendered exclusion.
- McFarland, M. R., H. B. Wehbe-Alamah and M. M. Leininger (2018). Leininger's Transcultural nursing: concepts, theories, research, & practice. New York, McGraw-Hill Education.
- McKechnie, V., et al. (2024). "Stigma experiences of adults living with diabetes: Results from a Diabetes UK survey." Diabet Med: e15289.
- McNiff, S. (2018). "Philosophical and practical foundations of artistic inquiry." Handbook of arts-based research: 22-36.
- Merriam, S. B., et al. (2001). "Power and positionality: negotiating insider/outsider status within and across cultures." International Journal of Lifelong Education **20**(5): 405-416.
- Mhango, M. W. and L. S. Niehm (2005). "The second-hand clothing distribution channel." Journal of Fashion Marketing and Management: An International Journal **9**(3): 342-356.
- Milligan, L. (2016). "Insider-outsider-inbetweener? Researcher positioning, participative methods and cross-cultural educational research." Compare: A Journal of Comparative and International Education **46**(2): 235-250.
- Mills, K. T., A. Stefanescu and J. He (2020). "The global epidemiology of hypertension." Nat Rev Nephrol **16**(4): 223-237.
- Minkler, M. (2004). "Ethical Challenges for the "Outside" Researcher in Community-Based Participatory Research." Health Education & Behavior **31**(6): 684-697.
- Miranda, J. J., et al. (2019). "Understanding the rise of cardiometabolic diseases in low- and middle-income countries." Nature Medicine **25**(11): 1667-1679.
- Mlotha, V., et al. (2016). "Glycemic responses to maize flour stiff porridges prepared using local recipes in Malawi." Food Sci Nutr **4**(2): 322-328.
- Modesti, P. A., et al. (2018). Disparities in Hypertension in the Ethnic Minority Groups: Beneficial Aspects of Minority Ethnic Group Cultures. Ethnic Diversities, Hypertension and Global Cardiovascular Risk. P. A. Modesti, F. P. Cappuccio and G. Parati. Cham, Springer International Publishing: 139-153.
- Mohamed, S. F., et al. (2021). "Prevalence of uncontrolled hypertension in people with comorbidities in sub-Saharan Africa: a systematic review and meta-analysis." BMJ Open **11**(12): e045880.
- Moon, K. and D. Blackman (2014). "A Guide to Understanding Social Science Research for Natural Scientists." Conservation Biology **28**(5): 1167-1177.
- Moon, K., et al. (2021). "Five Questions to Understand Epistemology and Its Influence on Integrative Marine Research." Frontiers in Marine Science **8**.

- Moore, A. P., et al. (2022). "Misalignment: understanding the challenge of engaging with self-management advice for people living with diabetes in UK Black African and Caribbean communities." Health Education Journal: 00178969221108563.
- Moore, A. P., et al. (2019). "Designing the Healthy Eating and Active Lifestyles for Diabetes (HEAL-D) self-management and support programme for UK African and Caribbean communities: a culturally tailored, complex intervention underpinned by behaviour change theory." BMC Public Health **19**(1): 1146.
- Moore, S. G., et al. (2023). "Feasibility of a Community Healthy Eating and Cooking Intervention Featuring Traditional African Caribbean Foods from Participant and Staff Perspectives." Nutrients **15**(17): 3758.
- Moralli, M. (2023). "Research as care: Positionality and reflexivity in qualitative migration research." Qualitative Research: 14687941231176946.
- Morin, S. F., et al. (2003). "Community consultation in HIV prevention research: a study of community advisory boards at 6 research sites." JAIDS Journal of Acquired Immune Deficiency Syndromes **33**(4): 513-520.
- Moss, H. and D. O'Neill (2019). "Narratives of health and illness: Arts-based research capturing the lived experience of dementia." Dementia **18**(6): 2008-2017.
- Movsisyan, A., et al. (2021). "Adapting evidence-informed population health interventions for new contexts: a scoping review of current practice." Health research policy and systems **19**: 1-19.
- Mphwanthe, G., et al. (2021). "Perceived barriers and facilitators to diet and physical activity among adults diagnosed with type 2 diabetes in Malawi." Global Public Health **16**(3): 469-484.
- Mpofu, V. (2016). Time. African Indigenous Knowledge and the Sciences: Journeys into the Past and Present. G. Emeagwali and E. Shizha. Rotterdam, SensePublishers: 65-78.
- Msyamboza, K. P., et al. (2012). "The burden of hypertension and its risk factors in Malawi: nationwide population-based STEPS survey." International Health **4**(4): 246-252.
- Msyamboza, K. P., C. J. Mvula and D. Kathyola (2014). "Prevalence and correlates of diabetes mellitus in Malawi: population-based national NCD STEPS survey." BMC Endocrine Disorders **14**(1): 41.
- Msyamboza, K. P., et al. (2011). "The Burden of Selected Chronic Non-Communicable Diseases and Their Risk Factors in Malawi: Nationwide STEPS Survey." PLOS ONE **6**(5): e20316.
- Muhammad, M., et al. (2014). "Reflections on Researcher Identity and Power: The Impact of Positionality on Community Based Participatory Research (CBPR) Processes and Outcomes." Critical Sociology **41**(7-8): 1045-1063.
- Munyogwa, M. J., et al. (2020). "Clinical characteristics and health care received among patients with type 2 diabetes attending secondary and tertiary healthcare facilities in Mwanza Region, Tanzania: a cross-sectional study." BMC Health Services Research **20**(1): 527.
- Myers, R. A. (1993). "Review of Curing Their Ills: Colonial Power and African Illness, by M. Vaughan." African Studies Review **36**(2): 147-149.

- Myroniuk, T. W. and C. F. Payne (2019). "The Longitudinal Dynamics of Household Composition and Wealth in Rural Malawi." Journal of Comparative Family Studies **50**(3): 242-260.
- National Records of Scotland (2024). Glasgow City Council Area Profile.
- NCDI Poverty Commission (2018). The Malawi Noncommunicable Disease and Injuries Poverty Commission Report.
- Ndambo, M. K., A. L. Nyondo-Mipando and C. Thakwalakwa (2022). "Eating behaviors, attitudes, and beliefs that contribute to overweight and obesity among women in Lilongwe City, Malawi: a qualitative study." BMC Women's Health **22**(1): 216.
- Netto, G. (2008). "Multiculturalism in the Devolved Context: Minority Ethnic Negotiation of Identity through Engagement in the Arts in Scotland." Sociology **42**(1): 47-64.
- Newman, S. D., et al. (2011). "Community advisory boards in community-based participatory research: a synthesis of best processes." Prev Chronic Dis **8**(3): A70.
- NHS England (2023). Health Survey for England, 2021 part 2. England.
- Nicolucci, A., et al. (2013). "Diabetes Attitudes, Wishes and Needs second study (DAWN2™): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes." Diabet Med **30**(7): 767-777.
- Nkoka, O., et al. (2024). "Association between physical multimorbidity and common mental health disorders in rural and urban Malawian settings: Preliminary findings from Healthy Lives Malawi long-term conditions survey." PLOS Global Public Health **4**(4): e0002955.
- Nnajiolor, O. G. (2016). "Justification of the concept of time in Africa." OGIRISI: A new journal of African studies **12**: 253-281.
- Ntanda, G. M., et al. (2024). "Factors Influencing the Acceptance or Rejection of Dietary and Body Norm Systems Favorable to the Prevention and Control of Type 2 Diabetes Among Sub-Saharan Africa migrants: A Scoping Review." Journal of Racial and Ethnic Health Disparities.
- Nthala, G. M. M. (2009). The Chewa art of drumming and its influence on modern Malawian music, University of the Free State.
- Nyamnjoh, F. B. and J. Fokwang (2005). "Entertaining repression: Music and politics in postcolonial Cameroon." African Affairs **104**(415): 251-274.
- Nyangulu, W., et al. (2019). "Compensation of subjects for participation in biomedical research in resource - limited settings: a discussion of practices in Malawi." BMC Med Ethics **20**(1): 82.
- Nyirenda, M. J. (2016). "Non-communicable diseases in sub-Saharan Africa: understanding the drivers of the epidemic to inform intervention strategies." International Health **8**(3): 157-158.
- O'Neill, M. (2018). "Walking, well-being and community: racialized mothers building cultural citizenship using participatory arts and participatory action research." Ethnic and Racial Studies **41**(1): 73-97.
- Ochieng, B. M. (2011). "Factors influencing the diet patterns and uptake of physical activity among Black families." International Journal of Health Promotion and Education **49**(4): 140-145.

- Ochieng, B. M. N. (2013). "Black families' perceptions of barriers to the practice of a healthy lifestyle: a qualitative study in the UK." Critical Public Health **23**(1): 6-16.
- Ogunrinu, T., et al. (2017). "A qualitative study of health education experiences and self-management practices among patients with type 2 diabetes at Malamulo Adventist Hospital in Thyolo District, Malawi." Malawi Med J **29**(2): 118-123.
- Ojo-Aromokudu, O., et al. (2023). "Views and experiences of primary care among Black communities in the United Kingdom: a qualitative systematic review." Ethnicity & Health **28**(7): 1006-1025.
- Ong, K. L., et al. (2023). "Global, regional, and national burden of diabetes from 1990 to 2021, with projections of prevalence to 2050: a systematic analysis for the Global Burden of Disease Study 2021." The Lancet **402**(10397): 203-234.
- Ong, W. J. (1982). Orality and Literacy : The Technologizing of the Word. Florence, US, Taylor & Francis Group.
- Ortiz, K., et al. (2020). "Partnerships, Processes, and Outcomes: A Health Equity-Focused Scoping Meta-Review of Community-Engaged Scholarship." Annu Rev Public Health **41**: 177-199.
- Osei-Kwasi, H., et al. (2023). "Transitioning food environments and diets of African migrants: implications for non-communicable diseases." Proceedings of the Nutrition Society **82**(1): 69-79.
- Osei-Kwasi, H. A., et al. (2017). "The influence of migration on dietary practices of Ghanaians living in the United Kingdom: a qualitative study." Annals of Human Biology **44**(5): 454-463.
- Otu, A., et al. (2020). "One country, two crises: what Covid-19 reveals about health inequalities among BAME communities in the United Kingdom and the sustainability of its health system?" International Journal for Equity in Health **19**(1): 189.
- Parsons, T. (1991). The Social System. Oxford, Taylor & Francis Group.
- Pauw, K., I. Verduzco-Gallo and O. Ecker (2018). Poverty, food prices, and dietary choices in Malawi. International Food Policy Research Institute: 41-52.
- Pavli, A. and H. Maltezou (2017). "Health problems of newly arrived migrants and refugees in Europe." Journal of Travel Medicine **24**(4).
- Perry, H. (2022). The Status of NEET in Malawi: A Quantitative Analysis of Youth Not in Employment, Education or Training (NEET) (15 - 24 years old). UN Women. Nairobi, UN Women.
- Phillips, L., M. B. Christensen-Strynø and L. Frølund (2022). "Arts-based co-production in participatory research: harnessing creativity in the tension between process and product." Evidence & Policy **18**(2): 391-411.
- Phiri Kampanje, B. (2022). "Considerations for devaluation and depreciation of Malawi Kwacha against major trading currencies in National Development Agendas-Litmus Test for Malawi Vision 2063."
- Piacentini, T. (2015). "Missing from the picture? Migrant and Refugee Community Organizations' responses to poverty and destitution in Glasgow." Community Development Journal **50**(3): 433-447.

- Piggin, J. (2012). "Turning health research into health promotion: A study of causality and 'critical insights' in a United Kingdom health campaign." Health Policy **107**(2): 296-303.
- Powell, R. A., et al. (2022). "Tackling racism in UK health research." BMJ **376**: e065574.
- Price, A. J., et al. (2018). "Prevalence of obesity, hypertension, and diabetes, and cascade of care in sub-Saharan Africa: a cross-sectional, population-based study in rural and urban Malawi." The Lancet Diabetes and Endocrinology **6**(3): 208-222.
- Public Health England (2020). Major new campaign encourages millions to lose weight and cut COVID-19 risk.
- Public Health Scotland (2022). General Practice Workforce Survey 2022.
- Qureshi, A., M. Morris and L. Mort (2020). Access denied: The human impact of the hostile environment. Insitute for Public Policy Research. London.
- Ramachandran, N. (2021). The self and the system: Social protection experiences of asylum seekers and refugees living in Glasgow, Edge Hill University.
- Ramachandran, N. and Z. Vathi (2022). "Agency in waiting? Everyday tactics of asylum seekers and refugees in Glasgow." European Journal of Social Work **25**(6): 1104-1116.
- Renwick, C. (2016). "Biology, social science and history: interdisciplinarity in three directions." Palgrave Communications **2**(1): 16001.
- Reverby, S. M. (2012). "Ethical Failures and History Lessons: The U.S. Public Health Service Research Studies in Tuskegee and Guatemala." Public Health Reviews **34**(1): 13.
- Riley, L. and B. Dodson (2016). "'Gender hates men': untangling gender and development discourses in food security fieldwork in urban Malawi." Gender, Place & Culture **23**(7): 1047-1060.
- Riley, L. and B. Dodson (2016). "Intersectional identities: Food, space and gender in urban Malawi." Agenda **30**(4): 53-61.
- Risi, L., et al. (2004). "Media interventions to increase cervical screening uptake in South Africa: an evaluation study of effectiveness." Health Educ Res **19**(4): 457-468.
- Roscoe, A. (2007). The Columbia Guide to Central African Literature in English Since 1945. New York Chichester, West Sussex, Columbia University Press.
- Ryan, J., et al. (2019). "It's not raining men: a mixed-methods study investigating methods of improving male recruitment to health behaviour research." BMC Public Health **19**(1): 814.
- Ryan, R. M. and E. L. Deci (2000). "Self-Determination Theory and the Facilitation of Intrinsic Motivation, Social Development, and Well-Being." The American psychologist **55**(1): 68-78.
- Scarborough, P., et al. (2015). "Reds are more important than greens: how UK supermarket shoppers use the different information on a traffic light nutrition label in a choice experiment." International Journal of Behavioral Nutrition and Physical Activity **12**(1): 151.

- Scharff, D. P., et al. (2010). "More than Tuskegee: understanding mistrust about research participation." Journal of health care for the poor and underserved **21**(3): 879-897.
- Scholte, J. A. (2014). "Transculturalist path to democratic global cooperation." Global Dialogues (4): 43-36.
- Scotland's Census (2023). Ethnicity. Edinburgh, National Records of Scotland.
- Scottish Government (2023). The Scottish Health Survey 2022-volume 1: main report. Edinburgh.
- Semu, L. (2002). "Kamuzu's Mbumba: Malawi Women's Embeddedness to Culture in the Face of International Political Pressure and Internal Legal Change." Africa today **49**(2): 77-99.
- Sikweyiya, Y. and R. Jewkes (2013). "Potential Motivations For and Perceived Risks In Research Participation: Ethics in Health Research." Qualitative Health Research **23**(7): 999-1009.
- Smith, C., J. T. Viljoen and L. McGeachie (2014). "African drumming: a holistic approach to reducing stress and improving health?" Journal of Cardiovascular Medicine **15**(6).
- Smith, L. T. (2021). Decolonizing methodologies: research and indigenous peoples. London [England], Zed Books.
- Soong, H., et al. (2021). "Reimagining transcultural identity: a case study of field experiences for international preservice teachers." Teaching Education **32**(4): 420-436.
- Southby, K. (2017). "Reflecting on (the challenge of) conducting participatory research as a research-degree student." Research for All.
- Speight, J., et al. (2024). "Bringing an end to diabetes stigma and discrimination: an international consensus statement on evidence and recommendations." The Lancet Diabetes & Endocrinology **12**(1): 61-82.
- Spivak, G. C. (2005). "Scattered speculations on the subaltern and the popular." Postcolonial Studies **8**(4): 475-486.
- Sport England (2024). Cost of living and its impact on sport and physical activity. Sport England.
- Stanifer, J. W., et al. (2016). "Prevalence, Risk Factors, and Complications of Diabetes in the Kilimanjaro Region: A Population-Based Study from Tanzania." PLOS ONE **11**(10): e0164428.
- Stuckey, H. L. and E. J. Tisdell (2009). "The Role of Creative Expression in Diabetes: An Exploration Into the Meaning-Making Process." Qualitative Health Research **20**(1): 42-56.
- Talbot, C. V. and D. Branley-Bell (2021). "#BetterHealth: A qualitative analysis of reactions to the UK government's better health campaign." Journal of Health Psychology **27**(5): 1252-1258.
- Tanner, J. (2003). Sociology of Art: A Reader. Oxford, UK, Taylor & Francis Group.
- Thakwalakwa, C., et al. (2020). "Drivers of food consumption among overweight mother-child dyads in Malawi." PLOS ONE **15**(12): e0243721.
- The Scottish Government (2020). The Scottish Health Survey: 2019 edition-volume 1- main report.

- The World Bank. (2022). "The World Bank in Malawi: An Overview." Retrieved 05/09/24, from <https://www.worldbank.org/en/country/malawi/overview>.
- Thompson, R. G. A., J. J. Nutor and J. K. Johnson (2021). "Communicating Awareness About COVID-19 Through Songs: An Example From Ghana." Frontiers in Public Health **8**.
- Thorpe, J. and T. Gore (2019). A beginner's guide to devising theatre. London, Bloomsbury Methuen Drama.
- Tiessen, R. (2008). "Small Victories But Slow Progress." International Feminist Journal of Politics **10**(2): 198-215.
- Tillin, T., et al. (2013). "Insulin Resistance and Truncal Obesity as Important Determinants of the Greater Incidence of Diabetes in Indian Asians and African Caribbeans Compared With Europeans: The Southall And Brent REvisited (SABRE) cohort." Diabetes Care **36**(2): 383-393.
- Tiwale, S. (2019). "Materiality matters: Revealing how inequities are conceived and sustained in the networked water infrastructure - The case of Lilongwe, Malawi." Geoforum **107**: 168-178.
- Tribe, R. (2002). "Mental health of refugees and asylum-seekers." Advances in psychiatric treatment **8**(4): 240-247.
- Tuck, E. and K. Yang (2014). "R-words: Refusing research. Humanizing research: Decolonizing qualitative inquiry with youth and communities, 223-248." Undergraduate Review **14**(1): 155-165.
- UNDP (2023). Policy Brief Summary on the impact of the Russia Ukraine conflict on Malawi's economy, United Nations.
- Van der Vaart, G., B. van Hoven and P. P. Huigen (2018). Creative and arts-based research methods in academic research. Lessons from a participatory research project in the Netherlands. Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, Freie Universität Berlin.
- van Maanen, H. (2009). Pierre Bourdieu's Grand Theory of the Artistic Field. How to Study Art Worlds, Amsterdam University Press: 53-82.
- Vaughan, M. (1991). Curing their ills: colonial power and African illness, Stanford University Press.
- Vaughan, M., et al. (2018). "Dietary change, noncommunicable disease and local knowledge: results of a small-scale study of the views of older Malawians." Wellcome Open Res **3**: 158.
- Velzeboer, L., M. Hordijk and K. Schwartz (2018). "Water is life in a life without water: Power and everyday water practices in Lilongwe, Malawi." Habitat International **73**: 119-128.
- Waite, L. and J. Cook (2011). "Belonging among diasporic African communities in the UK: Plurilocal homes and simultaneity of place attachments." Emotion, Space and Society **4**(4): 238-248.
- Wallerstein, N. and B. Duran (2008). The Theoretical, Historical and Practice Roots of CBPR. Community-Based Participatory Research for Health : From Process to Outcomes. M. Minkler and N. Wallerstein. Hoboken, US, John Wiley & Sons, Inc: 25-46.

- Wallerstein, N. and B. Duran (2010). "Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity." Am J Public Health **100 Suppl 1**(Suppl 1): S40-46.
- Wallerstein, N., et al. (2017). Community-based participatory research for health: Advancing social and health equity, John Wiley & Sons.
- Wallerstein, N., et al. (2008). What Predicts Outcomes in CBPR? Community-Based Participatory Research for Health. From Process to Outcomes. M. Minkler and N. Wallerstein. San Francisco, Jossey-Bass: 371-392.
- Wallerstein, N., et al. (2020). "Engage for Equity: A Long-Term Study of Community-Based Participatory Research and Community-Engaged Research Practices and Outcomes." Health Education & Behavior **47**(3): 380-390.
- Wallerstein, N. B. and B. Duran (2006). "Using Community-Based Participatory Research to Address Health Disparities." Health Promotion Practice **7**(3): 312-323.
- Walsh, D., et al. (2019). "Increasingly Diverse: the Changing Ethnic Profiles of Scotland and Glasgow and the Implications for Population Health." Applied Spatial Analysis and Policy **12**(4): 983-1009.
- Walsh, D., et al. (2017). "History, politics and vulnerability: explaining excess mortality in Scotland and Glasgow." Public Health **151**: 1-12.
- Walter, F. M. and J. Emery (2006). "Perceptions of family history across common diseases: a qualitative study in primary care." Family Practice **23**(4): 472-480.
- Watson, D., et al. (2023). "Men's motivations, barriers to and aspirations for their families' health in the first 1000 days in sub-Saharan Africa: a secondary qualitative analysis." BMJ Nutr Prev Health **6**(1): 39-45.
- West-Olatunji, C., et al. (2017). "Highlighting the Challenges When Conducting Cross-National Studies: Use of Transcultural Theory." Journal of Counseling & Development **95**(4): 457-464.
- Whicher, C. A., S. O'Neill and R. I. G. Holt (2020). "Diabetes in the UK: 2019." Diabetic Medicine **37**(2): 242-247.
- White, S. A., et al. (2017). Regional Supply Chains and the Food Economy of Malawi: Expanding Livelihood Opportunities and Enhancing Food Security, Michigan State University and Lilongwe University of Agriculture and Natural Resources.
- Whyte, B., M. Young and K. Timpson (2021). Health in a changing city: Glasgow 2021. A study of changes in health, demographic, socioeconomic and environmental factors in Glasgow over the last 20 years. GCPH. Glasgow,.
- Wieland, M. L., et al. (2012). "Physical Activity and Nutrition among Immigrant and Refugee Women: A Community-Based Participatory Research Approach." Women's Health Issues **22**(2): e225-e232.
- Winschiers-Theophilus, H., T. Zaman and C. Stanley (2019). "A classification of cultural engagements in community technology design: introducing a transcultural approach." AI & SOCIETY **34**(3): 419-435.
- Wise, J. (2023). "Cholera: Malawi is in grip of its deadliest outbreak." BMJ **380**: p328.
- Wood, N. and L. Waite (2011). "Editorial: Scales of belonging." Emotion, Space and Society **4**(4): 201-202.

- Wood, R., et al. (2015). "Quality of care for patients with non-communicable diseases in the Dedza District, Malawi." 2015 **7**(1).
- World Health Organization. (2022). "Noncommunicable diseases progress monitor 2022." Retrieved 26/09/2024, from <https://www.who.int/publications/i/item/9789240047761>.
- World Health Organization. (2023). "Hypertension." Retrieved 3rd May, 2023, from <https://www.who.int/news-room/fact-sheets/detail/hypertension>.
- Wray, K., et al. (2020). "Aligning Intentions with Community: Graduate Students Reflect on Collaborative Methodologies with Indigenous Research Partners." Sustainability **12**(18): 7534.
- Wyse, D., et al. (2012). "Place-related identity, texts, and transcultural meanings." British Educational Research Journal **38**(6): 1019-1039.
- Yiga, P., et al. (2020). "Determinants of dietary and physical activity behaviours among women of reproductive age in urban sub-Saharan Africa: a systematic review." British Journal of Nutrition **124**(8): 761-772.
- Zhang, H., et al. (2017). "White blood cell subtypes and risk of type 2 diabetes." Journal of Diabetes and its Complications **31**(1): 31-37.
- Zhou, B., et al. (2021). "Worldwide trends in hypertension prevalence and progress in treatment and control from 1990 to 2019: a pooled analysis of 1201 population-representative studies with 104 million participants." The Lancet **398**(10304): 957-980.
- Zhou, B., et al. (2021). "Global epidemiology, health burden and effective interventions for elevated blood pressure and hypertension." Nature Reviews Cardiology **18**(11): 785-802.
- Zimmermann, M., et al. (2018). "Experiences of type 2 diabetes in sub-Saharan Africa: a scoping review." Global Health Research and Policy **3**(1): 25.

## Appendices

### Appendix 1: TABPA Refined Workshop Protocol

#### Transcultural Arts-Based Participatory Approach Refined Protocol

Focus: Diabetes OR Hypertension

~3-hour workshop

3 Facilitator Roles:

Facilitator 1 Lead: Overall lead and point of contact, facilitating activities, questions, prompts, follow ups, (audio-recording, and notetaking in group work)

Facilitator 2: Support, timekeeping, (audio-recording and notetaking during group work)

Facilitator 3: Consent forms, audio-recording, latecomer support, photos/videos, dispensing travel money, small practical challenges that emerge

Additional Considerations: everyone should receive transport money on the day. Drinks and snacks will be provided for the break.

Notes on facilitation: positive, supportive environment, avoid triggering questions, remind participants about the agreements where necessary.

### PART 1: 30 minutes

#### Welcome

Duration: 15 mins

- *All: Introduce ourselves to participants as they come in.*
- 1. *F1: Introduce self as participants arrive, tell people to take a seat,*
- 2. *F2 and F3 will go around each participant doing the following:*
- 3. *F2: Ask participant for their name, confirm contact details. Explain that photographs and videos will be taken during the workshop, but these will not be shared unless they provide permission which we will ask for later. Ask if they are comfortable with having their photo taken for the purposes of data analysis.*

#### **When most participants have arrived/ after 5/10 minutes**

- *Facilitator 1: explain the workshop and what it will involve. **Read through Participant Information Sheet.** All participants will have received a copy*
- *F1: Explain what the Consent forms and Privacy notices are-we're going to do this together; participants should tick and sign as we go along.*
- *F3: Hand the participant a consent form and a privacy notice and a pen.*
- *F3: will collect the forms when completed- make a note next to each participant's name when we have them. Check no boxes have been missed.*

- F3: if any late comers arrive, run through the consent and privacy forms with them.
- F2: be available to make sure people are completing the forms.

### **Activity 1: Getting to know each other through a Game**

Duration: 15 minutes

This activity is a game, designed to help participants to get to know one another, open up and think creatively.

*Facilitator 1 ask:*

- Do you know of any games that we could play or songs that we could sing to get to know one another? For example. a song where we sing our names and a personal fact, or a dance circle.
- If someone has a suggestion- ask community member to explain to the rules to everyone.
- If they do not suggest any the F1 will introduce one. For example., counting game warm up.

*Facilitator 1 should then remind participants of the following to help build a positive atmosphere:*

There are no right or wrong answers and we're all learning and playing together, so any art forms we create don't need to be highly skilled or polished.

- You do not have to tell anyone if you have the condition we are discussing. If you would like to, as a group we will try to be supportive and empathetic to your experience.
- We would encourage everyone to have an open mind and will work together to share our experiences and perceptions in a positive way.
- If anyone feels uncomfortable at any time either due to the topics or something someone has said, you can speak to any of the researcher's privately and we will listen and support you however we can.
- Does anyone have any questions or would like to add anything that might help us create a supportive atmosphere?

## **PART 2: 1 hour 15 minutes**

### **Activity 2: Visualisation Task**

Duration: 15 minutes

This activity is a short visualisation task where participants will be asked to put their initial perspectives on the noncommunicable disease (Diabetes OR Hypertension) down on paper, either through drawing or writing. They can communicate whatever they might like e.g. causes, symptoms, treatment, feelings.

*Facilitator 2: Hand everyone a piece of A4 paper and a pen*

*Facilitator 3: Act as a float and support any latecomers with consent procedure*

## Part 1 (5 minutes):

*Facilitator 1:*

- Everybody close your eyes. I'm going to say a word. I want you to think about what comes to mind. The word is diabetes OR hypertension. What comes to your mind? Is it a picture? Is it a feeling? Is it a colour? Is it a thing? Are there any details, is it well defined, is it more blurry? How would you put that on paper? How can you put that feeling or that image on to a piece of paper.
- There is absolutely no wrong answer, anything you do here is correct. Trust your instincts. What comes to mind when you hear the word...? Open your eyes.
- Can you put that on the paper, there is no right or wrong way to do this. On the paper, put down the thing that comes into your mind when you think of diabetes OR hypertension? *[participants can draw or write this, give 2 minutes max]*

## Part 2 (10 minutes):

- Now we are going to go round and describe what we have put on the paper and why.  
*Ask other participants just to observe and listen here but not to respond.*

## Group Reflection

- Does anyone have any responses to what people have shared?
- Do you have any comments or questions? Would anyone like to expand?

**[BREAK] 10 mins****Activity 3: Causes of Noncommunicable Disease and Possible Solutions**

Duration: 1 hour

This activity aims to get participants thinking about the causes of and solutions to the causes of hypertension and beginning to work together. They can use any art form they want to explore this and create something to share back.

## Facilitator 1:

- Now we'll get into two groups. In a minute I'm going to give you a number 1 or 2. All the 1's will get together and go with F2. All the 2's come will come with me. Together, think about **the noncommunicable disease (Diabetes and Hypertension)**. What do you think are the causes? This could be very obvious or more complicated. Can you work together to explore this using art? Then consider how we might respond to the some of these issues or causes. How could you prevent that behaviour and minimise the risk? What information is missing from your story that you might want to add to **give a fuller picture about what might lead to these diseases and how they might be prevented.**

- **This is a place to play and try out different resources to consider the risk factors and causes- after 20 mins we can share what we talked about. Have fun and don't worry about how professional or polished it is.**
- You can draw, sing, write a poem, create a drama, dance. We have lots of different resources including paper, pens, pencils, crayons, paints, and tape. We also have music and can help if you want to make any props if you wanted to do a drama.

**The facilitators (1 and 2) will help you develop your ideas, they will ask about;**

- What wider circumstances could impact the cause you have chosen?
  - Who do you think is likely to get the disease? Why?
  - Do you know anybody who has the disease? How did it impact them? Did it impact anyone else?
  - What might stop someone performing that behaviour? What wouldn't work?
  - Who would need to be involved to prevent the behaviour or event? Would this be the individual, family, community?
- *Facilitator 1 and 2: Each will sit with one group asking questions, prompting participants to think deeply about the causes and helping where they can. Each will have a phone to audio record the conversations and will be taking notes.*

*Facilitator 3: will be going between both groups taking photographs and videos if appropriate and supporting any practical needs.*

## **PART 3: 45 minutes**

### ***Activity 4: Performance***

Duration: 40 minutes

Sharing Back: The two groups will share their final performance. They have 5-10 minutes each.

After each performance there will be 10 minutes for the facilitator to :

- Probe into the presentation and prompt participant's further on their choices- why did they choose to include this and not that? Why did this person make that decision?
- *Example prompts: Ask people why they think what they do? Where did they learn that X causes diabetes? What things might lead to certain behaviours or perspectives? Why did you choose that art form? Why did you choose to say X or*
- *Why did you choose that beat? If a drawing- was there a reason you chose those colours? What colour could you make that piece? Was there a reason you moved this way rather than that?*

- *If a drama-How did the group choose the character with diabetes? How old is the character? Why did you choose to make the character a man/woman/child?).*
- *Ask the rest of the group: What did you think of their presentation? What stood out for you? Do you agree or disagree with any of the information? Did you learn anything new, or would you like more explanation?*
- *How did you find creating the performance as a group? What did you like/dislike?*

### ***Activity 5: Final Discussion/Reflection***

Duration: 10 minutes

Facilitator 1 and Facilitator 2:

- Is there anything else you wanted to talk about but didn't?
- Is there anything else about diabetes and health more generally you wanted to discuss?
- How did you find the workshop overall, was there any part you liked or didn't like? Why?
- Is there anything that you would do differently? Is there anything you would like to do again?
- Is there anything we should do differently next time?

## **Finish**

**Thank everyone for their time, remind them that they have my contact details if they have any questions. Provide resources on the NCD, travel reimbursement and compensation if appropriate.**

## Appendix 2: Ethics Approvals



College of Social  
Sciences

### Appendix 2A: Phase 1 University of Glasgow Approval

08 August 2022

Dear Maria Bissett

#### College of Social Sciences Research Ethics Committee

**Project Title:** Development of a transcultural arts-based participatory approach to exploring the drivers of noncommunicable diseases among Black communities in Scotland and Malawi

**Application No:** 400210264

The College Research Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Start date of ethical approval: 08/08/2022
- Project end date: 01/10/2024
- Any outstanding permissions needed from third parties in order to recruit research participants or to access facilities or venues for research purposes must be obtained in writing and submitted to the CoSS Research Ethics Administrator before research commences: [socsci-ethics@glasgow.ac.uk](mailto:socsci-ethics@glasgow.ac.uk)
- The research should be carried out only on the sites, and/or with the groups and using the methods defined in the application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: ([https://www.gla.ac.uk/media/media\\_490311\\_en.pdf](https://www.gla.ac.uk/media/media_490311_en.pdf))
- Any proposed changes in the protocol should be submitted for reassessment as an amendment to the original application. The **Request for Amendments to an Approved Application** form should be used: <https://www.gla.ac.uk/colleges/socialsciences/students/ethics/forms/staffandpostgraduateresearchstudents/>

Yours sincerely,

Dr Susan A. Batchelor  
College Ethics Lead

## Appendix 2B: Phase 2 and 3 University of Glasgow Approval



College of Social  
Sciences

29 March 2023

Dear Maria Bissett

### College of Social Sciences Research Ethics Committee

**Project Title:** Development of a transcultural arts-based participatory approach to exploring the drivers of noncommunicable diseases among Black communities in Scotland and Malawi

**Application No:** 400220285

The College Research Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Start date of ethical approval: 16/06/2023
- Project end date: 01/10/2024
- Any outstanding permissions needed from third parties in order to recruit research participants or to access facilities or venues for research purposes must be obtained in writing and submitted to the CoSS Research Ethics Administrator before research commences: [socsci-ethics@glasgow.ac.uk](mailto:socsci-ethics@glasgow.ac.uk)
- The research should be carried out only on the sites, and/or with the groups and using the methods defined in the application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: ([https://www.gla.ac.uk/media/media\\_490311\\_en.pdf](https://www.gla.ac.uk/media/media_490311_en.pdf))
- Any proposed changes in the protocol should be submitted for reassessment as an amendment to the original application. The **Request for Amendments to an Approved Application** form should be used: <https://www.gla.ac.uk/colleges/socialsciences/students/ethics/forms/staffandpostgraduateresearchstudents/>

Yours sincerely,

Dr Susan A. Batchelor  
College Ethics Lead

## Appendix 2C: Phase 3 NCRSH Malawian Ethics



### NATIONAL COMMISSION FOR SCIENCE & TECHNOLOGY

Lingadzi House  
Robert Mugabe Crescent  
P/Bag B303  
City Centre  
Lilongwe

Tel: +265 1

+265 1

+265 1

Fax: +265 1

Email: [directorgeneral@](mailto:directorgeneral@ncst.mw)

Website: [http://www.](http://www.ncst.mw)

### NATIONAL COMMITTEE ON RESEARCH IN THE SOCIAL SCIENCES AND HUMANITIES

Ref No: NCST/RTT/2/6

4<sup>th</sup> August 2023

Ms Maria Bissett,  
University of Glasgow,  
Adam Smith Building,  
Bute Gardens,  
Glasgow, G12 8RT.

Email: [m.bissett.1@research.gla.ac.uk](mailto:m.bissett.1@research.gla.ac.uk)

Dear Ms Bissett,

**RESEARCH ETHICS AND REGULATORY APPROVAL AND PERMIT FOR  
PROTOCOL NO P.06/23/770: DEVELOPMENT OF A TRANSCULTURAL ARTS-  
BASED PARTICIPATORY APPROACH TO EXPLORING THE DRIVERS OF  
NONCOMMUNICABLE DISEASES AMONG BLACK  
COMMUNITIES IN SCOTLAND AND MALAWI**

Having satisfied all the relevant ethical and regulatory requirements, I am pleased to inform you that the above referred research protocol has officially been approved. You are now permitted to proceed with its implementation. Should there be any amendments to the approved protocol in the course of implementing it, you shall be required to seek approval of such amendments before implementation of the same.

This approval is valid for one year from the date of issuance of this approval. If the study goes beyond one year, an annual approval for continuation shall be required to be sought from the National Committee on Research in the Social Sciences and Humanities (NCRSH) in a format that is available at the Secretariat. Once the study is finalised, you are required to furnish the Committee and the Commission with a final report of the study. The committee reserves the right to carry out compliance inspection of this approved protocol at any time as may be deemed by it. As such, you are expected to properly maintain all study documents including consent forms.

Wishing you a successful implementation of your study.

Yours Sincerely,

Yalonda .I. Mwanza  
**NCRSH ADMINISTRATOR**  
**HEALTH, SOCIAL SCIENCES AND HUMANITIES DIVISION**

## Appendix 3: Example Participant Information Sheets

### Appendix 3A

#### Walkalong Participant Information Sheet (*English and Chichewa*)



College of Social  
Sciences

**Project Title:** Development of a transcultural arts-based participatory approach to exploring the drivers of noncommunicable diseases (hypertension/diabetes) among African communities in Scotland and Malawi.

*Kupeza njira zachikhalidwe komanso za luso pofuna kuthandiza kufufuza zomwe zimayambisa matenda osapatsilana (shuga komanso kuthamanga kwa magazi) pakati pa anthu okuda ku sikotilandi koamso ku Malawi.*

#### Participant Information Sheet

**Principle Researcher:** Maria Bissett      **Contact details:** +265  
m.bissett.1@research.gla.ac.uk

**Supervisors:**

- Prof. Cindy Gray [cindy.gray@glasgow.ac.uk](mailto:cindy.gray@glasgow.ac.uk)
- Dr. Chris Bunn [christopher.bunn@glasgow.ac.uk](mailto:christopher.bunn@glasgow.ac.uk)

You are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. Ask the researcher/s if there is anything that is not clear or if you would like more information. Take some time to decide whether or not you wish to take part.

*Mulikuitanidwa kutenga nawo mbali mu kafukufuku, koma musanasankhe kutenga nawo mbali/gawo ndikofunika kuti mumvesese chifukwa chomwe kafukufukuyi akuchitikila komanso zomwe atakhuze. Chonde werengani mfundo zosatilazi mosamala komanso muli oloedwa kukambilana ndi ena ngati mungafune kutelo. Afunzeni ofufuza ngati pali chomwe sichikumveka bwino kapena ngati mukufuna kuziwa dzambili. Pangani chiganizo mofasa ngati mukufuna kutenga nawo gawo mu kafukufukuyi kapena ayi.*

Thank you for reading this.

*Zikomo powelenga*

**1. What is the purpose of the study?**

*1. Kodi cholinga cha kafukufukuyi ndi chani?*

High blood pressure and type 2 diabetes are two diseases that are affecting Black communities in Scotland and in Malawi. Researchers are trying to find new ways to understand how local communities experience these diseases.

*Nthenda za kuthamanga kwa magazi komanso shuga wa mtundu wachiwili ndi zomwe zikukhudza anthu akuda ku maiko a Scotland ndi Malawi. Akatswiri a kafukufuku akuyesera kupeza njira zatsopano zofuna kumvetseka mmene anthu a mdera lino amakhuzidwila ndi matendawa.*

Arts-based participatory methods involve researchers and community members working together and using creative activities (e.g., songs, theatre, dance) to ask about and understand local experiences.

*Potengera zaluso popanga kafukufuku, opanga kafukufuku komanso anthu amu dera amagwilitsa ntchito zaluso (monga nyimbo, zisudzo, kuvina) pofuna kufunsa komanso kumveseka zomwe zimachitika mderalo.*

This project aims to develop an arts-based participatory approach to understand experiences of high blood pressure and diabetes among Black communities in Scotland and in Malawi. It will involve partnerships with local organisations (REACH Community Health project in Glasgow and Art and Global Health Centre Africa in Malawi), artists, local leaders and community members such as yourselves.

*Kafukufukuyi akufuna kupanga njira ya zaluso yothandizira kumvetsetsa zomwe anthu akuda ku Sikotilandi komanso ku Malawi amakumana nazo pokhuzza matenda a shuga ndi kuthamanga magazi. Izi zitheka pogwira ntchito ndi mabungwe opezeka mmaiko awiriwa monga A REACH Community Health project in Glasgow and Art and Global Health Centre Africa in Malawi komanso anthu a zaluso osiyanasiyana, atsogoleri a mmadera komaso anthu awo ngati inu.*

These findings from this research will help to create new ways to prevent diabetes and high blood pressure that communities will want to engage in.

*Zosatila za kafukufukuyi zitithandiza kupeza njira zatsopano zopewela matenda a shuga komanso kuthamanga kwa magazi zimene anthu mmadera ano azigwiritsa ntchito.*

We will be asking community members about their daily lives and running arts-based participatory workshops to understand:

*Tikhala tikufunsa zokhunza moyo wa tsiku ndi tsiku komanso kukhala ndi mkumano pogwilisa zaluso pofuna kumveseka;*

- how community is defined in Area 25, Lilongwe
  - *mmene dela la 25 limadziwikila /mmene anthu amaliziwila*
- the art forms that the community enjoy;
  - *ndi zaluso ziti zomwe anthu a mdela la 25 amasangalala nazo*

- community knowledge about diseases including high blood pressure and diabetes;
  - *zomwe anthu a mdela la 25 amadziwa zokhunza matenda osiyana siyana kuphatikizilapo matenda a shuga komanso othamanga magazi.*
- their experiences of these diseases, and what increases their risk;
  - *zomwe mumadziwa zokhunza matenda omwe atchulidwawa ndizomwe zimaonjezela chiopseyo chotenga matendawa.*
- how to work with local people to develop a way to understand experiences of these diseases.
  - *Tingagwire bwanji ntchito ndi anthu a mdera lino pofuna kupeza njira zomwe zingatithandize kumvesesa zokhunza matendawa.*

## 2. Why have I been chosen?

### 2. *Ndichifukwa chani ndasankhidwa?*

You are being invited to take part because you are at least 18 years old and live in Area 25, Lilongwe, Malawi.

*Mwasankhidwa kutenga nawo gawo /mbali mu kafukufuku ameneyi chifukwa munakwanisa zaka khumi, zisanu ndi zitatu(18) zakubadwa komanso mumakhala mu dela lino la 25 mu nzinda wa Lilongwe.*

## 3. Do I have to have diabetes and/or high blood pressure to take part?

### 3. *Kodi ndikuyenela kuhala ndi mthenda ya shuga kapena kuthamanga magazi (BP) kuti nditenge nawo mbali mu kafukufukuyi?*

No. You do not have to have or have had high blood pressure or diabetes to take part. **You do not have to share any personal medical information with us.** It is entirely your choice if you would like to share anything in response to the discussions.

*Ayi. Simukuyenela kukhala nayo kapena kuti munakhalako nazo nthendazi . simukuyenela kuti uza chilichonse chokhuza umoyo wanupazokambilana zathu. Ngati mungakonde ndichisankho chanu kugawana za umoyo wanu mkatikati mwaku cheza kwathu. .*

## 4. Do I have to take part?

### 4. *Kodi ndiyenela kutenga nawo mbali mu kafukufukuyi?*

No. It is your decision if you wish to participate or not. We will be happy to answer any questions you may have and explain the study further. If you agree to take part, you will be asked to sign a consent form. If so, you will receive a copy to keep.

*Ayi. Ndichisankho chanu kutenga nawo mbali kapena ayi. Tikhala okondwa kukuyankhani mafunso omwe mungakhale nawo komanso kukulongosolelani zambiri zokhuza kafukufukuyi. Mukavomela kutenga nawo mbali muzapephedwa kusaina fomu yovomela kukhala nawo mu kafukufukuyindipo muzasala ndi kopeya pepalayi ngati umboni wanu.*

You may leave the study at any time without needing to provide a reason.

*Ndinu oloedwa kusiya kutenga nawo mbali mu kafukufukuyi pa nthawi iliyonse popanda kupeleka chifukwa chilichonse.*

## 5. What will happen if I take part?

### 5. Kodi chingachitike ndi chani ndikatenga nawo mbali mu kafukufukuyi?

If you agree to take part, you will participate in the following activity:

*Ngati mungavomele kutenga nawo mbali, mukuyenela kuchita izi:*

- A walk-along/walking interview where we will ask if we can go for a walk with you. During this walk we will ask you questions about your understanding of community in Area 25 and your understanding of diseases including high blood pressure and diabetes.

*Kuyankhulana tikuyenda/tidzakupemphani ngati tingapite nanu kokayenda. Pa ulendewu tizakufusani zokhunza dela la 25 komanso kufuna zomwe mumaziwa zokhunza matenda a sugar ndi kuthamanaga kwa magazi.*

- We will observe, audio-record and take notes about what you tell us.

*Tidzaona, kukutepani mau komanso kulemba zomwe mungatiuze.*

- It is expected that the walk will last ~60-90 minutes, although we can adapt this according to your abilities and comfort. You can decide where we go on the walk and what route we take. You can include the walk in your daily tasks if you wish (e.g. going to the shops).

*Kuyenda kumeneku kukuembezeke kutenga nthawi yosachepela ola limodzi koma osaposela ola ndi theka, ngakhale izi zitha kusitha kutengela kuthekela kwanu komanso mpata umene muli nawo. Pa ulendowu mutha kusankha kopita komanso njira yodusila. Muli oloedwa kuphatikiza zithu zomwe mumapanga tsiku ndi tsiku pa ulendowu(mwachitsanzo kupita kunsika, ku golosale ku chipatala).*

## 6. What are the benefits and risks of my participation?

### 6. Kodi ubwino ndi kuipa kwa kutenga nawo mbali ndi chiyani?

- By participating, you will help us understand how people in your local community experience diseases like high blood pressure and diabetes. This will help us develop ways to improve health that will be engaging to the community.

*Potenga nawo mbali muzatithandiza kumvetsetsa momwe anthu am'dela la 25 amamvesesela/zomwe amakumana nazo pa matenda a shuga komanso kuthamanga kwa magazi zomwe zizathandizile kupeza njira zopitisira pasogolo umoyo wa thanzi wa anthu a m'dela la 25.*

- This study is considered low risk; however, if you find any concerns emerging relating to the subject matter or have mobility difficulties you can discuss these privately with the researchers at any time or withdraw from the research without needing to provide a reason.

*Kafukufukuyi alibe chiopsyezo koma ngati mungapeze zovuta chifukwa cha kafukufukuyi komanso muli ndi vuto la kuyenda mutha kukambilana mwa chinsisi*

*ndi ofufuza nthawi iliyonse kapena mutha kusiya kutenga nawo mbali pa thawi iliyonse opanda chifukwa.*

## 7. Will my taking part in this study be kept confidential?

### 7. Kodi anthu azaziwa kuti ndinatenga nawo mbali mu kafukufukuyi?

- Any personal information (e.g., name, contact details) you provide us will not be shared outside of the research team. You will be identified by an ID number and any information about you will have your name and address removed so that you cannot be recognised from it.

*Zonse zokhuza inu (monga dzina, njira zolumikizana nanu) zomwe mutatipase sizizagawidwa kwa anthu kupatula okhawo amene akupanga nawo kafukufukuyi. Muzizaziwika ndi nambala yachinsisi imene muzapasidwe ndipo chili chonse chokhunza inu chizachosedwapo kuti anthu asakudziweni.*

- Any personal information will be kept in a locked cabinet in a secure building and only the researcher and supervisors will be able to access it.

*Chilichonse chukhunza inu chizasamalidwa ndipo chizasungidwa ku malo otetezedwa komwe ekhayo opanga kafukufukuyi ndi omuyang'anila ndi okhawo angakwanise kufikila.*

- Confidentiality may be limited and conditional – and the researcher has a duty of care to report to the relevant authorities possible harm/danger to participant or others.

*Chinsisi chikhonza kukhala chochepa komanso chokhazikika ndipo opanga kafukufukuyi ali ndi udindo oteteza za chinsisi zanu ngati malamulo osungila zinthuzi akuonongedwa pokanena kwa anthu oyenela.*

## 8. What will happen to the results of the research study?

### 8. Kodi chizachitike ndi chani ndi zotsatira za kafukufukuyi?

- The results will be reported in the form of a PhD thesis (October 2024), journal articles and conference papers.

*Zosatilazi zidzafotokozedwa ngati maphunzilo a PHD (October 2024) kulembedwa mu nyuzipepala komanso ma pepala a misonkhano.*

- Anything we use in reports, presentations and publications will not identify you, unless you have given us permission to use your identity.

*Zonse zosatila zokhuza kafukufukuyi polemba ma lipoti, zoonesa komanso zofalisila uthenga siziza ulula kuti munatenga nawo gawomu kafukufukuyi pokhapokha mutatipasa chilolezo kutelo.*

- A written summary of results will be made available to you on request.

*Zotsatira zakafukufukuyu tidzaperekedwa kwa omwe angazatipemphe kuti tiwauze..*

- Your non-personal information will be retained for a period 10 years after the project ends in accordance with University of Glasgow guidance.

*Zosatila za kafukufukuyi zomwe sizizakuululani zizasungidwa kwa zaka khumi(10) potengela lamulo la sukulu ya ukachenjede ya Glasgow.*

- Other authenticated researchers will have access to non-personal information only if they agree to preserve the confidentiality of the information.

*Ena opanga kafukufuku azaloledwa kugwilisa ntchito zosatila za kafukufukuyi pokhapokha atavomela kusunga chinsisi.*

- Other authenticated researchers may use non-personal information in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information.

*Ena opanga kafukufuku azaloredwa kugwirisa nawo ntchito zosatila za kafukufukuyi polemba zinthu monga malipoti , pasamba la intaneti ndi zosatira zina za kafukufuku pokhapokha atavomela kusunga chinsisi.*

## **9. Who has reviewed the study?**

### **9. Ndani adaunikila komanso kuvomeleza kafukufukuyi?**

This study has been reviewed by the University of Glasgow, College of Social Sciences Ethics Committee to ensure research is conducted considering the safety of the participant and to the best standards.

*Kafukufukuyi anaunikidwa ndi sukulu ya ukachenjede ya Glasgow pofuna kuonosa kuti kafukufuku akuchitidwa poganzizila za chitetezo za omwe akutenga nawo mbali komanso asapwanyilidwe malamulo.*

## **10. Who is funding the study?**

### **10. Akuthandiza ndani pa kafukufukuyi?**

This study is being funded by the University of Glasgow College of Social Sciences.

*Kafukufukuyi akuthandizidwa ndi sukulu ya ukachenjede ya Glasgo.*

## **11. Contact for Further Information/Mukafuna kuziwa zambili?**

If you have any further questions, please contact Maria Bissett at

[m.bissett.1@research.gla.ac.uk](mailto:m.bissett.1@research.gla.ac.uk)/+265....who will be happy to answer them.

To pursue any complaint about the conduct of the research: contact the College of Social Sciences Lead for Ethical Review, email [socsci-ethics-lead@glasgow.ac.uk](mailto:socsci-ethics-lead@glasgow.ac.uk)

*Ngati pali chidandaulo chilichonse pa nkhani yakafukufukuyi tumizani madando anu kwa oyang'anira kafukufuku wabwino ku sukulu ya ukachenjede ya za Social Science pa email address iyi [socsci-ethics-lead@glasgow.ac.uk](mailto:socsci-ethics-lead@glasgow.ac.uk)*

## Appendix 3B

### Phase 2 and 3 TABPA Participant Information Sheet (*English and Chichewa*)



#### Project Title: Arts, Diabetes and High Blood Pressure

Development of a transcultural arts-based participatory approach to exploring the drivers of noncommunicable diseases (hypertension/diabetes) among Black communities in Scotland and Malawi.

Kupeza njira zachikhalidwe komanso za luso pofuna kuthandiza kufufuza zomwe zimayambisa matenda osapatsilana (shuga komanso kuthamanga kwa magazi) pakati pa anthu okuda ku sikotilandi koamso ku Malawi.

### Participant Information Sheet

Principle Researcher: Maria Bissett. Contact details:

[m.bissett.1@research.gla.ac.uk](mailto:m.bissett.1@research.gla.ac.uk)

Supervisors:

- Prof. Cindy Gray [cindy.gray@glasgow.ac.uk](mailto:cindy.gray@glasgow.ac.uk)
- Dr. Chris Bunn [christopher.bunn@glasgow.ac.uk](mailto:christopher.bunn@glasgow.ac.uk)

You are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. Ask the researcher/s if there is anything that is not clear or if you would like more information. Take some time to decide whether or not you wish to take part.

*Mulikuitanidwa kutenga nawo mbali mu kafukufuku, koma musanasankhe kutenga nawo mbali/gawo ndikofunika kuti mumvesesechifukwa chomwe kafukufukuyi akuchitikila komanso zomwe atakhuze. Chonde werengani mfundo zosatilazi mosamala komanso muli oloedwa kukambilana ndi ena ngati mungafune kutelo. Afunzeni ofufuza ngati pali chomwe sichikumveka bwino kapena ngati mukufuna kuziwa dzambili. Pangani chiganizo mofasa ngati mukufuna kutenga nawo gawo mu kafukufukuyi kapena ayi.*

Thank you for reading this.

## 1. What is the purpose of the study?

### 1. Kodi cholinga cha kafukufukuyi ndi chani?

High blood pressure and type 2 diabetes are two diseases that are affecting Black communities in Scotland and in Malawi. Researchers are trying to find new ways to understand how local communities experience these diseases.

*Nthenda za kuthamanga kwa magazi komanso shuga wa mtundu wachiwili ndi zomwe zikukhudza anthu akuda ku maiko a Scotland ndi Malawi. Akatswiri a kafukufuku akuyesera kupeza njira zatsopano zofuna kumvetseka mmene anthu a mdera lino amakhuzidwila ndi matendawa.*

Arts-based participatory methods involve researchers and community members working together and using creative activities (e.g., songs, theatre, dance) to ask about and understand local experiences.

*Potengera zaluso popanga kafukufuku, opanga kafukufuku komanso anthu amu dera amagwilitsa ntchito zaluso (monga nyimbo, zisudzo, kuvina) pofuna kufunsa komanso kumveseka zomwe zimachitika mderalo.*

This project aims to develop an arts-based participatory approach to understand experiences of high blood pressure and diabetes among Black communities in Scotland and in Malawi. It will involve partnerships with local organisations and community members such as yourselves.

*Kafukufukuyi akufuna kupanga njira ya zaluso yothandizira kumvetsetsa zomwe anthu akuda ku Sikotilandi komanso ku Malawi amakumana nazo pokhuzza matenda a shuga ndi kuthamanga magazi. Izi zitheka pogwira ntchito ndi mabungwe opezeka mmaiko awiriwa komanso anthu a zaluso osiyanasiyana, atsogoleri a mmadera komaso anthu awo ngati inu.*

The development of the approach will contribute to new approaches to diabetes and high blood pressure prevention that reflect the interests of the community.

*Pogwilisa ntchito zaluso zitithandizila kupeza njira zatsopano zopewela matenda a shuga kpmanso kuthamanga magazi zimene anthu amu mu dela lino angasankhe.*

We will be asking community members running arts-based participatory workshops to understand:

*Tikhala tikufunsa zokhunza moyo wa tsiku ndi tsiku komanso kukhala ndi mkumano pogwilisa zaluso pofuna kumveseka:*

- community knowledge about high blood pressure and diabetes.

*zomwe anthu a mdela la 25 amadziwa zokhunza matenda osiyana siyana kuphatikizilapo matenda a shuga komanso othamanga magazi.*

- their experiences of these diseases, and what increases their risk; *zomwe mumadziwa zokhunza matenda omwe atchulidwawa ndizomwe zimaonjezela chiopseyo chotenga matendawa.*
- how to work with local people to develop a way to understand experiences of these diseases. *Tingatani pofuna kupeza njira zomwe zingatithandize kumvesesa zokhunza matendawa.*

## 2. Why have I been chosen?

### 2. *Ndichifukwa chani ndasankhidwa?*

You are being invited to take part because you are at least 18 years old and live in Area 25, Lilongwe, Malawi.

*Mwasankhidwa kutenga nawo gawo /mbali mu kafukufuku ameneyi chifukwa munakwanisa zaka khumi, zisanu ndi zitatu(18) zakubadwa komanso mumakhala mu dela lino la 25 mu nzinda wa Lilongwe.*

## 3. Do I have to have diabetes and/or high blood pressure to take part?

### 3. *Kodi ndikuyenela kuhala ndi mthenda ya shuga kapena kuthamanga magazi (BP) kuti nditenge nawo mbali mu kafukufukuyi?*

No. You do not have to have or have had high blood pressure or diabetes to take part. **You do not have to share any personal medical information with us.** It is entirely your choice if you would like to share anything in response to the discussions.

*Ayi. Simukuyenela kukhala nayo kapena kuti munakhalako nazo nthendazi. Simukuyenela kutiuza chilichonse chokhuza umoyo wanu pazokambilana zathu. Ndichisankho chanu kugawana nafe zokhuza umoyo wanu ngati mungakonde kutelo.*

## 4. Do I have to take part?

### 4. *Kodi nduyenela kutenga nawo mbali mu kafukufukuyi?*

No. It is your decision if you wish to participate or not. We will be happy to answer any questions you may have and explain the study further. If you agree to take part, you will be asked to sign a consent form. If so, you will receive a copy to keep.

*Ayi. Ndichisankho chanu kutenga nawo mbali kapena ayi. Tikhala okondwa kukuyankhani mafunso omwe mungakhale nawo komanso kukulongosolelani zambiri zokhuza kafukufukuyi. Mukavomela kutenga nawo mbali muzapephedwa kusaina fomu yovomela kukhala nawo mu kafukufukuyi ndipo muzasala ndi kopeya pepalayi ngati umboni wanu.*

You may leave the study at any time without needing to provide a reason.

*Ndinu oloedwa kusiya kutenga nawo mbali mu kafukufukuyi pa nthawi iliyonse popanda kupeleka chifukwa chilichonse.*

## 5. What will happen if I take part?

### 5. Kodi chingachitike ndi chani ndikatenga nawo mbali mu kafukufukuyi?

If you agree to take part, you will participate in the following activity:

*Ngati mwavomela kutenga nawo mbali, mukuyenela kuchita izi:*

- An arts-based participatory workshop where we will ask you to participate in creative activities about high blood pressure OR diabetes (~3 hours)  
*Kuzakhala nawo pa mkumano omwe muzayenela kutenga nawo mbali popanga zaluso zosiyanasiyana zokhudza za kuthamanga kwa magazi(BP) kapena/komanso shuga.*
- We may take video-recordings of what you do as well as photographs and audio-recordings  
*Tikhonza kukujambulani zithunzi kanema kapena kutapa mau anu pamene mukutenga nawo mbali.*

## 6. What are the benefits and risks of my participation?

### 6. Kodi ubwino ndi kuipa kwa kutenga nawo mbali ndi chiyani?

- This research is designed to be fun and promote creativity. The outcome will be an approach that can be used to develop ways to prevent disease that communities might want to engage in.  
*Kafukufukuyi wakonzedwa kuti akhale ngati kungocheza mwa nsangulutso komanso alimbikise anthu kukhala aluso, koma Zosatila zake zikhala zophunzisa athu mudelali za umoyo wabwino komanso anthu amvesese zokhunzana ndi matenda osapasilana.*
- Transport costs will be supported (10,000 MK)  
*Mudzapatsidwa MK 10,000 ngati chipukuta misozi mayendedwe*
- This study is considered low risk; however, if you find any concerns emerging relating to the subject matter you can discuss these privately with the researchers at any time or withdraw from the research without needing to provide a reason.  
*Kafukufukuyi alibe chiopsyezo koma ngati mungapeze zovuta chifukwa cha kafukufukuyi komanso muli ndi vuto la kuyenda mutha kukambilana mwa chinsisi ndi ofufuza nthawi iliyonse kapena mutha kusiya kutenga nawo mbali pa thawi iliyonse opanda chifukwa.*

## 7. Will my taking part in this study be kept confidential?

### 7. Kodi anthu azaziwa kuti ndinatenga nawo mbali mu kafukufukuyi?

- Any personal information you provide us will not be shared outside of the research team. You will be identified by a different name (pseudonym) and any information about you will have your name and details removed so that you cannot be recognised from it.  
*Zonse zokhuza inu (monga dzina, njira zolumikizana nanu) zomwe mutatipase sizizagawidwa kwa anthu kupatula okhawo amene akupanga nawo kafukufukuyi. Muzizaziwika ndi nambala yachinsisi imene muzapapidwe ndipo chili chonse chokhunza inu chizachosedwapo kuti anthu asakudziweni.*
- Any personal information (e.g. name and contact details) will be kept in a locked cabinet in a secure building and only the researcher and supervisors will be able to access it.  
*Chilichonse chukhunza inu chizasamalidwa ndipo chizasungidwa ku malo otetezedwa komwe ekhayo opanga kafukufukuyi ndi omuyang'anila ndi okhawo angakwanise kufikila.*
- Please note that confidentiality may not be guaranteed due to video-recording and photographs.  
*Dziwani kuti chinsisi chikhonza kukhala chovutilako chifukwa cha kanema komanso zithunzi zimene zingajambulidwe.*
- Confidentiality may be limited and conditional – and the researcher has a duty of care to report to the relevant authorities possible harm/danger to participant or others.  
*Chinsisi chikhonza kukhala chochepa komanso chokhazikika ndipo opanga kafukufukuyi ali ndi udindo oteteza za chinsisi zanu ngati malamulo osungila zinthuzi akuonogedwa pokanena kwa anthu oyenela.*

## 8. What will happen to the results of the research study?

### 8. Kodi chizachitike ndi chani ndi zotsatira za kafukufukuyi?

- The results will be reported in the form of a PhD thesis (October 2024), journal articles and conference papers.  
*Zosatilazi zidzafotokozedwa ngati maphunzilo a PHD (October 2024) kulembedwa mu nyuzipepala komanso ma pepala a misonkhano.*
- Anything we use in reports, presentations and publications will not identify you.  
*Zonse zosatila zokhuza kafukufukuyi polemba ma lipoti, zoonesa komanso zofalisila uthenga siziza ulula kuti munatenga nawo gawomu kafukufukuyi pokhapokha mutatipasa chilolezo kutelo.*
- If you give us permission to audio/video-record or take photographs of you we will take care to make sure that recordings and photographs will only be used by the research team and that anything we use in reports, presentations and publications will not identify you, unless you have given us permission to use your identity.

*Mukatipasa chilolezo khotepa mau komanso chojambula kanema kapena kutenga zithunzi zomwe zizagwilisidwe ntchito ndi okhawo opanga kafukufuku ndipo polemba ma lipoti, zoonesa komanso zofalisila uthenga, dziwani kuti siziza ulula kuti munatenga nawo gawomu kafukufukuyi pokhapokha mutatipasa chilolezo kutelo.*

- A written summary of results will be made available to you on request.  
*Zosatila zonse zizalembedwa ndipo mukazazifuna muzapasidwa.*
- Your non-personal information will be retained for a period 10 years after the project ends in accordance with University of Glasgow guidance.  
*Zosatila za kafukufukuyi zomwe sizizakuululani zizasungidwa kwa zaka khumi(10) potengela lamulo la sukulu ya ukachenjede ya Glasgow.*
- Other authenticated researchers will have access to non-personal information only if they agree to preserve the confidentiality of the information.  
*Ena opanga kafukufuku azaloledwa kugwilisa ntchito zosatila za kafukufukuyi pokhapokha atavomela kusunga chinsisi.*
- Other authenticated researchers may use non-personal information in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information.  
*Ena opanga kafukufuku azaloredwa kugwirisa nawo ntchito zosatila za kafukufukuyi polemba zinthu monga malipoti , pasamba la intaneti ndi zosatira zina za kafukufuku pokhapokha atavomela kusunga chinsisi.*

## 9. Who has reviewed the study?

### 9. Ndani adaunikila komanso kuvomeleza kafukufukuyi?

This study has been reviewed by the University of Glasgow, College of Social Sciences Ethics Committee and the Malawi National Committee for Research in the Social Sciences and Humanities to ensure research is conducted considering the safety of the participant and to the best standards.

*Kafukufukuyi anaunikidwa ndi sukulu ya ukachenjede ya Glasgow ndi Committee ya ku Malawi yoyang'anira kafukufuku wa Social Sciences and Humanities pofuna kuonesa kuti kafukufuku akuchitidwa poganizila za chitetezo za omwe akutenga nawo mbali komanso asapwanyilidwe malamulo*

## 10. Who is funding the study?

### 10. Akuthandiza ndani pa kafukufukuyi?

This study is being funded by the University of Glasgow College of Social Sciences  
*Kafukufukuyi akuthandizidwa ndi sukulu ya ukachenjede ya Glasgow.*

## 11. Contact for Further Information

### 11. Mukafuna kuziwa zambili?

If you have any further questions, please contact Maria Bissett at [m.bissett.1@research.gla.ac.uk](mailto:m.bissett.1@research.gla.ac.uk) who will be happy to answer them.

*Ngati muli ndi mafunso ena yankhulani ndi Maria Bissett kudzera pa email ya [m.bissett.1@research.gla.ac.uk](mailto:m.bissett.1@research.gla.ac.uk) yemwe adzakhala okondwa kukuthandizani.*

To pursue any complaint about the conduct of the research: contact the Lead for Ethical Review, College of Social Sciences: email [socsci-ethics-lead@glasgow.ac.uk](mailto:socsci-ethics-lead@glasgow.ac.uk) or the National Committee for Research in the Social Sciences and Humanities in Malawi: [ncrsh@ncst.mw](mailto:ncrsh@ncst.mw)

*Ngati pali chidandaulo chilichonse pa nkhani yakafukufukuyu tumizani madando anu kwa oyang'anira kafukufuku wabwino ku sukulu yaukachenjede ya za Social Science pa email address iyi [socsci-ethics-lead@glasgow.ac.uk](mailto:socsci-ethics-lead@glasgow.ac.uk) kapena a Committee ya ku Malawi yoyang'anira kafukufuku wa Social Sciences and Humanities*