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# Understanding the unmet needs, wellbeing, experiences of cancer care and beliefs towards cancer among ethnic Chinese immigrants in Scotland

Lin Cheng, MSc, BN, RN

**Thesis submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy**

School of Medicine, Dentistry and Nursing

College of Medical, Veterinary and Life Sciences

University of Glasgow

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# Abstract

## Background

Ethnic Chinese immigrants, one of the fastest growing minority groups in the United Kingdom (UK), commonly face language, cultural, and health system navigation barriers in accessing cancer care. Consequently, this population may face a greater risk of developing and dying from cancer than the native UK population, contributing to persistent health inequalities in cancer survivorship. Despite Scotland's new 10-year cancer strategy (2023-2033) prioritising health equality, ethnic Chinese immigrant cancer survivors and their informal caregivers remain underrepresented in research. More research is needed to inform healthcare services in Scotland to become more culturally aware and person-centred for minority groups. This project aimed to investigate the unmet needs, wellbeing, care experiences, and beliefs regarding cancer among ethnic Chinese immigrants living in Scotland.

## Methods

This theory-driven project was underpinned by the principles of person-centred care, adopted a pragmatic research paradigm, and employed a five-phases hybrid, multistage mixed-methods design. Patient and public involvement and engagement was embedded throughout the research process. Phase 1 comprised a mixed-methods systematic review, synthesising evidence on unmet needs, health-related quality of life, and cancer care experiences among Asian immigrants living in very high Human Development Index western countries. Phase 2 involved an online survey that explored unmet needs and wellbeing among ethnic Chinese immigrant patients and informal caregivers affected by cancer in Scotland. Phase 3 used semi-structured interviews to generate more in-depth understanding of the lived experiences of cancer care that were reported in Phase 2. Phase 4 consisted of a focus group with health and social care professionals to gather their perspectives on delivering care to ethnic Chinese immigrants living with cancer. To examine how public preconceptions and views about cancer might contribute to the experiences of ethnic Chinese immigrants affected by cancer, Phase 5 concluded the project with a community-based survey investigating cancer knowledge, beliefs, and intentions to engage in cancer prevention behaviours among ethnic Chinese adults without a cancer diagnosis living in the Greater Glasgow area.

## Results

Unmet information needs were consistently reported throughout this project. Ethnic Chinese immigrants affected by cancer reported that they need bilingual and culturally appropriate information, and information help to navigate the national healthcare system. The community setting was highly valued as a context for receiving cancer-related knowledge and support services. Communication challenges with healthcare professionals were reported as the main barriers for optimal cancer care experience. This challenge is extended beyond language barriers to include limited recognition of patient autonomy. Informal caregivers reported poorer health related quality of life than patients, frequently prioritising the patient's needs above their own, and experiencing heightened strain due to the absence of extended family support after migration. Patient, informal caregivers and health and social care professionals reported cancer is often perceived as taboo within the Chinese community. Fatalistic beliefs were more common among the ethnic Chinese sample from the public, who were primarily older women and had lower levels of education. The community sample also showed reluctance to engage in cancer prevention behaviours. This appeared to be influenced by limited recognition of the importance of cancer screening, perceived difficulties in accessing healthcare, and psychological fear of screening results.

## Conclusion and Recommendations

This project identified five key areas of health inequality affecting ethnic Chinese immigrants living with cancer in Scotland: unmet information needs, difficulties navigating and accessing the healthcare system, suboptimal communication with healthcare professionals, limited support for addressing cancer-related stigma, and insufficient support for informal caregivers. This project recommends that cultural differences should be considered as a fundamental component of person-centred care, particularly in culturally diverse healthcare settings. It also recommends that Scotland's new 10-year cancer strategy develop initiatives to address unmet information needs and strengthen policies to support the wellbeing of informal caregivers. Given the important role that community health workers could play in bridging healthcare services and ethnic Chinese communities, this project recommends exploring their role in delivering cancer-related information and promoting awareness of the importance of early detection. This aligns with the aim of Scotland's new 10-year cancer strategy to reduce late cancer diagnosis.

## Plain language summary

Cancer can change a person's life in many ways. People with cancer often need more than medical treatment. They may also need emotional support, clear and easy-to-understand information, practical help, and care that respects their culture. People who were born in place with Chinese culture (e.g. China, Singapore, Malaysia), but now living in other countries, such as Scotland, can bring challenges when using cancer care services. These challenges can include language barriers, cultural differences, and having fewer family members nearby to support them. Ethnic Chinese people are one of the largest groups who have immigrated to the UK, but very little research has studied the cancer experiences of this population. Without this knowledge, healthcare services may not be able to provide the right support. This PhD project gave ethnic Chinese people a chance to share their voices, by understanding the needs, wellbeing, and cancer care experiences of both patients and family caregivers who grew up in China and now live in Scotland.

This PhD project first gathered research from published papers to better understand the real lived experiences among ethnic Chinese people with cancer living in Scotland. None of published papers were conducted in Europe, which added value to the novelty and importance of this project. This study asked people to share their lived experiences after a cancer diagnosis, or when caring for someone with cancer. Participants talked about what help they needed, in relation to their daily life and wellbeing. Health and social care staff discussed how to improve services for ethnic Chinese people. Throughout the project, it became evident that many people were scared to talk about cancer, and it felt important to arrange "Cancer Talk" seminars across five communities in Glasgow. These seminars helped people learn about cancer, share their thoughts, and understand where to get help. In addition, these "Cancer Talk" sessions provided the opportunity to collect data on the public's views of cancer.

Overall, this project found that Chinese people living with cancer need clear information to help them manage their health. The Scottish healthcare system is not designed for people whose English is their second language and is often difficult to follow. Many Chinese people who live in Scotland for marriage or work have fewer family members nearby. This can make cancer even harder for both patients and their family caregivers. Family caregivers also have their own needs, but these are often overlooked by themselves and by

others. People who do not have cancer often think cancer is a death sentence. This belief is more common among older people and people with less education.

This PhD project suggests that the Scottish Government should make healthcare easier to access for everyone. One way could be to have community health workers who speak the same first language and share a similar cultural background with the communities they serve. These staffs could teach the public about cancer symptoms and help people access healthcare services. When caring for patients from ethnic minority group, it is important to understand and respect for their culture. The Scottish Government should also help people whose first language is not English to understand medical information more easily. Finally, more support is needed for family caregivers, so they can also look after their own health and wellbeing.

## Simplified Chinese translation of the plain language summary

## 简体中文版通俗摘要

癌症可能会在很多方面改变一个人的生活。癌症患者通常不仅需要医疗治疗，也需要情感支持、清晰易懂的信息、实际生活中的帮助，以及尊重其文化背景的照护。对于出生和成长于华人文化背景地区，后来移居到其他国家（例如苏格兰）生活的人来说，在使用癌症照护服务时可能会遇到一些额外困难。这些困难包括语言障碍、文化差异，以及身边可以提供支持的家人较少等。华裔是英国较大的移民群体之一，但目前关于这一群体癌症经历的研究仍然很少。如果缺乏这些方面的认识，医疗卫生服务可能无法提供最合适的支持。这个博士研究通过了解在中国文化背景下出生、现居苏格兰的华裔癌症患者及其家庭照护者的需求、福祉和癌症照护经历，为他们提供表达自身经历和需求的机会。

本博士研究首先综合了已经发表的相关研究，以更好地了解华裔人群在癌症诊断、治疗和照护过程中的真实生活经历。此前已发表的相关研究中，没有一项是在欧洲开展的，这进一步体现了本研究的创新性和重要性。研究邀请癌症患者以及照护癌症患者的家庭成员分享他们的亲身经历，并讲述他们在日常生活和福祉方面需要哪些帮助。医护人员与社会照护专业人员也讨论了如何改善面向华裔人群的服务。在整个研究过程中，我们发现许多人害怕谈论癌症。因此，本项目在格拉斯哥五个社区开展了“癌症话题”（Cancer Talk）教育活动。这些活动帮助社区成员了解癌症、分享自己的看法，并了解在需要帮助时可以去哪里寻求支持。同时，这些活动也为收集公众对癌症的看法提供了机会。

总体而言，本研究发现，华裔癌症患者需要清晰的信息，以帮助他们更好地管理自己的健康。对于英语并非第一语言的人来说，苏格兰的医疗卫生系统往往较难理解和使用。许多华裔移民的身边缺少家庭成员的陪伴，这会让癌症患者和家庭照护者的生活变得更加困难。家庭照护者也有自己的需求，但这些需求往往被忽视。很多华裔移民认为，患有癌症就意味着死亡。这种看法在年龄较大和受教育程度较低的人群中更为常见。

本博士研究建议，苏格兰政府应让医疗卫生服务对所有人都更加容易获得。其中一种可行方式是建立社区卫生工作者，这一角色由与所服务社区拥有相同第一语言、

相似文化背景的人来担任。这些工作人员可以向公众普及癌症相关知识，并帮助人们使用和获得医疗卫生服务。在照护少数族裔患者时，理解并尊重他们的文化背景非常重要。苏格兰政府还应帮助第一语言不是英语的人更容易理解医疗信息。最后，需要为家庭照护者提供更多支持，使他们在照护患者的同时，也能够关注和维护自己的健康与福祉。

## Traditional Chinese translation of the plain language summary

## 繁體中文版通俗摘要

癌症可能會在很多方面改變一個人的生活。癌症患者通常不僅需要醫療治療，也需要情感支持、清晰易懂的資訊、實際生活中的幫助，以及尊重其文化背景的照護。對於出生和成長於華人文化背景地區，後來移居到其他國家（例如蘇格蘭）生活的人來說，在使用癌症照護服務時可能會遇到一些額外困難。這些困難包括語言障礙、文化差異，以及身邊可以提供支持的家人較少等。華裔是英國較大的移民群體之一，但目前關於這一群體癌症經歷的研究仍然很少。如果缺乏這些方面的認識，醫療衛生服務可能無法提供最合適的支持。這個博士研究透過了解在中國文化背景下出生、現居蘇格蘭的華裔癌症患者及其家庭照護者的需求、福祉和癌症照護經歷，為他們提供表達自身經歷和需求的機會。

本博士研究首先綜合了已經發表的相關研究，以更好地了解華裔人群在癌症診斷、治療和照護過程中的真實生活經歷。此前已發表的相關研究中，沒有一項是在歐洲開展的，這進一步體現了本研究的創新性和重要性。研究邀請癌症患者以及照護癌症患者的家庭成員分享他們的親身經歷，並講述他們在日常生活和福祉方面需要哪些幫助。醫護人員與社會照護專業人員也討論了如何改善面向華裔人群的服務。在整個研究過程中，我們發現許多人害怕談論癌症。因此，本項目在格拉斯哥五個社區開展了「癌症話題」（Cancer Talk）教育活動。這些活動幫助社區成員了解癌症、分享自己的看法，並了解在需要幫助時可以到哪裡尋求支持。同時，這些活動也為收集公眾對癌症的看法提供了機會。

總體而言，本研究發現，華裔癌症患者需要清晰的資訊，以幫助他們更好地管理自己的健康。對於英語並非第一語言的人來說，蘇格蘭的醫療衛生系統往往較難理解和使用。許多華裔移民的身邊缺少家庭成員的陪伴，這會讓癌症患者和家庭照護者的生活變得更加困難。家庭照護者也有自己的需求，但這些需求往往被忽視。很多華裔移民認為，患有癌症就意味著死亡。這種看法在年齡較大和受教育程度較低的人群中更為常見。

本博士研究建議，蘇格蘭政府應讓醫療衛生服務對所有人都更加容易獲得。其中一種可行方式是建立社區衛生工作者，這一角色由與所服務社區擁有相同第一語言、

相似文化背景的人來擔任。這些工作人員可以向公眾普及癌症相關知識，並幫助人們使用和獲得醫療衛生服務。在照護少數族裔患者時，理解並尊重他們的文化背景非常重要。蘇格蘭政府還應幫助第一語言不是英語的人更容易理解醫療資訊。最後，需要為家庭照護者提供更多支持，使他們在照護患者的同時，也能夠關注和維護自己的健康與福祉。

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## List of publications/dissemination outputs

The following is a list of publications and conference dissemination during the work of this project and PhD journey:

Publications arising from this PhD study (Appendix 13):

- **Chapter 5 (Phase 1 Systematic Review):** Cheng, L., Kotronoulas, G. & Cairns, D. 2026, Care Experiences and Well-being of Asian Immigrant Cancer Survivors Living in Countries of the Western World Ranked as Very High on the Human Development Index: A Systematic Review of International Evidence, Seminars in oncology nursing, pp. 152246. https://doi.org/10.1016/j.soncn.2026.152246
- **Abstract for the whole project:** Cheng, L., Kotronoulas, G., Cairns, D. & Sham, W. 2024, CN66 Healthcare needs, experiences of cancer care, and attitudes towards cancer among ethnic Chinese immigrants in Scotland", Annals of oncology, vol. 35, p. S1188. https://doi.org/10.1016/j.annonc.2024.08.470 **(Cited by Scottish Government policy report)**
- **Abstract for Phase 5 (Chapter 9):** Cheng, L., Kotronoulas, G. & Cairns, D. 2025, CN32 Exploring knowledge and attitudes towards cancer among ethnic Chinese immigrants in Glasgow: A nurse-led community-collaborative survey, Annals of oncology, vol. 36, p. S1633. https://doi-org.ezproxy2.lib.gla.ac.uk/10.1016/j.annonc.2025.08.1107

International /National conference presentations and awards arising from this PhD study (Award certificates in Appendix 14):

- Oral presentation at International Conference on Cancer Nursing (ICCN) in Glasgow (2023), Scotland – Understanding the healthcare needs and experiences of care of ethnic Chinese affected by cancer in Scotland
- E-poster presentation at Multinational Association of Supportive Care in Cancer (MASCC) conference in Lille, France (2024) – Care experiences and well-being of Asian immigrants with cancer living in western countries – A systematic review of international evidence
- Proffered paper presentation at 17th European Oncology Nursing Society (EONS) conference in Barcelona, Spain (2024) -- Healthcare needs, experiences of cancer care, and attitudes towards cancer among ethnic Chinese immigrants in Scotland

- 5th EONS PhD Workshop at Ghent, Belgium (2024)
- Oral presentation and poster display at United Kingdom Oncology Nursing Society (UKONS) conference in Manchester, United Kingdom (2024) – Using community-based 'Cancer Talks' to explore knowledge and attitudes towards cancer among ethnic Chinese immigrants in Glasgow **Award with Young & Early Career Cancer Nurses (YECCN)**
- E-poster presentation at London Global Cancer Week Cancer Health Disparities Day Event in London, United Kingdom (2024) – Assessment of knowledge and attitudes towards cancer among ethnic Chinese immigrants – A community based collaborative survey in Glasgow **Award with Top 10 abstract, published in e-cancer journal**
- 3 Minutes Presentation (3MT) at U21 Health Sciences Nursing and Midwifery Discipline Group Research Postgraduate Symposium, online (2024) – Understanding healthcare needs, experience of care and attitudes towards cancer among ethnic Chinese immigrants in Scotland
- Rapid-fire presentation at 18th EONS conference in Berlin, Germany (2025) – Exploring knowledge and attitudes towards cancer among ethnic Chinese immigrants in Glasgow: A nurse-led community-collaborative survey
- E-poster presentation at London Global Cancer Week Cancer Health Disparities Day Event in London, United Kingdom (2025) – *Exploring supportive cancer care disparities among ethnic Chinese immigrants in Scotland: insights from a mixed methods study*" **Award with Top 10 abstract, published in e-cancer journal**

University of Glasgow Post Graduate Research (PGR) Events and Awards arising from the PhD study process (Award certificates in Appendix 14):

- 3MT presentation for my initial PhD project, Online, (2022) – *Developing a person-centred palliative care education package to empower patients and families living with metastatic breast cancer in China*
- Oral presentation for my initial PhD project at School of Medicine Dentistry and Nursing Postgraduate Research Day (2023) – *Developing of patient-centred palliative care education package to empower patients and families living with metastatic breast cancer in China* **Best Innovation (Oral presentation) Award**

- Oral presentation at School of Medicine Dentistry and Nursing Postgraduate Research Day (2024) – Care experiences and well-being of Asian immigrants with cancer living in western countries – A systematic review of international evidence
- Oral presentation at School of Medicine Dentistry and Nursing Postgraduate Research Day (2025) – Assessment of knowledge and attitudes towards cancer among ethnic Chinese immigrants – A community-based collaborative survey in Glasgow **Best Patient and Public Involvement and Engagement Award**

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Thanks for the unexpected turning points, including the moment when my research topic changed. What initially felt like disruption ultimately became a source of transformation, helping me discover new possibilities and find a sense of peace and direction in ways I had never anticipated.

Lastly, I thank myself, for not giving up, for standing back up when it was hard, and for proving that I am stronger, more resilient, and more capable than I ever knew.

## Author's declaration

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

Printed name: Lin Cheng

Signature:

# Abbreviations

| | |
|---|---|
| CEO | Chief Executive Officer |
| EU | European Union |
| FACT-G | Functional Assessment of Cancer Therapy – General |
| GP | General Practice |
| HDI | Human Development Index |
| HRQoL | Health-Related Quality of Life |
| MVLS | College of Medical, Veterinary & Life Sciences |
| NHS | National Health Service |
| PEO | Population, Exposure and Outcomes |
| PPIE | Patient and Public Involvement and Engagement |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PRO | Patient Reported Outcome |
| PROM | Patient Reported Outcome Measure |
| QuADS | Quality Assessment for Diverse Studies |
| SCNS-SF34 | Supportive Care Needs Survey – Short Form 34 |
| SD | Standard Deviation |
| TCM | Traditional Chinese Medicine |
| TPB | Theory of Planned Behaviour |
| UK | United Kingdom |
| USA | United States of America |
| WHO | World Health Organization |

# Chapter 1 : Introduction

This chapter introduces the PhD project, outlining the overall health and social care problems among supportive cancer care for ethnic minority groups. It also discusses the PhD researcher's personal motivation to carry out this project and the overall PhD timeline. The chapter concludes by presenting the overall structure of the thesis, providing an overview to guide readers.

## 1.1 Personal motivation and responding to challenge

My motivation to do research in supportive cancer care stems from both my professional background in nursing and my personal experiences. I was trained as a registered nurse in China and later pursued a master's degree with merit at the University of Glasgow, Scotland. During my master's studies, I developed a strong interest in the wellbeing of patients with cancer. My dissertation consisted of a scoping literature review examining the effectiveness of self-management interventions for patients with breast cancer. I published this work (my first ever publication) in the *European Journal of Oncology Nursing* (Cheng and Kotronoulas, 2020) and was honoured with the Novice Research Dissemination Award at the European Oncology Nursing Society in 2020. These academic achievements provided strong encouragement and motivation to further pursue this doctoral degree.

Subsequently, I worked in a breast cancer department in a Chinese hospital during the COVID-19 pandemic and my gap year, where I had daily contact with patients and their families. These experiences reinforced my understanding that breast cancer is not only a medical condition but also a profound life event that significantly affects both patients and their families. From my clinical experience, I observed that patients wished to remain as comfortable as possible during their treatment, even at the end of life. However, the existing palliative care services in China were far from sufficient to meet these needs. Motivated by these insights, my initial PhD project was designed to develop a palliative care education package for patients with metastatic breast cancer in mainland China, using a cross-sectional survey and Delphi study design.

Conducting research in a real-world context proved highly challenging. The first major obstacle emerged halfway through the second year of my PhD, when I sought ethical approval for the cross-sectional survey from a collaborating hospital in China. Although I had already secured ethical approval from the University of Glasgow, College of Medical, Veterinary and Life Sciences (MVLS) Ethics Committee on 5th April 2023 (Appendix 1),

with the University of Glasgow acting as the main responsible party, my application was rejected by the hospital in China without convincing justification. Following this rejection, my supervisors and I agreed to amend the study design to a public survey that did not require recruitment through hospitals. This amendment was subsequently approved by the University of Glasgow, College of MVLS Ethics Committee on 19th May 2023 (Appendix 1). Despite this, the hospital continued to impose significant barriers that prevented me from conducting the public survey in China. Although my supervisors and I made repeated attempts to negotiate with the institution, our efforts were unsuccessful. We were advised to submit the project to an external ethics review process, which would involve an exceptionally long waiting period for a decision and was highly likely to result in rejection, as the hospital considered the project to involve cross-national collaboration. This situation not only introduced prolonged delays but also carried no assurance that ethical approval would ever be granted.

Deciding to completely change the direction of my doctoral project was not easy. This was not only time-consuming but also challenging as I had to design and implement an entirely new research plan. I had to continue to think positively. I recognised that the first year of work had enabled me to gain valuable knowledge and insights into palliative care. After extensive discussions with my supervisors, I decided to reframe the project. As an international student settling into a new country, I had experienced first-hand the difficulties of overcoming linguistic, cultural, and social barriers coming from China to Scotland. I could only imagine how much harder this must be for non-native people affected by cancer, who must simultaneously manage the illness and adapt to a different cultural context. Through building personal networks in Scotland, I became increasingly aware of their unique healthcare experiences. Many of my friends expressed interest in my field of study and shared the challenges they faced in accessing care in Scotland. They often conveyed a sense of relief that someone was focusing on their lives and willing to listen to their stories.

These encounters strengthened my confidence in the new direction of my PhD project. I now believe the project was not only a piece of research but also an opportunity to amplify the voices of an underserved population and bring their experiences to the attention of wider society. The turning point I described above, though challenging, ultimately led to the development of the research reported in this thesis, which has deepened my motivation to contribute to culturally appropriate and equitable cancer care. The project had since received recognition and positive feedback from both national and international audiences.

## 1.2 PhD timeline

My PhD journey began in January 2022, and I submitted my thesis in June 2026. As explained above, due to challenges in obtaining ethical approval in China for my original PhD project idea (year 1), I had to substantially redesign the project in year 2. Figure 1-1 provides a flow chart outlining the key stages of my PhD journey.

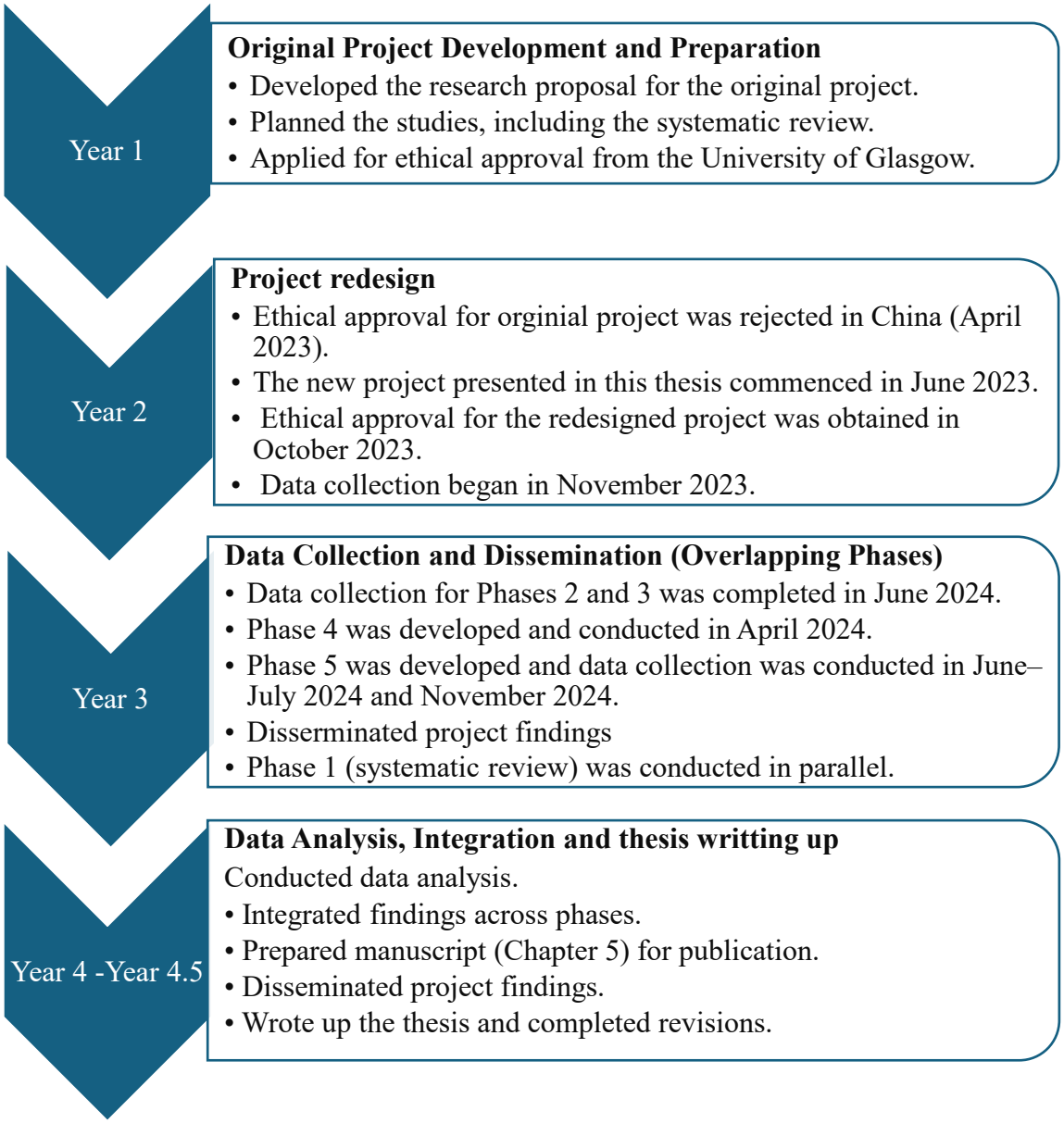



Figure 1-1 Flow chart of the PhD journey

## 1.3 Overall health and social care problems

Cancer is a major societal, public health, and economic challenge in the 21st century, accounting for more than one in five (22.8%) deaths from noncommunicable disease (Bray et al., 2024). Health inequalities refer to systematic differences in people's health status, the care they receive, and the opportunities available to lead healthy lives, all of which influence overall health outcomes (World Health Organization, 2018).

The Scottish government launched a new 10-year cancer strategy in 2023, around the time when this project was being developed. The updated vision and priorities of this strategy were to improve cancer survival and provide excellent, equitable and accessible care to all the people (Scottish Government, 2023a). Ethnic Chinese communities represent one of the fastest growing groups in Scotland (Scotland Census, 2025). In contemporary multicultural societies, understanding diverse cultural backgrounds and their corresponding behaviours has emerged as an important subject around the world (Chang et al.2012). Ethnic Chinese immigrants with cancer often experience barriers to optimal care, while individual responses to psychological and physical symptoms vary and are largely determined by cultural values and norms, which are often ignored or misunderstood by health professionals from different cultures (Yeom et al., 2022). Understanding how culture shapes the unmet needs, wellbeing, care experiences and beliefs of cancer among ethnic Chinese immigrants is essential to addressing inequalities in cancer care and echo the Scottish new cancer strategy.

## 1.4 Structure of the thesis

Including Chapter 1, this thesis comprises ten chapters as follows:

**Chapter 2** provides the background to this project, consolidates the rationale for why it is needed, and outlines the aim, objectives, and research questions.

**Chapter 3** outlines the theoretical underpinning framework that guided this project.

**Chapter 4** presents the research paradigms underpinning this project, the rationale for the selection of each research method, and the actions taken to enhance rigour and trustworthiness for each phase of this project.

**Chapter 5** reviews and synthesises evidence on unmet needs, HRQoL, and care experiences of Asian immigrant cancer survivors living in very high Human Development Index (HDI) Western countries (similarly wealthy to the UK), which provides a broader contextual understanding to inform subsequent empirical work outlined in Chapters 6 to 9.

**Chapters 6 to 9** present in detail the methods, findings, and discussions of the interconnected empirical research phases, as well as the strengths and limitations of each phase and the recommendations arising from them.

**Chapter 10** provides an integrated discussion of the findings, compares them with existing literature, and reflects on the overall strengths and limitations of the research. It also presents recommendations arising from the project, proposes next steps for future research, and includes personal reflections on the PhD journey.

# Chapter 2：Background

## 2.1 Introduction

This chapter presents the contextual background of this project. It begins with the first core concept, cancer, by outlining the current epidemiology both globally and within Scotland. It then provides definitions of cancer survivor, co-cancer survivor (the informal caregiver) and cancer survivorship, which represent the remain core concepts underpinning this project. The background also introduces a conceptual overview of the key issues that this project aims to address, particularly health disparities in cancer care. To understand these issues within Scotland, it is essential to first examine the Scottish healthcare system and the current 10-year cancer strategy set by the Scottish Government, which together highlight the relevance and alignment of this project with national priorities. Finally, this chapter presents the history and current trends of ethnic Chinese immigration to Scotland and offers an overview of key aspects of Chinese culture in relation to healthcare. This chapter concludes by presenting the overall research aim and identifying the knowledge gaps addressed in this project.

## 2.2 Cancer, cancer survivorship, and disparities in cancer care

### 2.2.1 Definition and burden of cancer worldwide

The National Cancer Institute defined cancer as: "*a disease in which some of the body's cells grow uncontrollably and spread to other parts of the body*" (National Cancer Institute, 2021). Recently, Brown et al. (2023) proposed a revised definition of cancer: "*Cancer is a disease of uncontrolled proliferation by transformed cells subject to evolution by natural selection*". Cancer is a major public health challenge in the 21st century and ranks among the three leading causes of premature death from noncommunicable disease in the 30-69 age group in 177 of 183 countries (Bray et al., 2021). Globally, lung, prostate, colorectal, stomach and liver cancers are the most common types of cancer in men, while breast, colorectal, lung, cervical, and thyroid cancer are the most common among women (Bray et al., 2021). The incidence of cancer and resultant mortality are increasing, which reflects population aging and the role of several risk factors such as tobacco and alcohol use, unhealthy diet, physical inactivity, and air pollution (Sung et al., 2021). The burden of cancer is not only limited to a significant barrier to the life expectancy and wellbeing, but also associated with substantial societal and macroeconomic costs for the whole society (Jolidon et al., 2024). A recent study showed that the total cost of cancer was €199 billion

in Europe (EU-27 plus Iceland, Norway, Switzerland, and the United Kingdom) in 2018, including cost from cancer-related health expenditures, productivity losses, and informal care costs (Hofmarcher et al., 2020).

The United Nations Development Programme defines the Human Development Index (HDI) as a composite indicator of a country's achievements in health, education, and income (United Nations Development Programme, 2024). Countries with an HDI score of 0.800 or above are classified as having a "very high" level of human development, whereas those with a score below 0.550 are classified as having low human development (United Nations Development Programme, 2024). Many cancer types are preventable, and very high HDI countries have made significant progress in cancer prevention and early diagnosis (Jolidon et al., 2024). Many low and middle HDI countries with limited national budgets face challenges in implementing effective national cancer control plans (Soerjomataram and Bray, 2021). By 2050, over 35 million new cancer cases are projected worldwide, and the greatest relative increases are expected in low HDI countries, where incidence is predicted to rise by 142%, compared with a 42% increase projected for very high HDI countries (Bray et al., 2024).

### 2.2.2 Cancer burden in the UK and Scotland

According to the Organisation for Economic Co-operation and Development, cancer could add £14.4 billion to the UK's health spending every year until 2050 (Annalisa Belloni, 2024). If current trends in cancer incidence continue, more than half a million new cancer cases could be diagnosed annually in the UK by 2040 (Annalisa Belloni, 2024). In Scotland, cancer remains one of biggest health challenges, with the updated statistical report from Public Health Scotland indicating that there were 36,036 new cancers registered in Scotland in 2022 (18,319 male; 17,717 female), representing a 1% increase compared with 2021 (Public Health Scotland, 2024a). The most common cancers in Scotland are lung, breast, prostate, and bowel, which together account for over half (55%) of all malignancies, excluding non-melanoma skin cancers (Public Health Scotland, 2024a). Lung cancer remains the leading cause of cancer-related deaths in Scotland, accounting for 24% of all cancer deaths (Public Health Scotland, 2025b). When combined with colorectal (bowel), prostate, and breast cancers, these four malignancies represent 46% of all cancer deaths (Public Health Scotland, 2025b).

Scotland has the highest proportion of cancers caused by preventable risk factors than any other UK nation (Brown, 2022). Smoking is the largest preventable risk factor for cancer in

Scotland, responsible for nearly 1 in 5 cases, and is more common in the most deprived populations, with 32% of the most deprived smoking compared to 6% in the least deprived (Brown, 2022). Early detection of cancer can significantly improve survival outcomes (Public Health Scotland, 2024b). Scottish ministers set screening policy for Scotland and National Health Service (NHS) Scotland offers a range of screening tests to different sections of the population, including bowel, breast, cervical screening for those in the population at high-risk (Scottish Government, 2024). The updated cancer incidence report in Scotland shows that half (51%) of breast cancers, 40% of cervical cancers and 35% of bowel cancers are diagnosed through screening, among those eligible for screening (Public Health Scotland, 2024a).

Scotland has made steady and sustained progress in increasing cancer survival rates over the past decade or so, which are broadly in line with those in England and Wales, although they lag behind several European countries such as Sweden, Norway, and Denmark (Burki, 2022). Countries with better cancer survival typically had higher use of chemotherapy and radiotherapy, shorter waits to start treatment, and fewer diagnosed as emergency hospital admissions (Martins et al., 2022; McPhail et al., 2024). Older patients were less likely to receive chemotherapy and radiotherapy (McPhail et al., 2024). Among patients aged 85 years and over, only 2.4% in the UK received chemotherapy, compared with 8.1% in Australia and 14% in Canada (McPhail et al., 2024). Patients in the UK faced long waits for treatment, and this varied depending on where people live. Scotland continues to fail to meet the target of 95% of cancer patients starting treatment within 62 days of urgent referral from their general practitioner (Burki, 2022; Public Health Scotland, 2025c). Evidence shows that the average time to start chemotherapy was shortest in England (48 days) and longest in Scotland (65 days) (McPhail et al., 2024). These issues raise important questions about whether worsening health inequalities are influencing cancer survival outcomes and require more targeted action to reach groups with poor survival rates (Burki, 2022).

### 2.2.3 Cancer survivors and survivorship care

The concept of people living with and beyond cancer as ‘cancer survivors’ was first introduced in the mid-1980s by Mullan (1985). In 1986, Mullan and a group of cancer survivors and oncology professionals founded the National Coalition for Cancer Survivorship, an association that worked to change the societal lexicon from cancer victim to survivor (National Coalition for Cancer Survivorship, 2016). In line with Mullan’s

concept of ‘cancer survivor’, the National Coalition for Cancer Survivorship defined someone as a cancer survivor from the time of diagnosis through the balance of life (Mayer et al., 2017). The definition was then expanded to include family members, friends, and caregivers of individuals with cancer (Mayer et al., 2017). The term ‘cancer survivor’ is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals (National Cancer Institute, 2020a).

Mullan (1985) defined three phases of survivorship: the acute phase, referring to the period of diagnosis and treatment; the extended phase, defined as the period following treatment; and permanent phase, in which survivorship is considered roughly equivalent to cure. Hewitt et al. (2006) proposed two possible trajectories of cancer survivorship experiences, including living cancer free or living with cancer. Living cancer free means having no detectable signs of cancer after treatment, allowing a return to normal life, but it does not always mean a permanent cure, requiring ongoing monitoring for potential recurrence (Demarco, 2021). Living with cancer means navigating a journey with significant physical, emotional, and practical challenges, such as managing chronic or intermittent disease (Demarco, 2021). Although each individual’s experience of survivorship is unique, the overall goals for cancer survivors remain consistent, either achieving cure or maximising quality of life (Mollica et al., 2025). Key issues related to cancer survivorship include access to healthcare and follow-up of treatment, management of side effects, risk of secondary cancers, and overall quality of life (National Cancer Institute, 2020b).

Human beings are multidimensional, encompassing not only physical needs but also emotional, psychological, social and spiritual aspects (Maslow, 1968). When significant life events such as a cancer diagnosis occurs, individuals may find that their usual strategies for meeting daily needs become ineffective, and their needs can no longer be addressed through routine approaches (Scotté et al., 2023). Integrating supportive care into cancer care offers an effective approach to addressing the diverse and complex human needs of individuals affected by cancer (Krishnasamy et al., 2023). The substantially increasing number of cancer survivors in Europe led the European Union Joint Action on Cancer Control to focus on survivorship and rehabilitation as part of the European guide on quality improvement in cancer control (European Cancer Organisation, 2020). European Union Joint Action on Cancer Control identified six areas for survivorship planning: medical follow-up, palliative care, psychological support, social rehabilitation, empowerment of cancer survivors, and coordination of care providers (European Cancer

Organisation, 2020). The survivorship care plan ensures individuals get the best possible healthcare as they go forward after treatment (European Cancer Organisation, 2020).

What it means to be a survivor may vary across cultures, and some individuals may prefer a different term to describe themselves. In consultation with a patient and public involvement and engagement (PPIE) representative, who has many years of experience supporting ethnic Chinese immigrants affected by cancer in England, this project uses the term 'patient' rather than 'survivor' for the empirical phases. This terminology decision was informed by public preference and Chinese cultural understandings of illness. Within Chinese culture, the term 'survivor' is often associated with someone who has experienced a serious illness, undergone substantial treatment, and then fully recovered.

### 2.2.4 "Co-cancer survivors" – informal caregivers

Informal caregivers are defined as individuals (e.g. adult children, spouses, parents, friends, and neighbours) who provide unpaid care and typically within the home setting (Biegel et al., 1991). Their role often extends over months or years and involves substantial time and energy, encompassing physical, emotional, social and financial demands (Biegel et al., 1991). The value and beliefs about caregiving is influenced by how care is culturally constructed within society (Ng and Indran, 2021). In East Asian contexts, culture norms regarding filial piety ("xiao" in Chinese) shape family behaviour (Marshall et al., 2013). Caring for ageing parents is regarded as a matter of honour and duty, and children need to make the utmost effort to care for their elderly parents (Du, 2022). Additionally, Chinese people advocate collectivist values which emphasise group interests over individual interests, and Chinese people are perceived to be obligated to take care of family members and older people (Du, 2022). In the UK and most western countries, individualistic societies typically champion independence and self-determination, and the receipt of caregiving may represent a reliance on others (Ng and Indran, 2021). Within Western cultures, older white adults are more likely to receive care primarily from their spouses rather than from their children (Lin et al., 2021).

Caregiving burden is defined as the distress that caregivers feel as a result of providing care (Given et al., 2001). Informal caregivers have been called "co-cancer survivors" to indicate that they have unique needs for support alongside the patient (Marshall et al., 2013). Informal caregivers of patients with cancer were more likely to co-reside with the patient and to provide greater than 20 hours of care per week than other caregivers (Washington et al., 2015). There are several distinctive differences between the experience

of caregiving for individuals with cancer from that of other chronic health conditions (Kent et al., 2016). Firstly, cancer recurrence and uncertainty regarding progression are distinctive features of the cancer experience, creating significant psychological distress for both patients and their informal caregivers (Washington et al., 2015). Secondly, caring for an individual with cancer requires informal caregivers to assume multiple roles and possess multidimensional knowledge (Lin et al., 2021). For example, patients with cancer experience symptoms and treatment-related toxicities from multimodal therapies and informal caregivers are often required to provide complex home-based care, including symptom management and treatment monitoring (Lund et al., 2014). The cancer care continuum includes several inflection points such as diagnosis, treatment, survivorship, recurrence, progression, and end of life (Washington et al., 2015). Each of these stages bring different challenges, resulting in fluctuating levels of caregiving burden and continual adjustments (Lin et al., 2021).

Although the definition of an informal caregiver can broadly include non-family relationships, such as friends, within the Chinese cultural context caregiving is understood predominantly as a family responsibility. Therefore, in this project, the term informal caregiver refers only to family members.

### 2.2.5 Informal caregivers in Scotland

There are an estimated 10.6 million informal carers (roughly one in five adults) in the UK providing unpaid care for their ill, older, or disabled family members or friends (Nuffield Trust, 2024). Approximately 800,000 people providing such unpaid care cost an estimated £13.1 billion every year to replace the care they provide (Scottish Government, 2022b). In Scotland, the majority (81%) of informal carers are female, 59% are aged over 55 years old, and 71% provide more than 35 hours of care per week (Carers Scotland, 2023a). Ninety percent of informal carers in Scotland provide care for someone with a long-term health condition or illness (Carers Scotland, 2023a). The relationship between informal carers and patients is relatively evenly distributed, with 35% caring for a parent or parent-in-law, 34% for a spouse or partner, and 38% for a son/daughter-in-law, 11% of another relative and 3% for someone else such as a friend or neighbour (Carers Scotland, 2023a). Notably, in this national survey, only 2% of respondents come from Black, Asian, or other ethnic groups, highlighting the underrepresentation of ethnic minority carers in current data (Carers Scotland, 2023b).

In Scotland, a range of organisations and policy initiatives are in place to support informal caregivers. The Scottish national carer organisations included: Carers Scotland, Carers Trust Scotland, Shared Care Scotland, Minority Ethnic Carers of People Project and Coalition of Carers in Scotland (Scottish Government, 2020). From March 2026, the Scottish Government plan to replace Carer's Allowance Supplement with the Scottish Carer Supplement for people in receipt of carer support payment (Scottish Government, 2025). Although the total annual amount remains £587, the payment structure has changed from two lump sum payments per year to an automatic weekly addition of £11.29 (Scottish Government, 2025).

### 2.2.6 Health inequalities, disparities, equity: what's in the name?

The terms "health inequalities," "health disparities," and "health equity" have become increasingly prominent in global public health and medicine. Health inequalities broadly refer to differences in health status, health outcomes, or access to health-related resources between individuals or population groups (World Health Organization, 2013a). This concept originally referred primarily to socioeconomic differences in health but has since broadened to encompass differences associated with ethnicity, gender, migrant status or national origin, sexual orientation, gender identity, disability, and religion (Bleich et al., 2012; World Health Organization, 2013a). Similarly, the term "health disparities" originally referred primarily to health differences between ethnic groups but has evolved to encompass health differences across broader dimensions of social advantage and disadvantage (Braveman, 2025). Consequently, health inequalities and health disparities are now commonly used to describe health differences associated with social disadvantaged groups.

The term "health equity" means that everyone has a fair and just opportunity to be healthy as possible (World Health Organization, 2013a). Pursuing health equity involves reducing and ultimately eliminating inequalities or disparities in health (Braveman, 2025). Health inequities are a subset of health inequalities or disparities that are considered systematic, avoidable, and unfair. All health inequities are health inequalities/disparities, but not all health inequalities/disparities are necessarily inequities (Braveman, 2025). Proving that a health difference is an inequity can be difficult, given the stringent standards for causal inference in medical science (Braveman, 2025). Therefore, throughout this project, the terms health inequalities and health disparities are used when describing health differences among ethnic Chinese immigrants in Scotland. The term health inequity is reserved for

contexts in which there is sufficient basis to interpret these differences as avoidable and unfair.

### 2.2.7 Health inequalities in cancer care

In the UK, health inequalities are often analysed and addressed by policy across four types of factors: socioeconomic status, geographical location, racial/ethnic background, and socially excluded groups (e.g. people experiencing homelessness) (Danielle et al.2020). Cancer is increasingly emerging as a major proximal driver of health inequalities (Tweed et al., 2018). Scott and Hoskin (2024) reported that, in the UK, inequalities in cancer care are reflected in access to services and timely diagnosis. Socioeconomic status acts as a fundamental determinant of health, shaping individuals' ability to access information, afford care, and remain motivated to engage in health enhancing behaviours (Jolidon et al., 2024). The Scottish Government has highlighted that people from ethnic minority groups are often less likely to engage with cancer services and less likely to participate in cancer screening programmes (Scottish Government, 2023b). This reduced engagement, in turn, increases the likelihood of cancer being diagnosed at a later stage (Scottish Government, 2022a). Moreover, the overall incidence of cancer (excluding non-melanoma skin cancer) was 24% higher in the most deprived areas compared with less deprived, with 736 per 100,000 and 594 per 100,000, respectively (Public Health Scotland, 2025a). Health inequalities in Scotland are evident in specific cancer types, with large socioeconomic differences evident for lung, head and neck, prostate and cervical cancer (Public Health Scotland, 2025a). Lung cancer is over three times higher in the most deprived areas, largely due to higher levels of smoking (Public Health Scotland, 2025a). Reducing socioeconomic inequalities in cancer risk through improving cancer screening and reducing rates of smoking in more deprived areas are proposed by Public Health Scotland (2025a).

### 2.2.8 Cancer care inequalities among ethnic minority groups

Despite immigrants residing in very high HDI countries with advanced healthcare systems, inequalities across the cancer care continuum persist (Bansal et al., 2012). Ethnic minority groups experience variations in cancer incidence and outcomes due to genetics, cultural differences, and socioeconomic status within their communities (Martins et al., 2022). These disparities are evident at multiple stages of cancer care, from early detection to cancer survivorship support (Forbes et al., 2011; Walter et al., 2012).

In the UK, health inequalities in cancer care among ethnic minority groups are reflected in multiple forms of delay, including appraisal delay, illness and behavioural delay, scheduling delay, and treatment delay (Scott and Hoskin, 2024). Delays in the cancer care pathway often stem from appraisal stage (Scott and Hoskin, 2024). Niksic et al. (2016) examined how cancer symptom awareness and barriers varied by ethnicity and found that Chinese participants had the lowest recognition of cancer symptoms, with 49% lower odds compared with White British. Because of this low awareness of cancer symptom, in the UK, patients from ethnic minority groups had the highest proportion of diagnosis with cancer via the emergency route followed by white patients (Martins et al., 2022). When appraisal delay occurs, it leads to a delay in decision to seek medical assistance, known as illness and behavioural delay (Scott and Hoskin, 2024). A systematic review reported that limited knowledge, cultural beliefs, and language barriers further exacerbate illness and behavioural delays (Saunders et al., 2021).

The first two types of delay in cancer care related to personal factors, whereas scheduling and treatment delays are more closely associated with healthcare system issues. Scheduling delay among ethnic minority groups was also compounded by the individual's understanding of the National Health Service (NHS) system, and the ability to navigate telephone or digital triage systems (Sørensen, 2020). Patients from ethnic minorities reported fewer positive experiences across various dimensions of care including general practice (GP) access (Saunders et al., 2021). In terms of treatment inequality, bias in doctor-patient interactions can contribute to disparities in cancer treatment, often driven by subconscious stereotypes or assumptions about a patient's ethnicity, gender, or socioeconomic status (Schinkel et al., 2016). For example, a study in England showed that mixed, Black and Asian patients with cancer were more likely to have visited their GP on three or more occasions before being referred for further investigations, irrespective of age, sex and socioeconomic status (Lyratzopoulos et al., 2012). Such biases can result in inequalities in the timeliness and quality of cancer diagnosis and treatment for underrepresented populations (Scott and Hoskin, 2024).

Regardless of disparities in caregiving roles, some informal caregivers from Black, Asian, and ethnic minority groups reported higher rates of metal health problems, partly due to racism and discrimination in accessing services (Mental Health Foundation, 2024). Carers from ethnic minority groups reported feeling overlooked, inadequately supported, and disconnected from the policy process (Scottish Government, 2018a). The Good Practice Briefing reported recommendations for caring for informal caregivers from ethnic minority

groups included: providing translated materials; providing culturally sensitive services; improving health and wellbeing; creating a diverse and inclusive workplace; involving Black, Asian and minority ethnic carers in policy and practice (Carers Scotland, 2023b).

## 2.3 The 2023-2033 National Cancer Strategy for Scotland

The Scottish Government launched a new 10-year cancer strategy in 2023, which aims to *"significantly cut the numbers of people diagnosed with later stage cancer and to reduce the health inequalities associated with the disease"* (Scottish Government, 2023d) (Figure 2-1). Prior to this, the national approach was guided by the "Better Cancer Care Plan", which established the foundation for quality improvement within NHS Scotland across six key domains, including person-centred, safe, effective, efficient, equitable and timely care (Scottish Government, 2008). In 2016, the Chief Medical Officer for Scotland used the first Annual Report to encourage the practice of Realistic Medicine (Scottish Government, 2016). The aim of Realistic Medicine is to improve patient care by ensuring that people receive appropriate and beneficial care that is not only evidence based but also aligns with their personal preferences (Scottish Government, 2016). Underlying this Realistic Medicine approach, the healthcare system in Scotland places patients at the centre of care, encouraging healthcare professionals to treat them as equal partners in the decision-making process (Scottish Government, 2018b).

The new 10-year cancer strategy places a much stronger and more explicit emphasis on equitable cancer care than the earlier "Better Cancer Care Plan" (Scottish Government, 2008; Scottish Government, 2023d). In this strategy, actions to tackle inequalities are addressed from prevention and diagnosis through to treatment and post-treatment care (Scottish Government, 2023c). Additionally, the new strategy highlights that the Scottish Government will be supporting all people affected by cancer, including family and friends (Scottish Government, 2023a). Further, the Scottish Government has committed to improving the provision of cancer information to better meet patients' needs, alongside the development of education and training resources to support healthcare professionals in delivering person-centred care (Scottish Government, 2023a).

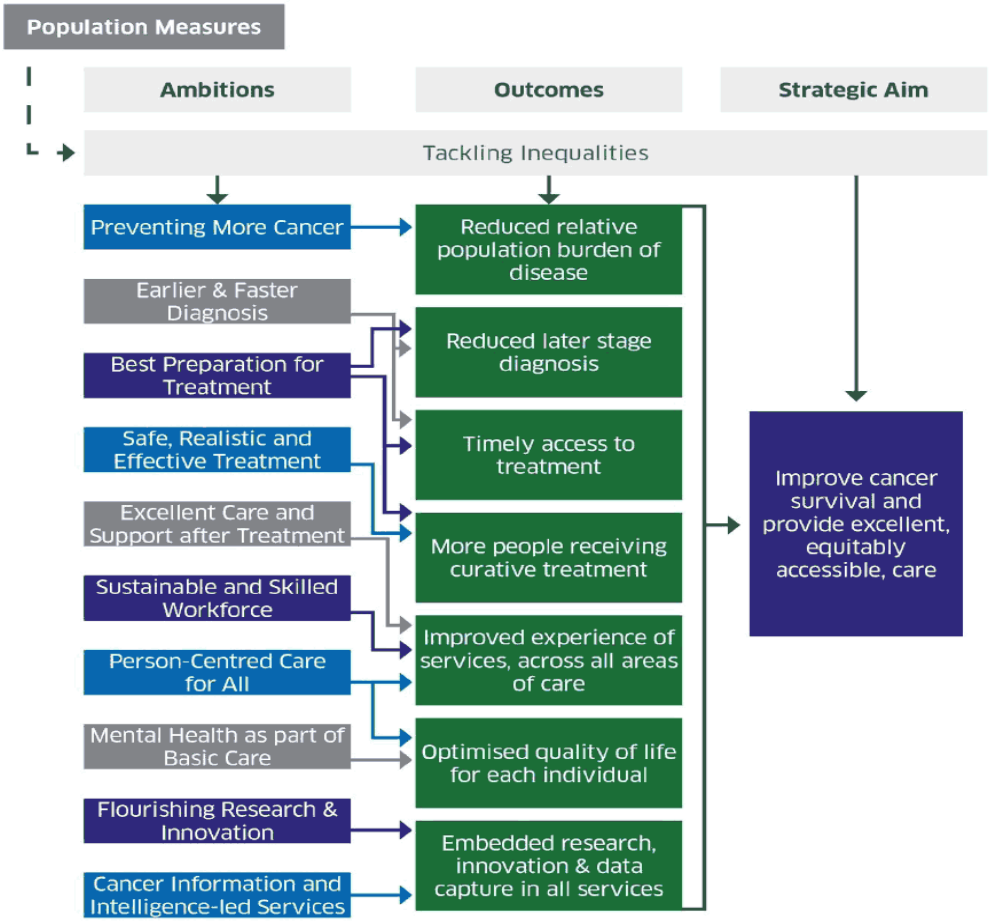



Figure 2-1 10-year cancer strategy between 2023 to 2033 (Scottish Government, 2023b)

To make the strategy realistic, the Scottish Government has divided this ten-year plan into three phases, with the aim to ensure that everyone affected by cancer is aware of the support services available and knows how to access them (Scottish Government, 2023a). The first three-year action plan (2023-2026) focuses on stabilising systems and services. The second phase (2026-2029) aims to renew services and strengthen cancer control, while the third phase (2029-2033) is designed to redesign services and harness innovations (Scottish Government, 2023a). The first phase of the Cancer Action Plan (2023–2026) sets out 133 actions (Scottish Government, 2023a). Actions related to help with ethnic minority groups included enhancing public education and empowerment, exploring the role of community workers in facilitating earlier diagnosis and encouraging NHS to collaborate with local communities (Scottish Government, 2023a).

## 2.4 Ethnic Chinese immigration in the UK and Scotland

The current definition of an international migrant refers to any person who has a change of usual residence (United Nations. Department of and Social Affairs. Statistics, 1998). Individuals choose to migrate for different kinds of reasons, including economic, political

or environmental reasons, income differences between developed and developing countries, inequitable distribution of social resources, violence or civil strife, or natural disaster in their birth countries (Castles et al.2020). Recent global immigration patterns reveal that, as of mid-2020, over 40% of the world's international immigrants originated from Asia, with a substantial number residing in very high HDI countries of the Western world (International Organisation For Migration, 2024). Definitions of Asian immigrants vary depending on the perspective or classification system used. In this project, the scope of "Asian immigrants" was defined according to the World Migration Report published by the International Organization for Migration. Accordingly, Asian immigrants were considered to include "*individuals whose origins lie in Southeast Asia, South Asia, East Asia, the Middle East, and Central Asia, based on geographical classification*" (International Organisation Migration, 2024).

In the UK, London became the most popular destination with 40% of its residents born abroad compared to only 10% for the whole of Scotland (Mihnea, 2024). Immigration trends in the UK have shifted since the 2016 European Union (EU) referendum, with net migration from the EU becoming negative as more EU citizens leave than arrive (Sumption et al., 2025). This change has been attributed to factors such as reduced attractiveness of working in the UK and increased uncertainty surrounding the political climate (Ben and Madeleine, 2025). In contrast, employment opportunities in the UK have become more attractive for non-EU citizens, particularly international students such as those from China (Ben and Madeleine, 2025). The proportion of international students holding skilled worker visas increased from less than 1% in 2016 to around 10% in 2022, and these people contributed more to long-term net migration in recent years than in the past (Sumption et al., 2025). Moreover, the Migration Observatory reported that 38% of East Asian migrants to the UK arrived through family unification, 29% for study, and 17% for work, and the remaining 16% for other reasons (Mihnea, 2024).

Today, Scotland is home to a significant number of Chinese people. Prior to the 1950s, few Chinese settled in the UK, and even visitors from China were rare (Barclay Price, 2024). The historical context of ethnic Chinese immigrants to the UK can be traced back to the 19th century, when a small number of Chinese seamen and traders began to settle in major port cities such as Liverpool, London, and Cardiff (Benton and Gomez, 2008). The first permanent large-scale settlement of Chinese occurred in the 1950s, when economic boom and labour shortages led to a relaxation of immigration laws to encourage immigrants from overseas British and commonwealth countries (Benton and Gomez, 2008). At that time,

migration from Hong Kong's New Territories brought predominantly poorer rural Chinese who established restaurants and catering businesses across the UK (Minority Rights Group, 2022). In contrast, at that time, migrants from Malaysia and Singapore were often more educated and economically advantaged, entering professional occupations or establishing business (Minority Rights Group, 2022). Nowadays, these ethnic Chinese immigrants consisted of the older generation Chinese immigrants in the UK, who are aged 60 and above and arrived here 30 or 40 years ago (GOV.U.K., 2020). The older generation were generally poorly educated with limited English proficiency (GOV.U.K., 2020).

In the 1990s a second wave of immigrants from Hong Kong came to the UK following the British handover of Hong Kong to China, and these immigrants were generally well educated, and many went into business or other professions (Minority Rights Group, 2022). While historically, many Chinese immigrants came from Hong Kong and Southeast Asia, the current trend sees a significant increase in people from mainland China, who are primarily seeking work and educational opportunities in the UK (BBC News, 2024). Not like the early ethnic Chinese immigrants for catering and restaurant services, currently, 12.8% of people from Chinese ethnic group were in 'higher managerial, administrative and professional occupations' in the UK, which was the second highest percentage out of all ethnic groups after the India group (GOV.U.K., 2020).

The ethnic Chinese immigrants present one of the largest and fastest growing global immigrant groups (United Nations, 2024). Globally, approximately 10.5 million people of Chinese origin reside overseas, with English-speaking developed countries being particularly popular destinations (Armstrong, 2022; United Nations, 2024). The USA hosts the largest Chinese population (5.82 million), followed by Canada (1.95 million) and Australia (1.45 million) (Textor, 2024). In Europe, France remains the most popular destination (0.75 million), followed by the UK (0.48 million) and Italy (0.31 million) (Textor, 2024). Scotland is an ethnically and culturally diverse country, with 12.9% of the population having a minority ethnic background (Scotland Census, 2025). Among Asian ethnic groups in Scotland, the Pakistani population remained the largest (50,000) people, followed by Chinese (34,000) and Indian (33,000) (Scotland Census, 2025). The overall proportion of the Chinese population in Scotland has increased from 0.64% to 0.87% over the decade (Scotland Census, 2025). However, the number of ethnic Chinese immigrants living in Scotland is much smaller than that of England and Wales, with around 34,000 compared with approximately 440,000 (Office for National Statistics, 2022; Scotland Census, 2025). In terms of the geographic distribution of ethnic Chinese people in

Scotland, Edinburgh and Glasgow each host around 10,000 residents (Scotland Census, 2022). Ethnic Chinese people account for 2.9% of the local population in Edinburgh, followed by Glasgow (2.3%), East Renfrewshire (1.2%), East Dunbartonshire (1.1%), Aberdeen City (1.0%), Dundee City (0.9%), Stirling (0.6%), Fife (0.5%), Midlothian (0.5%), and West Lothian (0.4%) (Scotland Census, 2022).

When referring to ethnic Chinese immigrants, there is often an assumption that Chinese immigrants represent a homogenous ethnic group. In reality, this community is highly heterogeneous. Within China, people originate from different provinces and speak distinct dialects. Furthermore, the diversity of ethnic Chinese immigrants is also shaped by their country of birth, as a considerable proportion of overseas Chinese were born in Southeast Asian countries such as Singapore, Malaysia, and Indonesia (Lockard, 2013). The term ethnic Chinese immigrants is used throughout the whole thesis, referring more broadly to people of Chinese ancestry who may have been born outside of China but who identify as ethnically Chinese. Additionally, according to European Migration Network's new asylum and migration glossary, the definition of first generation immigrants is an individual born in one country who has permanently resettled in another country (European Commission, 2025). The meaning of second generation immigrants is that the person who was born in and is residing in a country where at least one of their parents previously entered as a migrant (European Commission, 2025). In the context of this project, the term ethnic Chinese immigrants refer to first-generation documented migrants. These individuals differ from second- and later-generation Chinese immigrants, as lifelong exposure to the host culture significantly shapes acculturation processes, including language proficiency, cultural health beliefs, and lifestyle (Zeng et al., 2025).

As this project aimed to understand unmet needs, experiences, and beliefs among ethnic Chinese immigrants living within the Scottish healthcare context, greater emphasis was placed on individuals who were more established in Scotland and had greater opportunities to interact with local healthcare and community services. Despite the large number of Chinese students living in the UK, as noted earlier in this section, they were not specifically targeted in this project. Many Chinese students are temporary residents, particularly those enrolled in one-year postgraduate programmes. Their relatively short period of residence may limit their exposure to, and experience of, the Scottish healthcare system and cancer-related services. Given the project's focus on migration and cultural transition, the term "ethnic Chinese immigrants" therefore referred to first-generation immigrants living in Scotland and did not include temporary international students.

## 2.5 Chinese cultural beliefs in healthcare

Culture involves ways of thinking and acting in the word that distinguishes one person from another, or groups of people from each other (Hofstede, 1980). Culture becomes deeply rooted in people over time and through their experiences within social groups (Hofstede, 1980). Intercultural differences exist in values, expectations, nuances of meaning, attitudes, language, environment, and perceptions of individuals (Ahmed et al., 2016). China has distinct cultural values shaped by Confucianism, a cornerstone of Chinese moral and social traditions for millennia, which is deeply embedded in Chinese society and influences people's lifestyle, values, and behaviour patterns (Badanta et al., 2022). Confucian principles extend beyond China and have influenced broader Eastern cultures, including those of the Filipino and Vietnamese communities (Toyokawa and Toyokawa, 2013). The core beliefs of Confucianism are Ren (benevolence/humanity), Li (propriety/ritual), Yi (righteousness), Zhi (wisdom), Xin (sincerity/faithfulness) and Xiao (filial piety) (Badanta et al., 2022).

Culture shapes how diseases are defined and understood, including beliefs about their causes, treatment process, and curability (Arnault, 2018). A scoping review by Badanta et al. (2022) synthesised that health in Confucian context can be affected by beliefs, decision-making, healthcare behaviours, dignity, and mental health. In relation to the beliefs of cancer, the cognition on cancer among Chinese people is different from people in Western countries; Chinese people believe that the occurrence of cancer is determined by fate and is not affected by one's own behaviour (Shang et al., 2015). People with Chinese cultural background believe cancer diagnosis is a misdeed committed in a present or previous life, and nothing can be done to reduce the occurrence of cancer, which in directly affected their cancer prevention behaviour (Guo et al., 2021; Jiang et al., 2023).

Regarding cancer survivorship, Confucian philosophy advocates family harmony, filial piety, and social stability, consequently, the decision-making often prioritises family involvement (Badanta et al., 2022; Meng et al., 2024). This collectivist cultural norm often leads family members to make treatment decisions on behalf of patients, particularly in the context of serious illnesses such as cancer (Meng et al., 2024). For example, when decisions regarding the disclosure of a cancer diagnosis or the choice between aggressive treatment and palliative care, family members often work as the key decision-makers, expressing that this protects the patients (Yang et al., 2022). This cultural influenced family decision-making is very different compared with Western medical ethics, which

emphasises patient autonomy (Kilbride and Joffe, 2018). Confucian philosophy underscores social stability and maintaining harmonious social relationship, in which individuals have high respect for authority figures, such as healthcare professionals (Badanta et al., 2022).

In addition to Confucian values, traditional Chinese medicine (TCM) has also strongly influenced healthcare beliefs and practices. TCM is a distinct medical system that has evolved in China for more than 5000 years and adopts a holistic approach to health (Wu, 2021). According to the TCM holistic model, physical health is determined by a person's emotional functioning and is also subject to socioecological influences (Leung, 2011). Chinese people believe that daily conduct should aim to maintain the balance of 'yin' and 'yang' and ensure the harmonious flow of 'qi' (vital energy) within the body (Leung, 2011). 'Yin' and 'yang' are general terms describing two opposite yet complementary and interrelated forces found in all aspects of nature (World Health Organisation, 2007). Within TCM theory, disharmony between 'yin' and 'yang' is considered the fundamental cause of pathological changes and illness (Leung, 2011).

## 2.6 Knowledge gaps and overall research aim of this project

Drawing on the background outlined in Sections 2.2 to 2.5, the key knowledge gaps in supportive cancer care relate to 1) how Chinese culture shapes the unmet needs, wellbeing, care experiences of ethnic Chinese immigrants following a cancer diagnosis, and 2) how supportive cancer care services can better respond to their needs. To address these gaps, the overall aim of this project is to investigate the unmet needs, wellbeing, care experiences, and beliefs towards cancer among ethnic Chinese immigrants living in Scotland. In doing so, the findings may inform the implementation of Scotland's new 10-year Cancer Strategy and contribute to the delivery of equitable cancer care for all population groups.

To achieve the overall aim of this project, the thesis is structured into five phases. Each phase has its own objectives, but collectively contribute to achieving the overall aim of the project. Figure 2-2 present the overall flow of this project, and Table 2-1 presents the objectives, rationale for investigating the objectives and corresponding research questions for each phase of this project.

## 2.7 Chapter summary

This chapter has outlined both the historical and contemporary context underpinning this project. It has also provided the definitions of the terms “cancer survivors”, “informal caregivers”, “health inequalities, disparities and equity”, and “ethnic Chinese immigrants”, and explained how these terms were adopted in this project. Together with Chapter 1 (Introduction), it highlights the existing gaps and the rationale for this project. The next chapter presents the theoretical framework guiding this project.

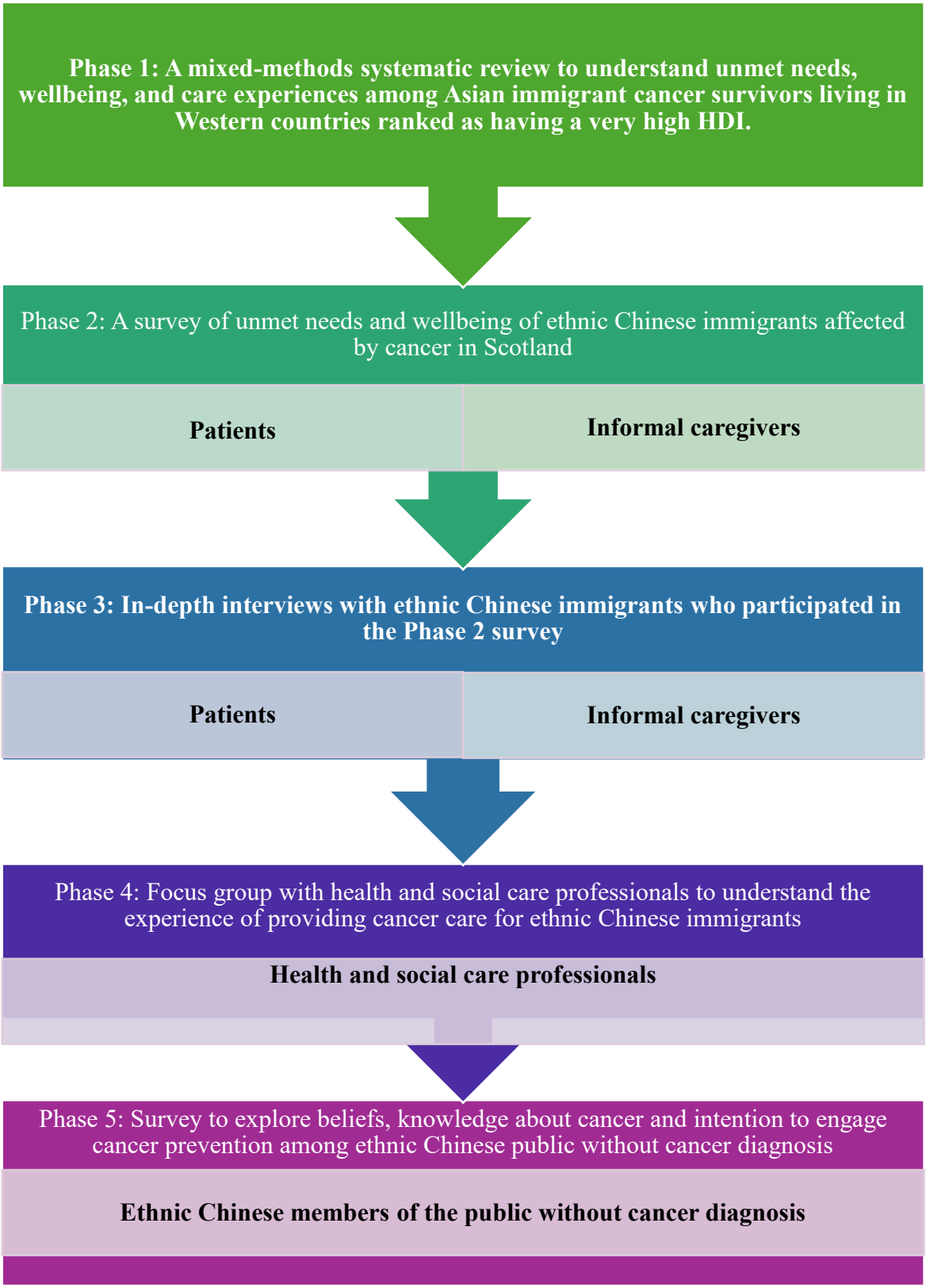



Figure 2-2 Flow chart of this project

Table 2-1 Overview of research objectives and corresponding research question(s) for each phase of the project

| | **Rationale** | **Objectives** | **Corresponding research question(s)** |
|---|---|---|---|
| Phase 1: A mixed-methods systematic review to understand unmet needs, HRQoL and care experiences among Asian immigrant cancer survivors living in western countries ranked as very high HDI | Synthesising research evidence from countries with a similar level of wealth to the UK helped identify gaps in knowledge relating to unmet needs, HRQoL and care experiences among Asian immigrant patients with cancer and informed the empirical phases of this project. | To identify the unmet needs, care experiences, and factors affecting the HRQoL of Asian immigrant cancer survivors who live in western countries ranked as very high HDI. | What are the unmet needs, factors affecting HRQoL and care experience of Asian immigrant cancer survivors living in very high HDI western countries? |
| Phase 2: A survey of unmet needs and HRQoL of ethnic Chinese immigrants affected by cancer in Scotland | This served as the first step in developing a basic understanding of the unmet needs and HRQoL of ethnic Chinese people affected by cancer in Scotland specifically. The survey was conceptualised to identify the prevalence of unmet needs and the aspects of HRQoL that were most impaired. | 1) To explore the unmet needs, HRQoL and care experience of ethnic Chinese patients with cancer living in Scotland.<br>2) To explore the HRQoL and care experience of informal caregivers supporting ethnic Chinese patients with cancer in Scotland. | What are the unmet needs, HRQoL, and care experiences among the ethnic Chinese immigrants affected by cancer in Scotland? |

| | | | |
|---|---|---|---|
| Phase 3: A qualitative exploration of care experiences of ethnic Chinese immigrants affected by cancer in Scotland | The quantitative findings from Phase 2 required in-depth exploration to understand how any needs were experienced and why any issues occurred. This phase could also allow to pinpoint how proposed solutions to address issues and enhance equality in cancer care in Scotland could be aligned with the preferences of ethnic Chinese immigrants affected by cancer. | 1) To understand the lived experiences of receiving care and interacting with care services from the perspective of ethnic Chinese immigrants affected by cancer in Scotland.<br>2) To better understand how unmet needs and problems affecting HRQoL are experienced by ethnic Chinese immigrants affected by cancer in Scotland. | How do ethnic Chinese immigrants affected by cancer in Scotland experience receiving care and interacting with care services about their healthcare needs? |
| Phase 4: A focus group with health and social care professionals to understand their experiences of providing cancer care to ethnic Chinese immigrants | Understanding the experiences of providing care to this population was considered important to help identify shared challenges and drivers of future attempts to enhance care. Including perspectives from health and social care professionals were conceptualised as bringing a diverse perspective to enrich and perhaps validate or challenge the findings from the previous phases | To bring together different perspectives and understand the experiences of health and social care professionals in interacting with and providing care to ethnic Chinese immigrants affected by cancer in Scotland. | How do health and social care professionals in Scotland experience interacting with and providing care to ethnic Chinese immigrants affected by cancer? |

| | | | |
|---|---|---|---|
| | to generate a more complete picture of care experiences in this population. | | |
| Phase 5: An exploratory survey on beliefs, knowledge about cancer and intention to engage in cancer prevention among ethnic Chinese communities without a cancer diagnosis | Findings from Phases 3 and 4 indicated that ethnic Chinese immigrants affected by cancer in Scotland often experienced cancer as taboo within their communities, which fostered secrecy and impaired help-seeking for cancer-related needs. It was hypothesised that cancer-free ethnic Chinese immigrants might have gaps in cancer knowledge or hold unhelpful beliefs. These could affect their experiences if they were later diagnosed with cancer and received cancer care.<br>It was therefore considered important to explore the magnitude of beliefs, knowledge and intention to engage in cancer prevention among cancer-free ethnic Chinese immigrants that might be considered problematic, and explore any possible variation in responses across demographic groups. | 1) To explore knowledge and beliefs about cancer among ethnic Chinese immigrants without a cancer diagnosis in Glasgow.<br>2) To explore intention to engage with cancer prevention among ethnic Chinese immigrants without a cancer diagnosis in Glasgow.<br>3) To explore variation in responses among different demographic subgroups. | 1) What beliefs about cancer are prevalent among cancer-free ethnic Chinese immigrants in Glasgow?<br>2) What is the level of knowledge about cancer and engagement with cancer prevention among cancer-free ethnic Chinese immigrants in Glasgow and what factors influence intention to engage in cancer prevention?<br>3) Are beliefs about cancer different between demographic groups (e.g. age, education)? |

# Chapter 3 : Theoretical underpinning

## 3.1 Introduction

Research is the process by which evidence is generated to support, reject, or modify theories and develop new ones (Parahoo, 2014). Theory refers to an abstract generalisation that explains how phenomena are interrelated (Merton, 1968). Theories differ in their level of generality and abstraction, and in nursing they are commonly classified as grand, middle-range, or micro/practice level theories (Polit and Beck, 2017).

So far, there is no relevant systematic review that identifies the exact number of theories, models, or frameworks available to support individuals affected by cancer. Nekhlyudov et al. (2019) proposed a quality cancer survivorship framework and outlined its implications for clinical practice by identifying what support people with cancer need, how it should be delivered, and when it should be provided. Delivering high quality survivorship care based on population needs is desirable (Nekhlyudov et al., 2019). Krishnasamy et al. (2023) revisited the concept of supportive cancer care, which is a conceptual model published almost 20 years ago by Fitch (2008). The supportive cancer care framework is well suited for examining patients' unmet needs (Krishnasamy et al., 2023). It adopts a person-centred approach and supports optimal patient experiences and outcomes across the entire cancer pathway, including informational, emotional, practical, physical, psychological, social, and spiritual domains (Krishnasamy et al., 2023). The person-centred nursing framework developed by McCormack and McCance (2010) is a middle-range theory for general nursing practice. This middle- range theory emphasises that care should be delivered with respect to the individual's values, preferences, needs, and autonomy (McCormack and McCance, 2010).

When this project was first conceived, person-centred care framework developed by McCormack and McCance (2010) was the primary theory informing its development. However, as the project evolved, it became clear that additional theories and frameworks were needed to guide specific components. Therefore, the conceptual framework for implementing person-centred care, the social determinants of health framework and the theory of planned behaviour were included. These theories and frameworks operate at the practical level of theory. The use of theories and frameworks within this project was dynamic and shaped by a problem-solving approach. This chapter provides an overview of

the theories, models, and frameworks that informed this project, explaining why they were included and how they contributed to the development of this project.

## 3.2 Rationale for including person-centred care framework

As introduced earlier, there is increasing recognition of the importance of delivering person-centred care. World Health Organization (WHO) has developed policy frameworks in which patient centredness is a core competency for health workers and a fundamental component of healthcare quality (World Health Organization, 2013b). Scotland's new 10-year Cancer Strategy emphasises that cancer care should be delivered in a respectful, individualised, and culturally appropriate way (Scottish Government, 2023d). Although person-centred care is not a theory developed specifically for cancer nursing practice, it aligns closely with relevant policy requirements for clinical care. It was therefore selected as the core theory underpinning this project.

Person-centred care is based on the philosophy that care should focus on the individual, not just a cluster of diseases (Epstein, 2000). Person-centred care assumes that patients can identify their own needs and be actively involved in decisions about their care (Lutz and Bowers, 2000). The acknowledged dimensions of person-centred care comprised seven dimensions (Figure 3-1) (Gerteis et al., 2002; McCormack and McCance, 2010). Furthermore, the person-centred nursing process focuses on building meaningful connections through key processes such as respecting individuals' values, engaging authentically, being present, sharing decisions, and delivering holistic care (McCance and McCormack, 2025).

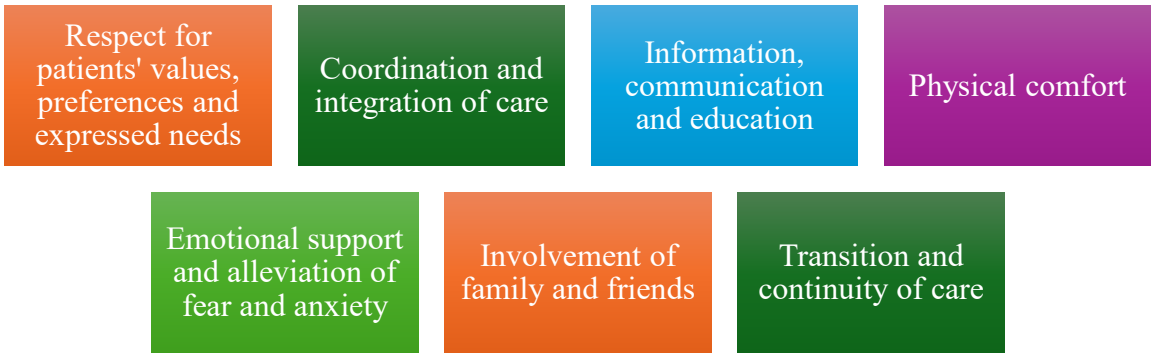



Figure 3-1 Dimensions of person-centred care (Gerteis et al., 2002; McCormack and McCance, 2010)

## 3.3 Rationale for including conceptual framework to implement person-centred care

The overall aim of this project is to investigate unmet needs, wellbeing, care experience, and beliefs towards cancer among ethnic Chinese immigrants living with cancer in Scotland. The application of person-centred care theory aligns with clinical care policy in Scotland, but there is still a need to understand how this project could be designed to achieve this. Santana et al. (2018) proposed a conceptual framework for the implementation of person-centred care (Figure 3-2), highlighting three key domains: structure, process, and outcomes.




**Structure (Healthcare system/Organisation level)**

- Creating a PCC culture
- Co-designing the development and implementation of educational programmes
- Co-designing the development and implementation of health promotion and prevention programmes
- Supporting a workforce committed to PCC
- Providing a supportive and accommodating PCC environment
- Developing and integrating structures to support health information technology
- Creating structures to measure and monitor PCC

**Process (Patient - Healthcare Provider Level)**

- Cultivating communication
- Respectful and compassionate care
- Engaging patients in managing their care
- Integration of care

**Outcome (Patient-Healthcare Provider - Healthcare systems )**

- Access to care
- Patient reported outcomes

Figure 3-2 Framework for implementation of person-centred care (Santana et al., 2018)

In the structure level, it emphasises the importance of collaboration and empowerment of patients, communities, and organisations in the design and delivery initiatives (Santana et al., 2018). This principle guides the inclusion of patient and public involvement and engagement (PPIE) activities and the adoption of a community-collaborative approach. At the process level, integrated care refers to the coordination of support across the cancer care pathway, with informal caregivers recognised as key stakeholders (Santana et al., 2018). Accordingly, this project included informal caregivers to reflect the understanding of care as an integrated process that extends to the whole family. At the outcome level, the implementation of person-centred care framework informs the use of patient reported outcome measures (PROMs) to capture information directly from patients, ensuring that outcomes reflected patients' own perspectives and experiences of care.

## 3.4 Rationale for including social determinants of health framework

When designing the demographic questionnaire for the Phase 2 survey (Chapter 6), it was recognised that this process should be guided by a relevant theory or framework to better address the overall research aim. As outlined in the Background (Chapter 2), socioeconomic status affects health inequalities in cancer care. Social determinants of healthcare broadly defines the conditions in which people are born, grow, live, work, and age, and people's access to power, money, and resources (Marmot, 2005; Solar and Irwin, 2010). Marmot (2005) proposed the "social causation" perspective, suggesting that the lower the socioeconomic position, the greater the risk of poor health outcomes, thereby reinforcing health inequities. The social determinants of health framework (Figure 3-3), proposed by the WHO Commission, was identified as an appropriate framework. This framework identifies key structural factors (e.g., income, education, occupation, social class, gender, and ethnicity) as proxies for social position, which shapes health outcomes through intermediary factors like behaviour, life conditions, and psychological stressors (Solar and Irwin, 2010). Details of how the social determinants of health framework guided the development of the demographic questionnaires of this project are presented in Chapters 6 and 9.

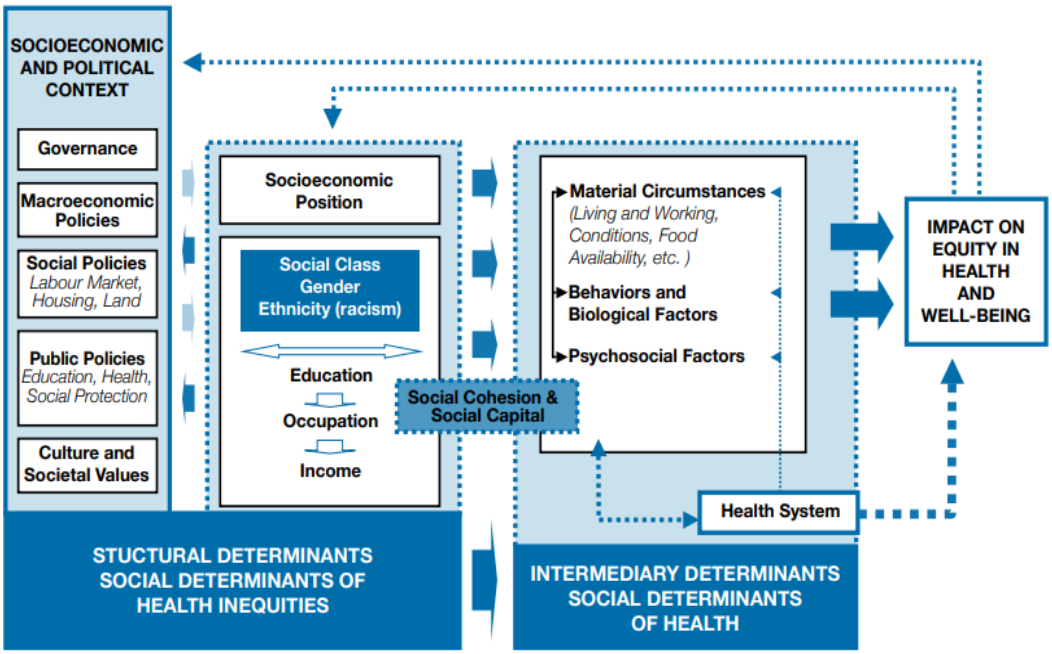



Figure 3-3 Social Determinants of Health Conceptual Framework (Solar and Irwin, 2010)

## 3.5 Rationale for including the theory of planned behaviour

The findings and reflections from Phases 2-4 highlighted the need to extend the project to understand attitudes towards engagement in cancer prevention behaviours among the ethnic Chinese immigrant public. Currently, the most widely utilised theories related to understand behaviours in healthcare are the health belief model introduced by Rosenstock (1974) and theory of planned behaviour developed by Ajzen (1991). The health belief model is a cognitive framework viewing people as rational beings who use a multidimensional approach to decision-making regarding whether to perform a health behaviour (Rosenstock, 1974). The development of the health belief model included two central elements: the belief that an action will improve health or prevent ill health; and the motivation to avoid ill health (Wright, 2015). The initial version of the health belief model identified four components: perceived susceptibility (perception of individual risk); perceived severity (extend to which a person deems the condition as serious); perceived benefits (one's opinion on the usefulness of a behaviour in decreasing risk); and perceived barriers (evaluation of the obstacles to adopting a behaviour) (Glanz et al., 2008). Other constructs were later added including "cues to action" (events, people, or things that are associated with change in behaviour) and "self-efficacy" (one's confidence to act) (Glanz et al., 2008). The health belief model emphasises an individual's evaluation of the perceived benefits and barriers to adopting a behaviour (Glanz et al., 2008).

The theory of planned behaviour (TPB) is a socio-cognitive model and classified as a middle range theory (Ajzen, 1991) (Figure 3-4). TPB posits that health behaviour is directly determined by people's intention to perform that behaviour (Ajzen, 2005). The intention to engage in or avoid a particular behaviour is shaped by three key factors: attitudes toward the behaviour, referring to the individuals' overall evaluation of the behaviour; subjective norms, which involve the perceived social pressure to perform or not perform the behaviour; and perceived behaviour control, which reflects the anticipated ease or difficulty of engaging in the behaviour (Ajzen, 2005). The perceived behaviour control is related to intention but it can also directly influence behaviour (Ajzen, 2005). Furthermore, the extent to which attitude, subjective norm, and perceived behavioural control shape intention may vary according to the behaviour and context under investigation (Ajzen, 2005). The TPB has demonstrated stronger performance in explaining behavioural intention than in predicting actual behaviour (Ritchie et al., 2021).

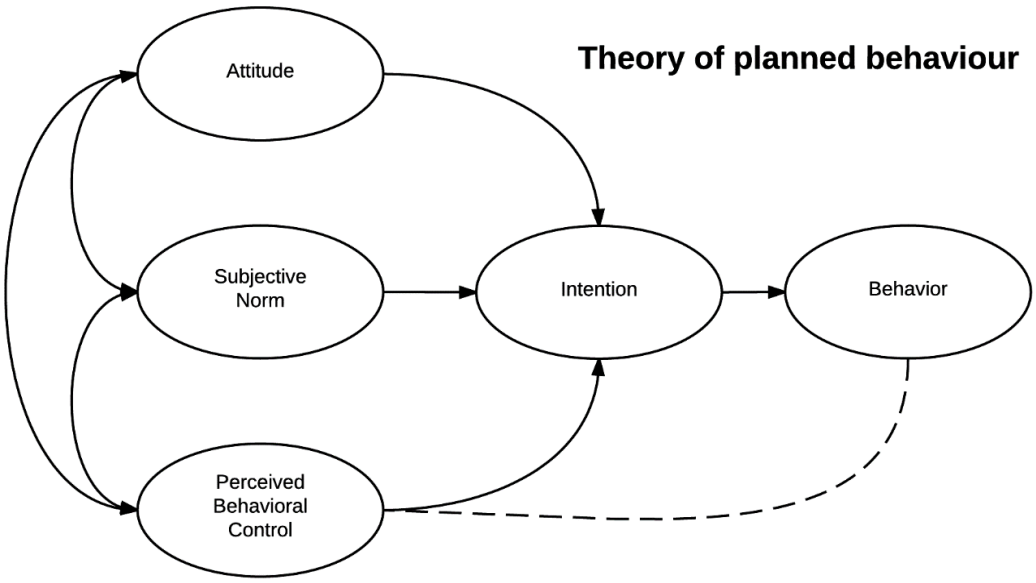



Figure 3-4 Theory of planned behaviour (Ajzen, 2005)

Finally, the TPB was selected to help interpret the findings related to cancer prevention in the Phase 5 survey (Chapter 9). The health belief model was not adopted because the purpose of extending the project to include Phase 5 was not to evaluate beliefs about the benefits and barriers associated with cancer prevention. Instead, the objective was to understand intentions, particularly how personal beliefs, attitudes and culture influence decisions about whether or not to engage in a behaviour.

## 3.6 Chapter summary

Two theories and two frameworks were applied at different stages of the project. Person-centred care theory was the primary theory informing the development of this project, aligning the project closely with World Health Organization policy and the Scottish National Cancer Strategy (2023–2033). The conceptual framework for implementing person-centred care guided the use of patient-reported outcome measures, the inclusion of informal caregivers' perspectives, and the implementation of patient and public involvement and engagement activities. The following Chapter 4 introduces these in detail. The social determinants of health framework informed the development of the demographic questionnaire used in the quantitative components of this project (Chapters 6 and 9). The theory of planned behaviour was used to guide and interpret intentions to engage in cancer prevention among ethnic Chinese publics in the Phase 5 (Chapter 9).

As noted in the introduction to this chapter, the application and inclusion of theories in this project were dynamic and guided by a problem-solving approach. To strengthen the rigour of the project, it was important to explain why this dynamic and problem-solving approach was adopted. This required consideration of the research paradigm and philosophical assumptions underpinning the study. Chapter 4 therefore outlines the research paradigm that informed how the study was designed and conducted in order to achieve the overall aim of the thesis.

# Chapter 4 : Research paradigm and design

## 4.1 Introduction

Justifying the choice to adopt or reject a particular research philosophy is a fundamental aspect of conducting rigorous research (Polit and Beck, 2022). This chapter outlines the philosophical paradigm, the overall study design, and the methodological strategies employed to enhance the rigour and trustworthiness of this project.

## 4.2 Philosophical and research paradigms

The term paradigm was coined by Kuhn (1962) and can be broadly described as schools of thought that provide the foundational framework that guides the entire research process. Philosophical paradigms can be understood as an overarching system of values and beliefs that include ontology, epistemology, and methodology, within which the research practice is situated (Guba and Lincoln, 1994). Ontology is known as the 'nature of existence' and structure of reality (Crotty, 1998). Ontological assumptions are about how researchers view the world; researchers need to take a stance on their own beliefs of how something really is and how it works (Creswell, 2017b). Epistemology is associated with the 'nature of knowledge'; it is the way of looking at the world and making sense of it (Crotty, 1998). Epistemological positions reflect assumptions about what constitutes meaningful and valid knowledge and how such knowledge can be generated (Creswell, 2017b).

Guided by these philosophical foundations, there are several research paradigms that apply in healthcare research. Positivism is a research paradigm rooted in the belief that an objective single reality exists independent of human perception (Parahoo, 2014). It is underpinned by a realist ontology and objectivist epistemology, which seek to reveal truth through measurable, quantitative, and empirical data (Parker and Burr, 1998; Crossan, 2003). Post-positivism is a research paradigm that critiques and amends traditional positivism by acknowledging that truth is objective, while it also shaped by researcher's values and culture context (Phillips and Burbules, 2000). It is commonly used for research where qualitative data is used instrumentally to support quantitative findings (Creswell, 2017b). Conversely, interpretivism and constructivism commonly guide qualitative research, both sharing similar relativist ontological and subjectivist epistemological assumptions (Milburn et al., 1995). Research which undertakes this lens believes that there is no single shared reality; instead, reality is socially constructed and shaped by individual experiences and interpretations (Ryan, 2018). The researcher plays an active role in

interpreting the meanings generated through dialogue and interaction with participants underlying interpretivism or constructivism (Denzin and Lincoln, 2011; Ryan, 2018). However, interpretivism and constructivism offer different lenses for exploring meaning-making (Denzin and Lincoln, 2011; Ryan, 2018). Interpretivism emphasises the interpretation of lived experiences, while constructivism places more focus on the active process of knowledge construction through social interaction and learning (Denzin and Lincoln, 2011).

This PhD project represents the first study to explore the unmet needs, wellbeing, care experiences and beliefs towards cancer among ethnic Chinese immigrants within the Scottish context. An exploratory approach was required to develop a comprehensive understanding of human actions and experiences. The sole application of (post-) positivism paradigm would have been inadequate for capturing personal experience, particularly given that this project focuses on individuals embedded within complex social and cultural environments, where cancer care experiences are deeply personal, context-dependent, and shaped by subjective meanings. Conversely, the exclusive use of an interpretivist or constructivists lens would not allow for the quantification of the prevalence of unmet needs or the objective assessment of wellbeing. Therefore, the exclusive adoption of either a (post-) positivist or an interpretivist/constructivist paradigm was not enough to achieve the research aims of this project.

As outlined above, it was necessary to adopt a paradigm capable to bring these philosophical foundations together. Pragmatism and critical realism can serve as a bridge to bring (post-) positivism and interpretivism/constructivism together, but with a different practical meaning (Johnson and Onwuegbuzie, 2004; Ryan, 2018). The central tenet of critical realism is the concept of stratified reality, including real, actual and empirical level (Hoddy, 2019). The aim of research using critical realism is to gain an in-depth understanding of what causes things to happen, even if those causes are not directly observable (Hoddy, 2019). In terms of pragmatism, it prioritises practical solutions to research problems and values multiple perspectives (Creswell, 2017a). The central epistemological underpinning of pragmatism is that knowledge is rooted in experience and shaped by the practical consequences of action (Al-Ababneh, 2020). Within a pragmatic paradigm, knowledge is understood as both constructed through human experience and interpretation, while also informed by a mid-independent reality that exists beyond the individual (Johnson and Onwuegbuzie, 2004).

In this project, pragmatism was ultimately adopted as the research paradigm. This was not only because, as discussed in Chapter 3, the project required the dynamic inclusion of relevant theories, but also because of the challenges encountered during data collection for the Phases 2 survey (Chapter 6) and Phase 3 in-depth interviews (Chapter 7). Despite seven months of data collection, the response rate remained limited for these two phases. Therefore, in order to achieve the overall aim of the project, the study evolved to include a further two phases: a focus group with health and social care professionals (Chapter 8) and a survey with the ethnic Chinese public without cancer diagnosis (Chapter 9).

## 4.3 Research design

The term "mixed-methods" and "multi-methods" are widely used in health and social care research. Anguera et al. (2018) revisit the differences between mixed-methods and multi-methods research. Anguera et al. (2018) argued that multi-methods study is driven by a common overall research goal and employs a series of complementary methodologies selected according to a particular criterion. By contrast, the essence of mixed-methods research is the inclusion of qualitative and quantitative components, which must be integrated to ensure the mixing of the information they generate (Anguera et al., 2018). In other words, integration is an essential component of mixed-methods study but not required in multi-methods studies (Anguera et al., 2018). In this project, the overall research design is framed as mixed-methods rather than multi-methods. Although the project consisted of five phases, these were undertaken as part of an interconnected whole, with the findings intentionally integrated to enable the mixing of results across phases.

### 4.3.1 Purposes and integration of mixed-methods design

Five major purposes and rationale for conducting mixed-methods research has been considered in depth by Greene et al. (1989): triangulation, complementarity, initiation, development, and expansion (Table 4-1). This project adopts the triangulation, complementarity, and development purpose of mixed-methods design. The triangulation purpose enhanced the validity and credibility of the study, as findings from the quantitative and qualitative components were compared to examine convergence and corroboration (Creswell, 2017a). Complementarity was achieved by using quantitative data to identify the frequency of issues affecting cancer care experiences, while qualitative data provided an in-depth understanding of how participants' lived experiences had been affected by these reported problems. In terms of the development purpose, the different phases of the

study were conducted in an iterative and sequential meaning, with findings from earlier phases informing subsequent stages (Creswell, 2017a).

Table 4-1 Purpose and rationale of mixed-methods research (Creswell, 2017a)

| **Purpose** | **Description** | **Rationale** |
|---|---|---|
| Triangulation | Convergence and corroborations of results from different methods and designs studying the same phenomenon. | To enhance the credibility, validity, and trustworthiness in findings by confirming consistency across quantitative and qualitative data. |
| Complementarity | Elaboration, enhancement, illustration, or clarification of the results from one method with results from the other method. | To provide a more comprehensive understanding of the research problem by exploring different dimensions of the phenomenon. |
| Development | Results from one method are used to inform the development of the other method. | To improve the design and implementation of subsequent research phases and ensure relevance and appropriateness. |
| Initiation | Identification of contradictions, inconsistencies, or new perspectives arising from different methods. | To generate new insights, reinterpretations, or research questions, and deepen understanding of complex phenomena. |
| Expansion | Extension of the breadth and range of inquiry by using different methods for different inquiry components. | To broaden the scope of the study and address different aspects of the research question. |

The integration in a mixed-methods design can occur at any stage of research (Creswell, 2017a). At the study design level, integration can be achieved through several basic designs, including: 1) convergent; 2) exploratory sequential; and 3) explanatory sequential (Fetters et al., 2013). In sequential designs, the intent is to have one phase of mixed-

methods study build on the other, whereas in the convergent designs the intent is to merge the phases in order that the quantitative and qualitative results can be compared (Fetters et al., 2013). Detailed explanations of each design are listed below:

- Convergent parallel design: Quantitative and qualitative data are collected concurrently but independently (Fetters et al., 2013). The data are analysed separately, and the results are merged or compared during the interpretation phase (Fetters et al., 2013). The convergent parallel design is primarily to use for triangulation or complementarity purpose (Fetters et al., 2013).
- Exploratory sequential design: Beginning with a qualitative phase to explore a phenomenon in depth, followed by a quantitative phase to validate or generalise qualitative data with a larger population (Doyle et al., 2016). The exploratory sequential design is useful when this topic is underexplored (Doyle et al., 2016).
- Explanatory sequential design: Beginning with a quantitative phase to collect and analyse numerical data, followed by a qualitative phase to explain or interpret initial quantitative findings (Doyle et al., 2016). The explanatory sequential design is particularly useful when quantitative results need a more in-depth understanding (Doyle et al., 2016).

More advanced mixed-methods design include a multistage design, which typically comprise three or more stages when a sequential component is present (Fetters et al., 2013). Multistage mixed-methods design involves multiple stages of data collection and may incorporate different combinations of exploratory sequential, explanatory sequential and convergent approaches (Morse and Niehaus, 2016).

At the methods level of integration, it can occur in several ways, including connecting, building, merging, or embedding (Creswell et al., 2011). In this project, connecting was included as participants who had completed the survey were subsequently invited to participate in in-depth interviews. In addition, integration through building was applied throughout the thesis, with findings from earlier phases informing the development of subsequent phases. At the reporting level, integration may be achieved through narrative approaches, data transformation, or joint displays (Creswell et al., 2011). In this project, integration at the reporting stage was achieved through a narrative weaving approach, whereby findings from the qualitative and quantitative datasets were brought together thematically to provide a comprehensive and contextualised understanding of the study phenomena. In addition to the classic integration of mixed-methods design, involving both

qualitative and quantitative data, the overall integration in this project also incorporated evidence from a mixed-methods systematic review conducted as the first step of the project. The integration of findings from the systematic review helped provide a more coherent understanding of the project as a whole.

### 4.3.2 Chosen design: Hybrid multistage sequential mixed-methods design

This project did not follow a conventional sequential design. Instead, it adopted a hybrid multistage mixed-methods design, incorporating both exploratory and explanatory sequential approaches. This project consists of five distinct but interconnected phases, including:

- **Phase 1: Integrated mixed-methods systematic review:** Conducting a systematic review is widely regarded as the gold standard for identifying, evaluating, and synthesising existing evidence to guide clinical practice and inform future research (Bettany-Saltikov and McSherry, 2024). The value of mixed-methods systematic review has been acknowledged for healthcare research (Sandelowski et al., 2012). Sandelowski et al. (2012) identified three models of mixed-methods systematic review designs, including segregated, integrated, and contingent. In a segregated mixed-methods systematic review, qualitative and quantitative findings are synthesised separately and later integrated (Sandelowski et al., 2012). The segregated mixed-methods systematic review has been found to be especially useful to evaluate the effectiveness of intervention research (Polit and Beck, 2017). In an integrated mixed-methods systematic review, qualitative and quantitative findings in an area of inquiry are perceived as able to confirm, extend, or refute each other (Sandelowski et al., 2012). In a contingent mixed-methods systematic review, it involves a coordinated and sequential series of syntheses, where the findings from one synthesis inform the conduct or interpretation of the next (Sandelowski et al., 2012). In this project, an integrated mixed-methods systematic review was conducted as Phase 1. Quantitative and qualitative evidence were grouped and synthesised to address the same review questions (Polit and Beck, 2017). The findings of the review indicated that no relevant research had been undertaken in Scotland, or more broadly in the UK. Consequently, the overall project was positioned as predominantly exploratory in nature.
- **Phase 2: Exploratory cross-sectional survey:** The empirical components of this project began with an exploratory cross-sectional survey, which served as an initial

step to develop an overview of unmet needs and HRQoL among ethnic Chinese immigrants affected by cancer in Scotland. This cross-sectional design is cost-effective and well suited to exploring research areas where existing knowledge is limited (Sedgwick, 2014).

- **Phase 3: Exploratory descriptive interviews:** Like the Phase 2 survey, the Phase 3 in-depth interviews also had an exploratory nature, as no qualitative studies on this topic had been conducted in Scotland. A descriptive exploratory qualitative approach was therefore adopted, as this approach provides a rich and straightforward description of experiences and contributes to the development of new knowledge (Sandelowski, 2004; Hunter et al., 2019). However, within the mixed-methods design, Phase 3 served an explanatory function. The quantitative findings from Phase 2 (survey) required in-depth contextual understanding to explain why these patterns existed and how they shaped individuals' cancer care experiences.
- **Phase 4: Explanatory focus group:** The focus group with health and social care professionals added a further explanatory component to the overall mixed-methods project. Up to this stage, Phases 1 to 4 could be characterised as an explanatory sequential mixed-methods design.
- **Phase 5: Exploratory cross-sectional survey:** The final survey had an exploratory purpose both in itself and within the overall project. As no relevant research had been conducted to understand beliefs and knowledge about cancer, and intentions to engage with cancer prevention among ethnic Chinese immigrants without a cancer diagnosis in Scotland, this phase was exploratory in nature. The findings from Phase 1 to Phase 4 mentioned that ethnic Chinese immigrants affected by cancer often experience a cancer diagnosis as taboo, which fosters a culture of silence and secrecy around discussing and getting help with cancer-related needs. Phase 5 survey explored these issues further with the ethnic Chinese public without a cancer diagnosis.; this progression aligned well with an exploratory sequential mixed-methods design.

### 4.3.3 Evaluating mixed-method designs

Rigour is best understood as the measure of quality and integrity within the research process, and a more rigorous approach enhances the trustworthiness of the study findings (Polit and Beck, 2017). O'Cathain et al. (2008) developed the Good Reporting of A Mixed Methods Study Framework, which provides useful guidance for evaluating and reporting

mixed-methods research. This framework comprises six items and each of them has been addressed as part of this project:

1) Justification for using a mixed-methods approach (Chapter 4, Section 4.2)
2) Describe the design in terms of purpose, priority, and sequence of methods (Chapter 4, Section 4.3.2)
3) Describe each method in terms of sampling, data collection, and analysis (Chapters 6 to 9)
4) Describe where integration has occurred, and how it occurred (Chapter 4, Section 4.3.1 and Discussion sections for Chapters 6 to 9)
5) Describe any limitation of one method associated with the presence of the other method (Chapter 4, Section 4.2)
6) Describe any insights gained from mixing or integrating methods (Discussion sections for Chapters 6 to 9).

## 4.4 Actions taken to increase the rigour of this project

Several strategies were employed in this project to enhance the overall rigour of the project. The integration of patient and public involvement and engagement activities represented an important initial step in ensuring that the evidence generated was consistent with the preferences and needs of the target population. In addition, the use of patient-reported outcome measures, alongside survey and interview approaches, helped to ensure that the problems identified were grounded in the individual's own accounts and experiences. Furthermore, specific measures were undertaken to strengthen the rigour of the quantitative and qualitative components individually.

### 4.4.1 Patient and public involvement and engagement

Involving patients and the public as partners in health research is a key strategy to produce more useful, person-centred evidence to guide healthcare decisions (Tanay et al., 2023). The WHO defines community participation as "*a process of developing relationships that enable stakeholders to work together to address health related issues and promote well being to achieve positive health impact and outcomes*" (World Health Organisation, 2017). Community and stakeholder involvement in decision-making about publicly funded health services and interventions is widely advocated as a means of fulfilling citizens' rights and improving health outcomes (Arthur et al., 2023). The National Institute for Health Research defines public involvement as research being carried out '*with*' or '*by*' members of the public rather than '*to*', 'about' or '*for*' them (National Institute for Health Research,

2021). It is an active partnership between patients, carers and members of the public with researchers that influence and shape research (National Institute for Health Research, 2021). Public engagement refers to the provision and dissemination of research-related information and knowledge, such as sharing study findings with research participants or members of the public (National Institute for Health Research, 2021).

The introduction of patient and public involvement and engagement (PPIE) in research brings both benefits and challenges. The benefits extend beyond enhancing the effectiveness and value of research to improving participant recruitment and retention rates (Skovlund et al., 2020). These benefits were clearly reflected in this project, particularly through the collaboration with PPIE representatives during community engagement activities. However, involving PPIE in this doctoral project as an early career researcher also presented several challenges, particularly in identifying suitable representatives, negotiating roles, managing time, organising activities, and funding support.

In this project, there are two main PPIE representatives actively involved. The first PPIE representative was the Chief Executive Officer (CEO) for the Chinese Association for Cancer Care, a charity organisation based in London. This charity organisation provides support for patients with cancer, primarily but not exclusively for individuals of Chinese ethnic background (https://cacaca.org.uk/). Liaison with the CEO of the organisation took place in June 2023. Following discussion and negotiation, the CEO agreed to display the e-poster within their group and to serve as a PPIE representative for this project. The CEO for Chinese Association for Cancer Care played a significant role in supporting this project and helped explore recruitment opportunities in Scotland through his extensive social networks. He facilitated a connection with the community coordinator who was involved in a Chinese health project for Hepatitis B prevention at Waverley Care in Glasgow. This health coordinator later joined the project as the second PPIE representative for this project. Detailed PPIE activities are described in the relevant sections of Chapters 6 to 9, including the recruitment procedures and the consultation processes undertaken to inform the research design.

### 4.4.2 Rigour and actions to enhance the quantitative components

Rigour in quantitative research was assessed by evaluating whether the research design, data collection instruments, and analytical techniques were appropriately structured and objectively applied to minimise bias and enhance validity and reliability (Bruce et al., 2018). Validity is a fundamental criterion for evaluating the quality of quantitative research

(Shadish et al., 2002). It concerns the degree to which the conclusions drawn from a study are accurate, meaningful, and supported by the evidence (Shadish et al., 2002). Actions taken in this project to enhance the rigour of the quantitative components included the use of patient reported outcome measures (PROMs). Chapter 6 presents in details of scoping, selection, and justification of each data collection instrument. In addition, a rich description was provided of how the self-designed data collection instruments were developed with reference to relevant supporting literature and theories (Chapters 6 and 9).

The definition of patient reported outcome (PRO) is straightforward, and has been described as "*any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's responses by a clinician or anyone else*" (U.S. Department of Health and Human Services Food and Drugh Administration, 2019). PROMs are designed to commonly include wellbeing, functional status, symptoms burden, health-related behaviours, and patients' experiences of healthcare (Cella et al., 2015). PROMs included self-report questionnaires or interviews (Fayers and Machin, 2016). A patient's self-assessment often differs substantially from the judgement of their doctors or other healthcare staff (U.S. Department of Health and Human Services Food and Drugh Administration, 2019). In 2022, the European Society for Medical Oncology developed a clinical practice guideline that highlighted emerging evidence supporting the implementation of PROM monitoring during long-term cancer survivorship (Di Maio et al., 2022).

In this project, PROs included unmet needs, wellbeing, and cancer-care experience. In medical research, the focus on quality of life is generally limited to aspects directly affected by the disease or its treatment (Fayers and Machin, 2016). The WHO declares health to be "*a state of complete physical, mental, and social well being, and not merely the absence of disease*" (Huber et al., 2011). To distinguish quality of life in its broader sense, the term health-related quality of life (HRQoL) is more frequently used to avoid ambiguity in medical research (Fayers and Machin, 2016). Accordingly, HRQoL is the term used throughout this project to assess wellbeing. The term "need" can be defined as the requirement of some actions or resources that are necessary, desirable, or useful to attain optimal wellbeing (Sanson‐Fisher et al., 2000). Unmet needs among individuals with cancer are closely linked to wellbeing, with a higher number of unmet needs being associated with poorer HRQoL and lower satisfaction with care (Husson et al., 2014; Cheng et al., 2016). Understanding and measuring cancer survivors' unmet needs helps to

identify gaps in patient care experiences, which in turn provides the opportunity to deliver a more patient centred service (Contri et al., 2023). The patient experience is increasingly recognised as one of the three core pillars of healthcare quality, alongside clinical effectiveness and patient safety (Kruk et al., 2018). Assessing patient's experiences of care could directly help to understand patient's satisfaction of care, and provide evidence to improve care delivery in the future (Tunçalp et al., 2015).

### 4.4.3 Rigour and actions to enhance the qualitative components

Lincoln and Guba (1985) suggested four criteria for developing the trustworthiness of a qualitative inquiry: credibility, dependability, confirmability, and transferability. These four criteria represent parallels to the positivists' criteria of internal validity, reliability, objectivity, and external validity, respectively (Polit and Beck, 2017). Credibility is a central criterion for ensuring trustworthiness in qualitative research and refers to the confidence in the truth of the data and interpretations of them (Lincoln and Guba, 1985). Credibility cannot be attained without dependability, which refers to the stability of the study's findings over time and conditions (Lincoln and Guba, 1985). In this project, actions taken for enhancing the credibility of the qualitative components, included triangulation and rich description. This project was supervised by two experienced qualitative researchers, with whom qualitative results were discussed at length; this ensured investigator triangulation. The qualitative results were also reviewed by PPIE representatives, and this form of triangulation is known as member checking (Stahl and King, 2020). In terms of rich description, Chapters 7 and 8 provide detailed contextual information about process, which allows other researchers to replicate the study under similar conditions in different contexts.

#### *4.4.3.1 Reflexivity*

Reflexivity represents a key consideration in qualitative research and has been recognised as a crucial strategy in the process of generating knowledge by means of qualitative research (Tuckett, 2005). The concept of reflexivity challenges the notion that knowledge production is independent of the researcher and that knowledge itself is entirely objective (Berger, 2015). Reflexivity is commonly viewed as the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome (Bryman et al., 2008; Dodgson, 2019). The position of the researcher refers to the researcher's social, cultural and professional background and how these

characteristics influence all stages of the research process (Berger, 2015). These factors shape the analytical lens through which data are filtered and understood, and may ultimately impact the findings and conclusions drawn from the study (Kacen and Chaitin, 2015). Debriefing technique involves ongoing, structured reflection with impartial colleague, and allowing for critical questioning of the research process (Spall, 1998). Regular meetings were held with supervisors who do not share the same cultural background. These supervisory discussions provided a critical lens to ensure that the findings remained grounded in participant's voices rather than shaped by the PhD researcher's personal experiences or expectations.

#### *4.4.3.2 Thematic analysis*

Thematic analysis is a method to identify, analyse, and report qualitative data, allowing researchers to organise and interpret rich, complex data in a systematic and flexible way (Braun and Clarke, 2022). Thematic analysis included six phases: *familiarisation with the dataset, data coding, initial theme generation, theme development and review, theme refining, and writing-up* (Braun and Clarke, 2022).

Thematic analysis can be conducted using either an inductive or deductive approach (Braun and Clarke, 2022). The inductive approach involves deriving themes directly from the data, without being constrained by pre-existing theories or frameworks (Boyatzis, 1998). The inductive approach focuses on semantic meaning of codes, where the analysis explores meaning at the surface, explicit or manifest level, staying close to participants' actual words and meanings (Boyatzis, 1998). In contrast, a deductive approach is theory-driven, which guided by existing concepts, theories or prior research, with data analysis structured around predefined themes or research questions (Crabtree and Miller, 1992). The deductive approach often focuses on latent meaning of codes, where the analysis explores meaning at the more underlying or implicit level, going beyond the surface-level content (Crabtree and Miller, 1992). A further division within thematic analysis involves the choice of between realist and relativist approach (Braun and Clarke, 2022). These two approaches are underpinned by fundamentally different research paradigms: realist thematic analysis aligns with (post) positivism, whereas relativist thematic analysis is grounded in non-positivist, such as interpretivism or constructivism (Braun and Clarke, 2022).

Given the exploratory nature of this project, the inductive and relativist thematic analysis was applied to allow themes to emerge directly from the participants' view without

imposing predefined theoretical frameworks. Additionally, an inductive approach enabled to remain open to novel insights and unexpected patterns in data. The adoption of a relativist thematic analysis aligns with the ontological position of the interpretivist paradigm guiding the qualitative component of this project.

## 4.5 Chapter summary

This project adopts the pragmatism research paradigm, which emphasises practical solutions to research questions and supports the use of quantitative and qualitative data within one study. Grounded in this paradigm, a hybrid multistage mixed-methods approach was chosen to address the overall research aim. The purposes of this mixed-methods design included the triangulation, complementarity, and development. This hybrid design involved both explanatory and exploratory forms of integration at the design level. Actions such as incorporating PPIE activities, providing clear justification for the selection of PROMs, conducting inductive relativist thematic analysis and reflexivity, strengthened the rigour of this project.

At this point, the introduction to the contextual background, theory, and research paradigm of this project have been provided. The subsequent chapters (5 to 9) will present this project in detail, beginning with the systematic review, followed by the empirical phases.

# Chapter 5 : Phase 1: Care experiences and wellbeing of Asian immigrant cancer survivors living in countries of the western world ranked as very high on the Human Development Index: A systematic review of international evidence

## 5.1 Introduction

This chapter presents the first phase in this project. This mixed-methods systematic review presents evidence from the wider literature and demonstrates the rationale for conducting the subsequent empirical phases in Scotland. The definition of Asian immigrants and very high Human Development Index (HDI) countries were clearly described in Chapter 2. Western countries are typically defined based on their historical, cultural, political, and economic influences originating from Western Europe and expanded through colonialism and globalisation (World Population Review, 2024). By combining the definition of "very high" HDI countries and western countries, a focused list of target nations for this systematic review are presented in (Table 5-1).

Although this project focuses specifically on ethnic Chinese immigrants, the systematic review adopted a broader focus on Asian immigrants rather than limiting the review to ethnic Chinese groups alone. Broadening the review to Asian immigrants could provide wider insights into whether there are common issues shared between ethnic Chinese groups and the broader Asian immigrant population. It also enables comparison between findings from Asian immigrant groups in the review and the results of the subsequent empirical phases of this project. The systematic review from this project was published in *Seminars in Oncology Nursing* (Appendix 13).

Table 5-1 List of "Very High" HDI countries and western countries

| | **Very High HDI countries** | **HDI (0 -1.0)** |
|---|---|---|
| **Western Countries** | Switzerland | 0.967 |
| | Norway | 0.966 |
| | Iceland | 0.959 |
| | Sweden | 0.952 |
| | Denmark | 0.952 |
| | Germany | 0.950 |
| | Ireland | 0.950 |
| | Australia | 0.946 |
| | Netherlands | 0.946 |
| | Belgium | 0.942 |
| | Finland | 0.942 |
| | United Kingdom | 0.940 |
| | New Zealand | 0.939 |
| | Canada | 0.935 |
| | United States | 0.927 |
| | Luxembourg | 0.927 |
| | Austria | 0.926 |
| | Malta | 0.915 |
| | Spain | 0.911 |
| | France | 0.910 |
| | Cyprus | 0.907 |
| | Italy | 0.906 |
| | Czech Republic | 0.895 |
| | Greece | 0.893 |
| | Poland | 0.881 |
| | Croatia | 0.878 |
| | Portugal | 0.874 |
| | Hungary | 0.851 |

## 5.2 Objectives

- To identify the unmet needs, factors affecting HRQoL and care experiences of Asian immigrant cancer survivors who live in western countries ranked as very high HDI.

## 5.3 Methods

This systematic review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009), and has been registered with PROSPERO (CRD42023448605) (Appendix 2).

### 5.3.1 Formulation of review questions

The formulation of a research question usually comprises identifying the Population, Exposure and Outcomes (PEO) (Bettany-Saltikov, 2012). PEO is suitable for systematic reviews that focus on observational studies and aim to understand experiences, associations and health-related outcomes (Bettany-Saltikov, 2012). The key components of the PEO for this systematic review are outlined below:

- Population: Adults of Asian origin who have immigrated to western countries (referred to as Asian immigrants).
- Exposure: Diagnosis of cancer and receiving care in the host country.
- Outcome: Metrics of overall HRQoL, unmet needs and care experience.

Based on the PEO components above, the systematic review questions are:

- What is the HRQoL of Asian immigrant patients with cancer who live in western countries?
- What are the unmet needs of Asian immigrant patients with cancer who live in western countries?
- What are the care experiences of Asian immigrant patients with cancer who live in western countries?

### 5.3.2 Search strategy

Three major electronic databases (MEDLINE, EMBASE and CINAHL) were searched using systematic search strategies (Appendix 3). These databases were selected because they are widely recognised as core sources for medical, nursing, and allied health research (Aromataris and Riitano, 2014). The reference lists of eligible papers and key relevant articles were also retrieved to identify further eligible studies. A senior librarian at the University of Glasgow was involved in providing guidance on the development of search strategies for different databases and reviewing the search strategies. The final search strategy was conducted by the PhD researcher. Searches were initially run in September 2023. No new eligible articles were found during the second iteration (May 2024).

### 5.3.3 Eligibility criteria

Eligibility criteria were determined based on each component of the PEO framework and the objectives of this review. The inclusion criteria were as follows:

- Adult immigrant cancer survivors of Asian ethnicity living in very high HDI western country as per Table 5-1.
- Any form of qualitative or quantitative or mixed-methods research that investigated participants' HRQoL and/or unmet needs and/or care experience as primary or secondary outcomes.
- Studies involving ethnically diverse samples were eligible for inclusion if data for participants of Asian ethnicity were analysed and reported separately.
- Studies involving mixed samples, in which the results for Asian immigrant cancer survivors were analysed and reported separately.
- Studies published in peer-reviewed journals and written in English.
- No time restrictions were applied to the searches.

Studies were excluded for the following reasons:

- Participants are immigrants not originally from an Asian country, or participants lived in countries not listed in Table 5-1.
- Participants include second generation immigrants which means that they were born in the host country.
- Mixed samples of Asian and non-Asian immigrants, where the Asian group was not analysed separately.
- Investigated outcomes not of relevance to the purpose of this review.
- Case study, abstract, study protocols, and commentaries.

### 5.3.4 Study selection and data extraction procedures

After duplicates were removed, the PhD researcher (LC) screened titles and abstracts and completed an initial round of full-text screening. The first supervisor (GK) and second supervisor (DC) independently reviewed articles in a second round of full-text screening to reach consensus. Any disagreements or uncertainties were resolved through discussion. Reasons for exclusion at the full-text stage were recorded and documented.

Data were extracted from the final sample of eligible articles. A bespoke data extraction table was developed for this review to aid in the data extraction. One researcher extracted all data, which were then double-checked by the first supervisor (GK) and second supervisor (DC). If information in any of the included articles was unclear, the PhD researcher (LC) contacted the corresponding author individually to request clarification. Where contact was not feasible, authors discussed the paper at a group meeting to decide

whether to include or exclude and how to use its data in the analysis. None of the full-text papers were excluded based on the reason of insufficient information.

### 5.3.5 Study methodological quality evaluation

Methodological quality evaluation was conducted via the Quality Assessment for Diverse Studies (QuADS) tool, which is a refined version of the Quality Assessment Tool for Studies with Diverse Designs (Harrison et al., 2021). The QuADS tool demonstrated moderate inter-rater reliability (k=0.66), face and content validity for application in systematic review with mixed, or multi-methods health services research (Harrison et al., 2021). The QuADS tool has 13 items, with each item scored from 0 to 3. Total scores can be calculated, although there is no cut-off score for a study to be considered high or low quality. In general, the higher the score, the better the quality. For easier interpretation and in line with previous literature (Abda et al., 2019), total QuADS scores were broken down into three groups, whereby a total score between 0 and 13 indicates a low-quality study, a score from 14 to 26 indicates a moderate quality study, and a score from 27 to 39 indicates a high-quality study. The methodological quality assessment helped to evaluate confidence in the evidence generated from this systematic review. The methodological limitations identified in the included studies informed the design and conduct of the subsequent empirical phases of this project, with the aim of improving methodological rigour.

### 5.3.6 Synthesis of study findings

A narrative approach was used, also creating thematic summaries of findings within a similar context (Popay et al., 2006). The aim of thematic synthesis is not simply to summarise the data content, but to identify and interpret, key but not necessarily all, features of the data, guided by the research questions. Another benefit of thematic analysis is that outcomes synthesised as a narrative are more contextualised and understandable for readers (Popay et al., 2006).

## 5.4 Results

### 5.4.1 Search results

The initial searches retrieved 480 studies. After removing duplicates (n=220), 260 studies remained for title and abstract screening. Subsequently, 43 studies were assessed by full text screening, and 22 studies were retained. Thirty-five additional studies were retrieved through websites and citation searching, with nine of them meeting the inclusion criteria (Figure 5-1). In total, 31 studies were included in the final sample and reviewed.

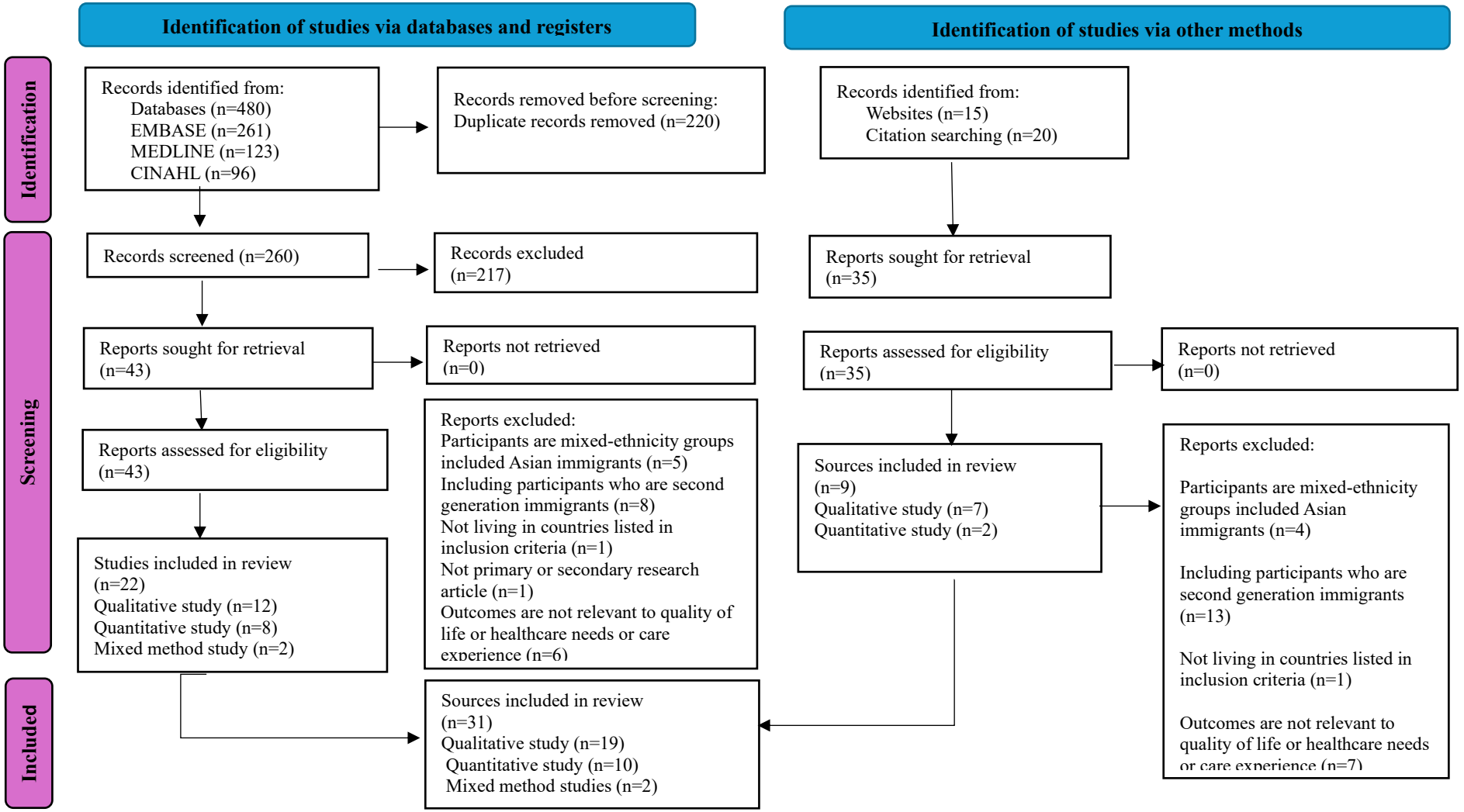



Figure 5-1 Diagram of the study selection process according to PRISMA

Table 5-2 Summary of methodological characteristics of 31 included studies

| ID | Study | Study Design | | | Sample Characters Asian Immigrants | | | | Data Analysis Method |
|---|---|---|---|---|---|---|---|---|---|
| | | **Methods** | **Recruitment Strategy** | **Data Collection Method (Relevant to this review aim)** | **Sample Size** | **Cancer Type** | **Immigrants place of birth** | **Host western country** | |
| 1 | Alananzeh et al. (2018) | Qualitative | Cancer centres; community | In-depth interview | 11 | Any Type | Arab heritage | Australia | Thematic analysis |
| 2 | Ming et al. (2015) | Quantitative | Cancer centres | 1): Demographic<br>2): FACT-G[1] | 571 for immigration group with 393 for Chinese and Arabic heritage; 274 Anglo-Australian | Any Type | Arab; Chinese; Greek heritage | Australia | Liner regression; Logistic regression |
| 3 | Levesque et al. (2020a) | Qualitative | Community | Focus group and in-depth interview | 24 | Breast Cancer | Chinese heritage | Australia | Thematic analysis |
| 4 | Hyatt et al. (2017) | Quantitative | Cancer centres | 1): Demographic<br>2): Self-designed healthcare experience and preferences scale | 848 for immigrant group with 591 for Chinese and Arabic; 593 Australian | 12 Common Cancer | Arab; Chinese; Greek Heritage | Australia | Chi-squared tests |
| 5 | Lim et al. (2019a) | Qualitative | Community | Focus group | 8 rounds (34 survivors; 28 carers) | Any Type | Chinese heritage | Australia | Content comparative analysis |
| 6 | Lim et al. (2019b) | Quantitative | Cancer centres; community | 1): Demographic<br>2): HLQ[2]<br>3): CCCQ[3] | 68 patients; 8 carers | Any Type | Chinese heritage | Australia | Linear regression; Canonical correlation analysis |
| 7 | Hsu et al. (2020) | Qualitative | Cancer centres | Focus group and in-depth interview | 37 Chinese American; 23 European American | Breast Cancer | Chinese heritage | USA | Content analysis |

[1] FACT-G: Functional Assessment of Cancer Therapy - General
[2] HLQ: The Health Literacy Questionnaire
[3] CCCQ: The Cancer Care Coordination Questionnaire

| ID | Study | Study Design | | | Sample Characters Asian Immigrants | | | | Data Analysis Method |
|---|---|---|---|---|---|---|---|---|---|
| | | Methods | Recruitment Strategy | Data Collection Method (Relevant to this review aim) | Sample Size | Cancer Type | Immigrants place of birth | Host western country | |
| 8 | Butow et al. (2013b) | Quantitative | Cancer centres | 1): Demographic<br>2): SCNS[4]<br>3): CASUN[5]<br>5): FACT-G | Immigrants: 277<br>Anglo-Australian: 319 | Any Type | Arab; Chinese; Greek heritage | Australia | Chi-squared and t-test; Logistic regression; Nonparametric Spearman's correlation; Baron and Kenney test |
| 9 | Ashing et al. (2021) | Quantitative | Cancer centres; community | 1): Demographic<br>2): FACT-G<br>3): Social support survey<br>4) SF-36[6] | 73 | Breast Cancer | Chinese heritage | USA | Descriptive; t test; Correlation analyses; Linear Regression; R-square |
| 10 | Wang et al. (2012) | Qualitative | Cancer centres | Focus group and in-depth interview | 73 (37 immigrants; 34 NHW[7] | Breast Cancer | Chinese heritage | USA | Content analysis |
| 11 | Wong-Kim et al. (2005) | Qualitative | Community | In-depth interview | 30 | Breast Cancer | Chinese heritage | USA | Narrative analysis using a constant comparative approach |
| 12 | Wang et al. (2013b) | Mixed methods | Cancer centres | Phase I: Focus group and telephone interview<br><br>Phase II: Survey | Phase I: 4 rounds focus group (n=19); 31 interviews<br>Phase II: 296 (148 NHW; 148 immigrants) | Breast Cancer | Chinese heritage | USA | Phase I: content analysis methods.<br><br>Phase II: Descriptive; Linear regression |
| 13 | Levesque et al. (2020b) | Qualitative | Community | Focus group and in-depth interview | 24 | Breast Cancer | Chinese heritage | Australia | Thematic analysis |

[4] SCNS: Supportive Care Needs Questionnaire
[5] CASUN: Cancer Survivors Unmet Needs Measure
[6] SF-36: Short Form 36 Health Survey
[7] NHW: non-Hispanic White

| ID | Study | Study Design | | | Sample Characters Asian Immigrants | | | | Data Analysis Method |
|---|---|---|---|---|---|---|---|---|---|
| | | Methods | Recruitment Strategy | Data Collection Method (Relevant to this review aim) | Sample Size | Cancer Type | Immigrants place of birth | Host western country | |
| 14 | Zhang et al. (2014) | Qualitative | Cancer centres; community | In-depth interview | 26 | Breast Cancer | Chinese heritage | New Zealand | Thematic content analysis |
| 15 | Lebel et al. (2016) | Quantitative | Cancer centres | 1): Demographic<br>2): Cancer-related stressor checklist<br>3): Positive and negative affect scale | 522 (118 immigrants; 404 WBC[8]) | Head and neck cancer | Chinese heritage | Canada | Descriptive; One-Way ANOVA; Multiple regression |
| 16 | Wang et al. (2013b) | Qualitative | Cancer centres | Focus group and in-depth interview | 44 immigrants; 28 NHW | Early-stage breast cancer | Chinese heritage | USA | Content analysis |
| 17 | Shaw et al. (2016) | Qualitative | Cancer centres | Focus group and in-depth interview | 18 | Any type | Arab; Chinese; Macedonian Heritage | Australia | Thematic analysis |
| 18 | Butow et al. (2012) | Quantitative | Cancer centres | 1): Demographic<br>2): FACT-G | 596 (277 immigrants; 319 Anglo-Australian) | 12 Common Cancer | Arab; Chinese; Greek Heritage | Australia | Chi-squared and t test; Linear regression; Sobel test |
| 19 | You et al. (2018) | Quantitative | Community | 1): Demographic<br>2): FACT-B[9]; | 96 | Breast cancer | Chinese heritage | USA | Descriptive; Regression |
| 20 | Lin (2008) | Qualitative | Community | In-depth interview | 12 | Any type of metastatic cancer | Chinese heritage | USA | Narrative analysis |

[8] WBC: Western Born Caucasians
[9] FACT-B: Functional Assessment of Cancer Therapy-Breast

| ID | Study | Study Design | | | Sample Characters Asian Immigrants | | | | Data Analysis Method |
|---|---|---|---|---|---|---|---|---|---|
| | | Methods | Recruitment Strategy | Data Collection Method (Relevant to this review aim) | Sample Size | Cancer Type | Immigrants place of birth | Host western country | |
| 21 | Leng et al. (2019) | Qualitative | Cancer centres; community | In-depth interview | 12 | Any type stage IV cancer | Chinese heritage | USA | Inductive analysis |
| 22 | Leng et al. (2012) | Qualitative | Cancer centres; community | Focus group | 28 | Any type | Chinese heritage | USA | Inductive analysis |
| 23 | Chou et al. (2007) | Quantitative | Cancer centres | 1): Demographic<br>2): SL-ASIAN[10]<br>3) MQOLS-CA[11]<br>4) SF-36 | 25 | Any type | Chinese heritage | USA | Descriptive |
| 24 | Warmoth et al. (2017) | Qualitative | Community | Expressive writing | 27 | Breast cancer | Chinese heritage | USA | Content analysis |
| 25 | Choi et al. (2023) | Qualitative | Community | Expressive writing | 15 | Breast cancer | Chinese heritage | USA | Thematic analysis |
| 26 | Sarpel et al. (2018) | Qualitative | Cancer centres | Focus group | 29 | Hepatocellular carcinoma | Chinese heritage | USA | Content analysis |
| 27 | Tsai et al. (2011) | Mixed methods | Cancer centres; community | Phase I: Survey;<br>Phase II: In-depth interview | Phase I: 107<br><br>Phase II: 16 | Breast cancer | Chinese heritage | USA | Phase I: One-way ANOVA;<br><br>Phase II: Thematic analysis |
| 28 | Leng et al. (2014) | Quantitative | Cancer centres | Self-designed, needs assessment | 59 | Any type | Chinese heritage | USA | Descriptive; Chi-squares and correlation; Factor analysis; General linear model |

[10] SL-ASIAN: Suinn-Lew Asian Self Identify Acculturation Scale
[11] MQOLS-CA: Multidimensional Quality of Life Scale-Cancer

| ID | Study | Study Design | | | Sample Characters Asian Immigrants | | | | Data Analysis Method |
|---|---|---|---|---|---|---|---|---|---|
| | | Methods | Recruitment Strategy | Data Collection Method (Relevant to this review aim) | Sample Size | Cancer Type | Immigrants place of birth | Host western country | |
| 29 | Kwok and White (2014) | Qualitative | Community | Focus group | 23 | Breast cancer | Chinese heritage | Australia | Thematic analysis |
| 30 | Tara et al. (2017) | Qualitative | Cancer centres | In-depth interview | 11 | Breast cancer | Chinese heritage | USA | Content analysis |
| 31 | Kwok and White (2011) | Qualitative | Community | Focus group | 23 | Breast cancer | Chinese heritage | Australia | Content analysis |

Table 5-3 Summary of main findings of 31 included studies

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | **Unmet needs** | **HRQoL** | **Care experience** |
| 1 | Alananzeh et al. (2018) | To explore the Arab migrant cancer survivor's experience of use of interpreter services to communicate with healthcare providers | High-quality interpreter services | N/A | Language barrier restricts the communication with healthcare professionals. |
| 2 | Ming et al. (2015) | To extend current knowledge to include migrant patients who were in the active treatment phase of the cancer trajectory, which represents the time of highest need for information, support, and practical assistance | 1) Information about navigating the health system.<br>2) Social support to optimise their cancer care. | 1) Migrant had significantly higher levels of anxiety, depression, and lower levels of quality of life.<br>2) Arab participants had the highest levels of anxiety and depression as well as lowest QoL than other ethnic groups. | Difficulty in navigating the healthcare system and language barriers threat to care experience. |
| 3 | Levesque et al. (2020a) | To explore the experience of breast cancer for Chinese-Australian women and gain insight into their coping behaviours. | 1) Information about side-effect management and psychological support.<br>2) Information about the compatibility of traditional Chinese medicine and western medicine. | 1) Psychological wellbeing affects HRQoL more than physical wellbeing.<br>2) Patients frequently experienced a fear of cancer recurrence then leads to anxiety. | Formal support from China-specific organisation has great value, as it is a platform of empowerment, encouragement, and information. |
| 4 | Hyatt et al. (2017) | To investigate the communication barriers and challenges experienced by Arabic, Greek and Chinese (Mandarin and Cantonese) speaking oncology patients in Australia. | 1) High-quality interpreter services.<br>2) Information about their treatment. | N/A | Insufficient information restricts them to managing their health and language barrier threat their care experience. |
| 5 | Lim et al. (2019a) | To explore the challenges and unmet needs experienced by the Australian Chinese community affected by cancer, and understand the contexts that hindered optimal care for this community. | 1) Culturally appropriate information regarding diet.<br>2) Information about treatment option.<br>3) Psychological, community and spiritual support | N/A | 1) Communication barriers impaired trust building with their clinicians.<br>2) Difficulty in navigating the health system leads to the delay in treatment and long waiting time.<br>3) Cultural differences produce conflict on views about wellness, |

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | **Unmet needs** | **HRQoL** | **Care experience** |
| | | | | | especially for the usage of traditional Chinese medicine. |
| 6 | Lim et al. (2019b) | To describe the levels of health literacy and experience of care coordination among Chinese migrant patients with cancer and their carers in Australia, to examine factors associated with these. | 1) Information about health condition.<br>2) Information about navigating the healthcare system. | N/A | Health literacy has a large and positive affect for care experience. |
| 7 | Hsu et al. (2020) | To identify culturally appropriate means of talking about cancer that would be understood as beneficial and supportive by Chinese patients. | N/A | N/A | Patients are less disclosing of their diagnosis, feeling like emotionally vulnerable. |
| 8 | Butow et al. (2013b) | To document unmet needs, and variables associated with these, in a population-based sample of first-generation immigrants and Anglo-Australians who had survived cancer. | 1) Unmet information needs.<br>2) Understanding the healthcare system<br>3) Immigrants who needed an interpreter had between two and four times higher unmet needs in all domains. | 1) Higher unmet needs contribute to higher levels of anxiety and depression.<br>2) Unmet needs were negatively correlated with HRQoL. These correlations were strongest for Arabic participants | N/A |
| 9 | Ashing et al. (2021) | To examine multilevel predictors of health-related quality of life among Chinese-American breast cancer survivors. | N/A | Social support, family communication, quality of care, and life stress have correlations with overall HRQoL. | N/A |
| 10 | Wang et al. (2012) | To understand how Chinese-American breast cancer survivors experience and cope with physical distress relative to non-Hispanic White survivors. | Information about the usage of traditional Chinese medicine | Chinese immigrant breast cancer survivors expressed less psychological wellbeing compared with US-born Chinese and non-Hispanic White. | Cultural values that emphasise respect for authority figures, such as doctors, may contribute to lower levels of disclosure among Chinese individuals. |
| 11 | Wong-Kim et al. (2005) | To explore cancer-related beliefs and quality of life among Chinese women with breast cancer. | N/A | 1) Family relationships and family support as central to a good HRQoL. | Chinese women with breast cancer often experience cancer-related stigma and hold fatalistic beliefs |

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | **Unmet needs** | **HRQoL** | **Care experience** |
| | | | | 2) Having wealth was cited frequently as a way of achieving a high-quality life. | about cancer, which are prevalent within Chinese communities. |
| 12 | Wang et al. (2013b) | To explore similarities and differences in survivorship care concerns among Chinese American and non-Hispanic White breast cancer survivors. | 1) Information about their diet after treatment<br>2) Social support to adapt to life after cancer treatment | Economic constraints affect their HRQoL. | Language barriers and the stress of immigration (e.g., changes in socioeconomic status, loss of social networks) impact their care experience. |
| 13 | Levesque et al. (2020b) | To broadly explore the experience of breast cancer and coping strategies utilised by Chinese-Australian women. | 1) High quality, accurate information about cancer and treatment options.<br>2) Psychological support to assist them to cope with psychological burden.<br>3) Written information with diverse languages.<br>4) Reliable interpreter services.<br>5) Culturally appropriate services. | N/A | Insufficient information on how to manage their health, along with difficulties accessing interpreter services, negatively affects the care experience of patients. |
| 14 | Zhang et al. (2014) | To investigate factors affecting Chinese women's understanding of, and access to, breast health services, to better understand reasons for low participation in screening and their experiences of breast cancer clinic care. | 1) Chinese speaking staff.<br>2) Information related their treatment.<br>3) Information about traditional Chinese medicine. | N/A | 1) Patients with limited English proficiency reported communication difficulties and expressed distrust in interpreter services.<br>2) Chinese females with breast cancer suffer with cancer related stigma and fatalistic beliefs about cancer. |
| 15 | Lebel et al. (2016) | To greater understanding of how Asian cancer survivors are affected by stigma and improve the provision of culturally sensitive care. | N/A | 1) Asian immigrant survivors reported significantly lower levels of wellbeing than western born Caucasians<br>2) Stigma was a significant predictor of emotional distress. | Stigma exerts a deleterious impact on care experience. |

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | **Unmet needs** | **HRQoL** | **Care experience** |
| | | | | 3) Stigma was a significant predictor of wellbeing | |
| 16 | Wang et al. (2013b) | To elucidate the similarities and differences in communication with physicians between Chinese and non-Hispanic Whites breast cancer survivors. | Information about evidence-based treatment options. | 1) Socioeconomic affect their HRQoL.<br>2) Chinese immigrants are more likely to have poorer quality physician communication and more unmet needs for survivorship care than other ethnic groups. | Respect for authority figures, such as doctors may contribute to lower levels of disclosure among Chinese individuals. Highly acculturated Chinese immigrant women are more likely to express their needs. Cultural difference shaped their communication experience with their treatment team. |
| 17 | Shaw et al. (2016) | To describe migrant patients' experience of care coordination to inform the development of items for inclusion in cancer- care coordination questionnaire sensitive to specific cultural needs of these patients. | 1) Information about treatment.<br>2) Information about the role and responsibilities of their treatment team.<br>3) Culturally appropriate support services. | N/A | Majority of them have positive view of their hospital experience. |
| 18 | Butow et al. (2012) | To compare prevalence and severity of anxiety and depression and quality of life in a population-based sample of first-generation immigrant Australian cancer survivors and Anglo-Australian born controls. | N/A | 1) Compared with Anglo-Australian, immigrants had higher levels of depression and lower levels of HRQoL.<br>2) Arab participants had the highest levels of depression, as well as the lowest HRQoL.<br>3) Understanding the health system was associated with lower values of depression.<br>4) Good health literacy contribute to good HRQoL. | N/A |
| 19 | You et al. (2018) | Investigating the associations between socioeconomic indicators and quality of life and the mediating roles of social support and social | N/A | 1) Annual personal income and education were positively related to HRQoL. | N/A |

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | **Unmet needs** | **HRQoL** | **Care experience** |
| | | constraints in these associations among Chinese American breast cancer survivors. | | 2) More social support and less social constraints were associated with better HRQoL. | |
| 20 | Lin (2008) | To explore how US-resident Chinese immigrants with metastatic cancer search for meaning at the end of their lives. | N/A | 1) Psychological suffering seriously affect their HRQoL.<br>2) Life satisfactory, good social support and personal positive attitude towards life contribute to better HRQoL. | 1) Guilt toward their family.<br>2) Social support and religious practices help them find meaning in life, fostering hope and faith.<br>3) Being open-minded about sharing their experience can empower them. |
| 21 | Leng et al. (2019) | To inform a culturally and linguistically responsive adaptation of meaning-centred psychotherapy for Chinese immigrants and identify salient issues that may affect how they receive cancer care and support. | 1) Information about traditional Chinese medicine.<br>2) Information about nutrition/ dietary. | N/A | 1) Patients with advanced cancer have cancer-related stigma and hold fatalistic beliefs about cancer, which are prevalent within Chinese communities.<br>2) Religion serves as a meaningful resource for care experience. |
| 22 | Leng et al. (2012) | To explore the informational and psychological needs of Chinese cancer patients to inform the development of culturally targeted support and survivorship interventions. | 1) Information about their treatment and health conditions.<br>2) Nutritional guidance, including recommendations on what foods to eat after diagnosis, during chemotherapy, and for recurrence prevention.<br>3) Both patients and family members require social and emotional support services. | N/A | 1) Language barriers and cultural values that emphasise respect for authority figures, such as doctors, may contribute to lower levels of disclosure among Chinese individuals.<br>2) Interpreter services may not as helpful as expected.<br>3) Culture shaped the different values of the usage of traditional Chinese medicine.<br>4) Stigma exerts a deleterious impact on care experience |
| 23 | Chou et al. (2007) | To explore the cancer symptom experience, self-care strategies and quality of life among Chinese Americans during outpatient chemotherapy. | N/A | Low to moderate levels of HRQoL among Chinese immigrant patients during outpatient chemotherapy. | Patients has strong trust of the usage of traditional Chinese medicine to help them heal after treatment. |

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | **Unmet needs** | **HRQoL** | **Care experience** |
| 24 | Warmoth et al. (2017) | To explore the social needs and challenges of Chinese American immigrant breast cancer survivors. | 1) Sufficient family support.<br>2) Information about navigating the healthcare system and dealing with insurance issues in USA.<br>3) cultural appropriate social support services. | N/A | Chinese female breast cancer patients experienced cancer related stigma, and they often put their family as priority rather than themselves. |
| 25 | Choi et al. (2023) | To identify the challenges and strengths of immigrant young adult Chinese American breast cancer survivors. | Need for psychological and social support. | N/A | Younger Chinese female with breast cancer suffer heavy cancer related stigma and psychological burden. They were mothers of young children and commonly concerned not about themselves, but about their children's fate if they lost their mothers. |
| 26 | Sarpel et al. (2018) | To identify barriers to care in treatment of hepatocellular carcinoma among affected individuals in the New York City Chinese immigrant community. | 1) Face-to-face interpreter service rather than phone translation.<br>2) Information about local health system and policy. | 1) Health insurance is a factor to affect HRQoL.<br>2) Financial issues affect HRQoL. | Language is barrier to care, and patients with liver cancer has suffered with stigma as public hold the misunderstanding about the transmission of hepatitis B. Additionally, patients also hold fatalistic beliefs about their diagnosis. |
| 27 | Tsai et al. (2011) | To explore how and to what extent acculturation and immigration affect Chinese-American immigrant women’s breast cancer experience. | 1) Social support to develop their new social networks.<br>2) Information related to their health condition | 1) Higher level of acculturation contributes to good HRQoL.<br>2) Functional social support and supports from partner were positively associated with the level of acculturation.<br>3) The pressure of immigration had negative influences on their HRQoL. | There is a fatalistic belief about cancer around ethnic Chinese communities. Cultural differences between American healthcare providers and Chinese-American families contribute to challenges in the breast cancer experience. |
| 28 | Leng et al. (2014) | To identify the specific support needs of Chinese immigrant cancer patients. | 1) Culturally appropriate services tailored for Chinese patients with cancer. | N/A | N/A |

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | **Unmet needs** | **HRQoL** | **Care experience** |
| | | | 2) Information needs about financial and social assistance, treatment options, and health conditions. | | |
| 29 | Kwok and White (2014) | To explore the perceptions of information needs and social support among Chinese-Australian breast cancer survivors and how these resources impacted their cancer experience. | 1) Culturally appropriate information on side-effect management and recovery.<br>2) Information about diet and nutrition.<br>3) Culturally appropriate social support services. | N/A | Limited English proficiency restrict their communication with treatment team, and Chinese female patients with breast cancer has stigma of their cancer diagnosis. |
| 30 | Tara et al. (2017) | To examine the experiences of Chinese-American immigrant breast cancer survivors with post-treatment breast cancer care and surveillance in New York City. | 1) Information about breast cancer recurrence and long-term breast health.<br>2) Information about their disease, treatment, and post-treatment care.<br>3) Social support. | N/A | Language barrier restricts them receiving good cancer care, and it was sensitive to discuss the cancer topic as there is a fatalistic belief about cancer around ethnic Chinese communities. |
| 31 | Kwok and White (2011) | To explore Chinese-Australian women's perceptions of the meaning and experience of a breast cancer diagnosis, treatment and coping mechanism. | Need culturally and linguistically appropriate information about cancer treatment. | N/A | 1) Limited English proficiency restricts them in communicating about their treatment and understanding the information.<br>2) There is a fatalistic belief about cancer around ethnic Chinese communities make patients suffer cancer-related stigma.<br>3) Chinese female patients with breast cancer always make their family a priority. |

### 5.4.2 Study characteristics

The final sample included:

- Nineteen qualitative studies: (Wong-Kim et al., 2005; Lin, 2008; Kwok and White, 2011; Leng et al., 2012; Wang et al., 2012; Wang et al., 2013b; Kwok and White, 2014; Zhang et al., 2014; Shaw et al., 2016; Tara et al., 2017; Warmoth et al., 2017; Alananzeh et al., 2018; Sarpel et al., 2018; Leng et al., 2019; Lim et al., 2019a; Levesque et al., 2020a; Levesque et al., 2020b; Hsu et al., 2020; Choi et al., 2023);
- Ten quantitative studies: (Chou et al., 2007; Butow et al., 2013a; Butow et al., 2013b; Leng et al., 2014; Ming et al., 2015; Lebel et al., 2016; Hyatt et al., 2017; You et al., 2018; Lim et al., 2019b; Cenik et al., 2020; Ashing et al., 2021);
- Two mixed-methods studies: (Tsai et al., 2011; Wang et al., 2013a).

Sample sizes ranged from 11 to 44 in qualitative studies, and from 25 to 591 in quantitative studies. Twenty-five of the 31 included studies either reported the mean age or provided sufficient data for the mean age to be calculated. Across the included studies, the reported mean age ranged from 37 to 64 years, with a grand mean age of 56 years.

Seventeen studies were from the U.S.A, followed by Australia (n=12). One study was from New Zealand and one from Canada. Twenty-five studies focused exclusively on participants of Chinese heritage. Five studies included multi-ethnic samples, involving participants of Chinese and Arab heritage. One study focused exclusively on Arab immigrants. Ten studies focused on early-stage breast cancer, while two studies exclusively recruited patients with metastatic cancer. The included studies recruited participants via three methods: 10 studies recruited via community groups, 14 studies recruited participants from cancer centres or clinics, and 7 studies used both recruitment methods. Full details of characteristics of the included papers are presented in Table 5-2 and Table 5-3.

### 5.4.3 Study methodological quality

The methodological quality of the included studies varied, with QuADS scores ranging from 19 to 36. The overall quality of the reviewed studies was moderate to high. The overall quality score for quantitative studies was generally higher than the qualitative, ranging from 25 to 36 (median = 30) and 19 to 33 (median = 25), respectively. The two mixed-methods studies scored 23 and 25 respectively. Table 5-4 provides a summary of how many reviewed studies scored for each grade across the QuADS statements.

Table 5-4 Summary of QuADS score among reviewed studies

| QuADS Statements | Score | | | |
|---|---|---|---|---|
| | 0 | 1 | 2 | 3 |
| 1. Theoretical or conceptual underpinning to the research | **0/31*** | **7/31** | **6/31** | **18/31** |
| 2. Statement of research aim/s | **0/31** | **0/31** | **4/31** | **27/31** |
| 3. Clear description of research setting and target population | **0/31** | **4/31** | **8/31** | **19/31** |
| 4. The study design is appropriate to address the stated research aim/s | **0/31** | **1/31** | **11/31** | **19/31** |
| 5. Appropriate sampling to address the research aim/s | **0/31** | **4/31** | **23/31** | **4/31** |
| 6. Rationale for choice of data collection tool/s | **5/31** | **1/31** | **12/31** | **13/31** |
| 7. The format and content of data collection tool is appropriate to address the stated research aim/s | **1/31** | **1/31** | **15/31** | **14/31** |
| 8. Description of data collection procedure | **2/31** | **12/31** | **12/31** | **5/31** |
| 9. Recruitment data provided | **15/31** | **4/31** | **1/31** | **11/31** |
| 10. Justification for analytic method selected | **4/31** | **18/31** | **3/31** | **6/31** |
| 11. The method of analysis was appropriate to answer the research aim/s | **0/31** | **2/31** | **3/31** | **26/31** |
| 12. Evidence that the research stakeholders have been considered in research design or conduct | **18/31** | **0/31** | **6/31** | **7/31** |
| 13. Strengths and limitations critically discussed | **0/31** | **10/31** | **16/31** | **5/31** |

### 5.4.4 Unmet needs

A range of unmet healthcare needs was reported in 23 out of 31 included papers (Kwok and White, 2011; Tsai et al., 2011; Leng et al., 2012; Wang et al., 2012; Butow et al., 2013b; Wang et al., 2013a; Wang et al., 2013b; Kwok and White, 2014; Leng et al., 2014; Zhang et al., 2014; Ming et al., 2015; Shaw et al., 2016; Hyatt et al., 2017; Tara et al., 2017; Warmoth et al., 2017; Alananzeh et al., 2018; Sarpel et al., 2018; Leng et al., 2019; Lim et al., 2019a; Lim et al., 2019b; Levesque et al., 2020a; Levesque et al., 2020b; Choi et al., 2023). Three unmet needs were the most frequently reported: access to quality

* The number before the slash indicates how many studies achieved the specified score; the number after the slash represents the total number of included studies (N = 31)

information, psychological and social support services, and high-quality interpreter services.

Comprehensive and high quality information about cancer diagnosis and treatment was the most frequently reported unmet needs among Chinese and Arab immigrant cancer survivors (Kwok and White, 2011; Leng et al., 2012; Butow et al., 2013b; Wang et al., 2013b; Kwok and White, 2014; Leng et al., 2014; Zhang et al., 2014; Shaw et al., 2016; Tara et al., 2017; Lim et al., 2019a; Lim et al., 2019b; Levesque et al., 2020a; Levesque et al., 2020b). Insufficient information limited their decision-making process (Leng et al., 2012; Shaw et al., 2016; Warmoth et al., 2017; Levesque et al., 2020a). Chinese cancer survivors reported having specific information needs, such as the usage of traditional Chinese medicine (TCM) (Chou et al., 2007; Leng et al., 2012; Wang et al., 2012; Zhang et al., 2014) and the information of diet during survivorship (Leng et al., 2012; Wang et al., 2013a; Kwok and White, 2014; Lim et al., 2019a).

Apart from the need of information related to their diagnosis, Chinese and Arab immigrant cancer survivors also reported a need for information to help them familiarise with and navigate the healthcare system in the host country (Butow et al., 2013b; Ming et al., 2015; Shaw et al., 2016; Tara et al., 2017; Warmoth et al., 2017; Sarpel et al., 2018; Lim et al., 2019b). Converging evidence shows that those cancer survivors who did not know how to navigate the healthcare system exhibited higher depression levels (Butow et al., 2013a), were twice as likely to have higher unmet needs (Butow et al., 2013b), and experienced delays in treatment (Sarpel et al., 2018; Lim et al., 2019a). Much of the confusion was also because of lack of understanding of the diverse roles and responsibilities of the different members of the multidisciplinary team (Shaw et al., 2016; Lim et al., 2019a), as well as the existence of support services within the hospital or their local communities (Shaw et al., 2016). A specific issue for Chinese immigrant cancer survivors living in the USA was lack of understanding of the private health insurance system, which in many cases resulted in putting themselves into financial burden (Tsai et al., 2011; Warmoth et al., 2017).

Both Chinese and Arab immigrant cancer survivors reported the need for appropriate psychological and social support services (Tsai et al., 2011; Leng et al., 2012; Kwok and White, 2014; Leng et al., 2014; Ming et al., 2015; Shaw et al., 2016; Tara et al., 2017; Warmoth et al., 2017; Lim et al., 2019a; Levesque et al., 2020a; Levesque et al., 2020b; You et al., 2018). Many studies consistently found that that peer support services involving individuals with the same ethnic background and health condition represented one of the

most prevalent unmet social needs among Chinese immigrants (Tsai et al., 2011; Kwok and White, 2014; Leng et al., 2014; Leng et al.; Levesque et al., 2020b).

Finally, five studies found that professional, reliable in-person interpreter services was an unmet need for both Chinese and Arab immigrants (Shaw et al., 2016; Hyatt et al., 2017; Alananzeh et al., 2018; Sarpel et al., 2018; Levesque et al., 2020b). The low uptake of interpreter services was partly attributed to the lack of appropriate guidance and advice for them (Leng et al., 2012; Levesque et al., 2020b). Existing services were frequently criticised for issues related to low accuracy and lack of privacy (Zhang et al., 2014; Alananzeh et al., 2018; Sarpel et al., 2018; Levesque et al., 2020b). Furthermore, the presence of multiple dialects within the same language added complexity to achieving satisfactory interpretation experience (Alananzeh et al., 2018; Sarpel et al., 2018).

### 5.4.5 HRQoL

Fifteen of the 31 studies reported on HRQoL (Wong-Kim et al., 2005; Chou et al., 2007; Lin, 2008; Tsai et al., 2011; Wang et al., 2012; Butow et al., 2013a; Butow et al., 2013b; Wang et al., 2013a; Wang et al., 2013b; Ming et al., 2015; Lebel et al., 2016; Sarpel et al., 2018; You et al., 2018; Levesque et al., 2020a; Ashing et al., 2021). These studies identified three determinants: psychological burden, personal socioeconomic factors, and social support. The dual pressure of being an immigrant while facing a life-threatening illness such as cancer significantly impacted their HRQoL (Wong-Kim et al., 2005; Tsai et al., 2011). Arab immigrant cancer survivors showed higher anxiety, depression, and lower HRQoL than individuals from Chinese speaking regions, who in turn reported lower HRQoL than Western-born Caucasians (Butow et al., 2012; Ming et al., 2015; Lebel et al., 2016).

Psychological burden was the most negative factor affecting HRQoL for Chinese and Arab immigrants, with anxiety and depression occurring more frequently (Chou et al., 2007; Lin, 2008; Butow et al., 2013a; Ming et al., 2015; Levesque et al., 2020a). Consistently across many studies, a common contributor to anxiety among Chinese immigrants was fear of cancer recurrence (Kwok and White, 2011; Wang et al., 2012; Tara et al., 2017; Levesque et al., 2020a). Additionally, female Chinese immigrant breast cancer survivors and Chinese patients with metastatic cancer experienced heightened psychological burden (Lin, 2008; Leng et al., 2012; Kwok and White, 2014; Zhang et al., 2014; Warmoth et al., 2017; Leng et al., 2019; Hsu et al., 2020; Choi et al., 2023). Those with metastatic cancer expressed concerns about their future (Lin, 2008; Leng et al., 2019), while women with breast cancer,

particularly younger women, feared the impact of their illness on their family and children, which was associated with increased depression (Kwok and White, 2011; Choi et al., 2023).

Personal income as a core component of socioeconomic status played a key role in influencing HRQoL among Chinese immigrant cancer survivors (Wong-Kim et al., 2005; Chou et al., 2007; Tsai et al., 2011; You et al., 2018; Choi et al., 2023), particularly in relation to functional wellbeing (You et al., 2018; Choi et al., 2023). In the USA, access to medical insurance was another critical socioeconomic factor affecting HRQoL among Chinese immigrants (Leng et al., 2014; Sarpel et al., 2018) and financial difficulties were commonly reported within this group (Wang et al., 2013b; Leng et al., 2014; Sarpel et al., 2018).

Sufficient family and social support were considered essential for maintaining good HRQoL (Wong-Kim et al., 2005; Tsai et al., 2011; You et al., 2018; Ashing et al., 2021). Among Chinese immigrants, participation in religious practices and community activities helped maintain social networks and was associated with better HRQoL (Lin, 2008; Kwok and White, 2011; Levesque et al., 2020a).

### 5.4.6 Experiences of care

Twenty-six of the 31 included papers discussed care experiences of Chinese and Arab immigrant cancer survivors living in their host countries (Wong-Kim et al., 2005; Chou et al., 2007; Lin, 2008; Kwok and White, 2011; Tsai et al., 2011; Leng et al., 2012; Wang et al., 2012; Wang et al., 2013b; Wang et al., 2013a; Kwok and White, 2014; Zhang et al., 2014; Ming et al., 2015; Lebel et al., 2016; Shaw et al., 2016; Hyatt et al., 2017; Tara et al., 2017; Warmoth et al., 2017; Alananzeh et al., 2018; Sarpel et al., 2018; Leng et al., 2019; Lim et al., 2019a; Lim et al., 2019b; Hsu et al., 2020; Levesque et al., 2020a; Levesque et al., 2020b; Choi et al., 2023). Five papers reported that Chinese or Arab immigrants perceived the cancer care they received in host countries to be poorer than that available in their countries of birth, and described negative attitudes towards that care (Zhang et al., 2014; Hyatt et al., 2017; Tara et al., 2017; Sarpel et al., 2018; Lim et al., 2019a).

Insufficient communication with the cancer treatment team was a significant barrier affecting care experience among Chinese and Arab immigrant cancer survivors (Leng et al., 2012; Wang et al., 2012; Butow et al., 2013b; Wang et al., 2013a; Wang et al., 2013b; Ming et al., 2015; Hyatt et al., 2017; Warmoth et al., 2017; Alananzeh et al., 2018; Sarpel et al., 2018; Levesque et al., 2020a). Chinese immigrant cancer survivors disclosed less to

their healthcare providers (Leng et al., 2012; Wang et al., 2012; Wang et al., 2013a; Wang et al., 2013b). Within the Chinese culture, doctors are viewed as authority figures, and they subsequently followed doctors' medical decisions without question, even when they struggled with them (Wang et al., 2013b). Additionally, inadequate English proficiency contributed to this communication challenge, as it impaired trust building with healthcare providers (Zhang et al., 2014; Lim et al., 2019a; Levesque et al., 2020b) and reduced Chinese and Arab cancer survivors' confidence and comfort in communicating (Butow et al., 2013b; Wang et al., 2013a; Ming et al., 2015; Hyatt et al., 2017; Alananzeh et al., 2018; Sarpel et al., 2018). Finally, cultural differences between Chinese immigrant cancer survivors and local healthcare professionals contributed to conflicting views on the use of TCM (Leng et al., 2012; Lim et al., 2019a).

Cancer stigma and fatalistic beliefs, particularly among Chinese immigrant cancer survivors, had a detrimental psychological impact (Wong-Kim et al., 2005; Lebel et al., 2016; Warmoth et al., 2017; Sarpel et al., 2018; Leng et al., 2019), leading to social isolation, feelings of loneliness (Tsai et al., 2011; Kwok and White, 2014; Warmoth et al., 2017; Choi et al., 2023), and a sense of rejection by others (Warmoth et al., 2017). As a result, some survivors choose to conceal their cancer diagnosis within their networks (Tsai et al., 2011; Warmoth et al., 2017; Choi et al., 2023), possibly due to cancer often being viewed as a matter of fate or a consequence of bad 'feng shui', interpreted as punishment for misdeeds in a past life (Wong-Kim et al., 2005; Kwok and White, 2011; Tsai et al., 2011). Therefore, the open discussion about cancer was often absent within the Chinese community (Tara et al., 2017).

While the care experiences and wellbeing of included immigrant cancer survivors were largely focused on the barriers toward good care experience, facilitators among Chinese immigrants were also reported, including good health literacy and acculturation (Wang et al., 2013b; Lim et al., 2019b). Keeping an open-mind and adopting a positive attitude towards cancer also contributed to a better care experience (Lin, 2008; Kwok and White, 2011; Leng et al., 2019). Receiving adequate social support was another key facilitator of a positive care experience (Lin, 2008; Kwok and White, 2014; Tara et al., 2017; Leng et al., 2019; Levesque et al., 2020b; Levesque et al., 2020a), including family support, which was shown to promote recovery following cancer treatment (Lin, 2008; Kwok and White, 2014; Tara et al., 2017; Leng et al., 2019). Additionally, participation in culturally specific organisational activities and religious practice enhanced the cancer experience (Lin, 2008; Leng et al., 2019; Levesque et al., 2020a; Levesque et al., 2020b), with empowerment and

encouragement by cultural organisations (Levesque et al., 2020a; Levesque et al., 2020b) and finding hope, having faith and receiving spiritual support through religious practices (Lin, 2008; Leng et al., 2019).

## 5.5 Discussion

### 5.5.1 Summary of main findings

The current systematic review identified 31 studies involving Asian immigrant cancer survivors from Chinese and Arab backgrounds. The representation of these ethnic groups was highly imbalanced, with 25 studies focusing exclusively on Chinese immigrants and a further five studies including multi-ethnic samples that involved Chinese participants. In addition to this ethnic imbalance, the distribution of the host countries was also uneven: no eligible study was conducted in Europe, indicating a lack of region-specific evidence from European settings. In this systematic review, cultural and linguistic factors were found to play significant roles in shaping cancer survivorship care needs and care experiences, influencing how this population accesses the healthcare system and manages their state of survivorship. Additionally, re-examining the role of interpreter services and accessibility of supportive cancer care in the host country emerged as areas for future action.

### 5.5.2 Connection with literature

Consistent with a systematic review of unmet supportive care needs for Chinese patients by Wu et al. (2022), culture emerged as a major driver of need for information. Chinese immigrant cancer survivors expressed a strong interest in receiving information related to TCM and dietary guidance. This preference reflects deeply rooted cultural beliefs about health and healing (Leng and Gany, 2014). In Chinese society, food holds a central role beyond simply meeting physiological needs, and certain ingredients are culturally regarded as having medicinal properties (Wang-Chen et al., 2022). The compatibility of TCM with standard anticancer treatment can be a standard query among this patient population. In the host country, where the demand for this kind of information is not met, survivorship care can be felt as not inclusive. Culturally appropriate, evidence-based information is needed to support informed decision-making and to honour the cultural values of patients who seek integrative approaches to care.

Certain traditional cultural beliefs, such as feudal superstitions surrounding cancer (Wong-Kim et al., 2005), can contribute to cancer-related stigma, which can lead to negative mental health and social outcomes for cancer survivors, including anxiety, depression, and

deterioration in social functioning (Cataldo and Brodsky, 2013; Teo et al., 2021). Cancer is considered taboo and often viewed as a form of punishment in life among Chinese communities (Tang et al., 2023b). Arabic cultural and religious beliefs also contribute to avoidance of mental health services, as seeking such support is often associated with social stigma (Elshahat and Moffat, 2022). Cancer survivors who are influenced by these cultural norms may disclose their cancer diagnosis only to their families and actively seek to keep their illness a secret (Coleman et al., 2024), which could lead to self-exclusion from potentially beneficial supportive care services (Tsai et al., 2019). Culturally appropriated initiatives that are fully integrated within the immigrant ethnic communities could help normalise conversations about cancer (Cheng et al., 2024b; Cheng et al., 2024a), which can enable Chinese and Arab immigrant cancer survivors and their communities to work together effectively to seek, sign up, and use available services in the host country.

Language is commonly seen as a barrier by both Chinese and Arab immigrants in managing cancer survivorship needs (Clarke and Isphording, 2017). Language barriers can contribute to a delay in seeking care, navigating the healthcare system, difficulties in obtaining information, and ultimately resulting in poorer health outcomes (Clarke and Isphording, 2017; Willis et al., 2016). Although interpreter services are available in very high HDI western countries, cancer survivors often disregard them due to lack of trust in confidentiality and accuracy (Alananzeh et al., 2018). Previous research has shown that where the family requested the cancer diagnosis not to be disclosed to the patient, interpreters struggled to convey information clearly, leading patients feeling the translation as vague and less accurate (Vange et al., 2024).

Barriers to communication between Chinese immigrants and healthcare professionals extend beyond language proficiency to include culture norms (Obeidat et al., 2013). This pattern seems to limit Chinese immigrants' involvement in medical decision-making (Wang et al., 2013b; Obeidat et al., 2013). Although reduced involvement has been observed among older adults in native populations, the underlying reasons appear to differ. Native older adults may prefer to assume less responsibility for medical decision-making and may be less willing to engage actively in treatment choices (Puts et al., 2017). In contrast, Chinese immigrants' lower engagement is often related to unfamiliarity with the principles of patient autonomy and empowerment, and how these align with their cultural values (Wang et al., 2013b; Obeidat et al., 2013). Such culturally shaped norms, which interfered with optimal communication, were not observed among Arab immigrants.

Immigrants often require substantial adaptation to function effectively in a new environment, and limited knowledge of the host country's healthcare system can hinder their ability to access and navigate care (Lim et al., 2017). When a cancer diagnosis is confirmed, it typically involves coordination across multiple healthcare settings, which can further exacerbate the anxiety that stems from being unfamiliar with the healthcare system (Mangrio and Forss, 2017). This can lead to reduced treatment adherence, reduced mental wellbeing and increased risk of isolation during an already challenging period (Mangrio and Forss, 2017). To address this issue, implementing a specialist community navigator/coordinator role in which a trained individual acts as a liaison between Asian immigrant cancer survivors and healthcare providers could be considered (Shommu et al., 2016). This role can help reduce healthcare disparities and improve the cancer survivorship experience by enabling access, enhancing knowledge and supporting ethnic minority groups in navigating complex healthcare pathways (Islam et al., 2023).

### 5.5.3 Confidence in evidence

The overall methodological quality of the included studies was moderate to high. However, more than half of the included studies did not report information for two QuADS statements. Firstly, 18 of the 31 studies did not report whether stakeholders had been involved in the research design or conduct. This may reduce confidence in the extent to which the findings reflected the perspectives and priorities of relevant stakeholders or the public. Secondly, 15 of the 31 studies did not report sufficient recruitment information, limiting assessment of participation rates, reasons for non-participation, and potential selection bias. The characteristics of the included samples suggested that most participants were relatively young. This reduced confidence in the representativeness and generalisability of the findings to older populations. In addition, because recruitment information was insufficiently reported, it was unclear whether older people were less likely to participate and, if so, what factors may have contributed to their non-participation.

### 5.5.4 Strengths and limitations

To the best of our knowledge, this is the first mixed-methods systematic review to focus on the unmet needs, HRQoL, and care experiences of Asian immigrant cancer survivors living in very high HDI Western countries. The reporting of this mixed-methods systematic review was grounded in the substantive findings, enabling an integrated narrative synthesis of quantitative and qualitative evidence. All included evidence was treated as contributing

to the same research questions, providing an in-depth and comprehensive understanding of the topic.

Limitations should also be acknowledged. In terms of methods, study screening and data extraction were primarily conducted by one reviewer (the PhD researcher), with verification and consultation provided by the first and second supervisors. Although this approach is commonly adopted in resource-constrained reviews, it may increase the risk of selection bias and data extraction errors, potentially affecting the reliability and reproducibility of the findings. Limiting the search to three core databases may have resulted in a few relevant studies being missed, particularly from discipline-specific databases such as PsycINFO. However, the use of citation tracking and searching online may have partially mitigated this limitation. In terms of the findings themselves, most participants in the included studies were women with breast cancer. The findings should be carefully considered when applied to other cancer types. Moreover, the evidence regarding immigrants' place of origin was markedly imbalanced, with 30 studies providing evidence on survivors of Chinese heritage, compared with only six reporting on Arab survivors. This imbalance limits the generalisability of the findings of this systematic review to the broader Asian immigrant population. Furthermore, among the six studies involving Arab cancer survivors, only two reported participants' specific countries of origin. Arab populations may originate from both North Africa and Western Asia (the Middle East); however, this information was not clearly specified in most studies. As a result, the applicability of these findings to Arab immigrants from Western Asia remains uncertain. Finally, no study was conducted in Europe, thus not allowing safe conclusions to be made about the care experiences of Chinese and Arab immigrant cancer survivors in the European very high HDI territory.

### 5.5.5 Recommendations

Firstly, future research should focus on underrepresented Asian ethnic groups and their cancer survivorship experiences, such as individuals from Southeast Asian countries. Secondly, little relevant evidence has been reported from European countries, including the UK. Cancer survivorship researchers in these countries should undertake further research to better understand and address cancer inequalities among Asian ethnic minority populations. Thirdly, evidence from this systematic review indicated that ethnic Chinese patients may be less likely to disclose their concerns and needs. Therefore, culturally tailored educational interventions should be developed to support ethnic Chinese

immigrants in understanding and engaging with patient empowerment. This should be accompanied by the development of toolkits and training for healthcare professionals to promote culturally sensitive patient engagement. Fourthly, dedicated training for interpreters and their effective integration into multidisciplinary oncology teams may enhance patient–provider communication, address concerns relating to trust, and support the accurate exchange of key information to meet patients' needs.

## 5.6 Chapter summary

The systematic review in Phase 1 revealed that cultural factors significantly shaped the unmet needs, wellbeing, and care experiences of Chinese and Arab immigrants living with cancer in very high HDI Western countries. Common unmet needs among these populations included information related to health, support with navigating the healthcare system, social support, and access to reliable interpreter services. Chinese immigrants specifically reported needs for information about the use of traditional Chinese medicine and diet during survivorship. Psychological factors, such as fear of cancer recurrence contributing to anxiety, as well as socioeconomic factors such as personal income, were found to affect HRQoL. In addition, Chinese women with breast cancer and patients with metastatic cancer reported a greater psychological burden. Insufficient communication was a common issue affecting care experiences among both Chinese and Arab cancer survivors, while Chinese participants were also particularly affected by cancer-related stigma. Some facilitators were also identified among Chinese cancer survivors, including sufficient social support, good health literacy, and acculturation.

Despite the richness of the systematic review findings, no relevant research had been conducted within the UK, or specifically in Scotland. As noted in the background chapter (Chapter 2), and in light of Scotland's new 10-year cancer strategy, it is important to understand the cancer care experiences of ethnic Chinese immigrants in the Scottish context. Therefore, from Chapter 6 onwards, the empirical phases of this project are introduced to provide an exploratory contribution to this under-researched area within Scotland.

# Chapter 6 : Phase 2: A survey of unmet needs and wellbeing of ethnic Chinese immigrants affected by cancer in Scotland

## 6.1 Introduction

The systematic review in Phase 1 identified that the experiences of ethnic Chinese immigrants affected by cancer in Scotland is absent. This gap highlights the importance of the current and following chapters. Bring the recommendations from the Phase 1 (Chapter 5), Chapter 6 marks the beginning of the empirical phases of the thesis and serves as an exploratory role in investigating the unmet needs, wellbeing, and experience of cancer care for ethnic Chinese immigrants affected by cancer in Scottish context. Chapter 6 presents the methods, results, and key considerations of this cross-sectional survey.

## 6.2 Objectives

- To explore the unmet needs, HRQoL and care experience of ethnic Chinese patients with cancer living in Scotland.
- To explore the HRQoL and care experience of informal caregivers supporting ethnic Chinese patients with cancer in Scotland.

## 6.3 Methods

An exploratory cross-sectional online survey design was employed. Data were collected from November 2023 to June 2024. Reporting of this survey was in line with the Consensus-Based Checklist for Reporting of Survey Studies (CROSS) (Sharma et al., 2021) (Appendix 4).

### 6.3.1 Sample

The target population comprised ethnic Chinese immigrants in Scotland who were affected by cancer, including both patients and informal caregivers. The accessible population was restricted to individuals who could be reached through local Chinese communities, PPIE representatives' networks, and social media platforms. Therefore, Phase 2 survey employed a combination of convenience, purposive, and snowball sampling methods.

- Convenience sampling was chosen as a practical approach, aligning with the use of a social media-based recruitment strategy. This method involves selecting participants who are most readily available and is commonly applied in exploratory research (Polit and Beck, 2017). It enabled broader reach and facilitated the

inclusion of participants who were geographically dispersed across Scotland. Convenience sampling is practical but has a notable risk of bias, as individuals self-selecting to participate, often in response to posted notices, may differ in important ways from those who choose not to volunteer (Polit and Beck, 2022). This trade-off was considered appropriate given the exploratory nature of the project.

- Purposive sampling was employed in line with the recruitment strategy through public sessions and connections with supportive cancer care organisations. This approach enables the intentional recruitment of individuals with relevant experiences to ensure data richness and relevance (Polit and Beck, 2017).
- Snowball sampling was used by asking participants to refer others who met the inclusion criteria for this project. Patients or informal caregivers were also invited to suggest their counterparts to take part. This approach is particularly useful for facilitating access to hard-to-reach populations and enhancing recruitment through social networks (Polit and Beck, 2017).

Although snowball sampling enabled patients and informal caregivers to nominate one another to participate, purposive and convenience sampling also allowed individuals from either group to participate independently, for example, if they encountered the recruitment poster and volunteered without being nominated. Participation was therefore not restricted to patient–caregiver dyads.

#### *6.3.1.1 Eligibility criteria*

The inclusion criteria for patient group:

- Over 18 years of age.
- Diagnosed with any type of cancer.
- Self-identified as ethnic Chinese immigrants, originally born in mainland China, Hong Kong, Macao, Taiwan, Malaysia, Singapore, or other regions with Chinese heritage.
- Currently residing in Scotland.

The inclusion criteria for informal caregiver group:

- Over 18 years of age
- Has experience caring for an ethnic Chinese immigrant patient with cancer who originally came from mainland China, Hong Kong, Macao, Taiwan, Malaysia, Singapore, or other regions with Chinese heritage, and currently living in Scotland.

- May self-identify as ethnic Chinese and originate from the aforementioned regions (not mandatory).
- May currently reside in Scotland.

This project did not apply any specific exclusion criteria. Individuals were excluded if they did not meet the predefined inclusion criteria.

#### *6.3.1.2 Sample size*

The sample size estimation was facilitated using the online sample size calculator provided by Qualtrics (https://www.qualtrics.com/blog/calculating-sample-size/). A rigorous sample size calculation should ideally be based on the incidence rate of the disease within the target population (Polit and Beck, 2017). However, there is no reliable data available on the incidence of cancer among ethnic Chinese immigrants living in Scotland. Sample size was therefore estimated from the prevalence of cancer among the Scottish population to approximate the potential size of ethnic Chinese immigrants with a cancer diagnosis.

Scotland's population reached 5.55 million in mid-2024 (National Record of Scotland, 2025) and the number of people living with a cancer diagnosis was projected to reach around 300,000 by 2025, accounting for around 5.4% of the total Scottish population (Laura Paterson, 2019). According to the updated Scottish Census, approximately 34,000 individuals self-identified as belonging to the Chinese minority (Scotland Census, 2025). Applying this prevalence rate, it can be estimated that around 1,800 ethnic Chinese immigrants in Scotland live with cancer. It was further anticipated that the accessible population would represent roughly 1 in 100 of the target population, equating to approximately 180 individuals. With a sampling confidence level set at 95% and a margin of error set at 7-10%, the total sample size was calculated to be between 63 and 94 patients. In terms of the sample size for informal caregivers, the same sampling methods were used as for the patient group, and data for both groups were collected concurrently. Therefore, the required sample size for the informal caregiver group was expected to be similar to that of the patient group.

### 6.3.2 Recruitment procedures

#### *6.3.2.1 Onsite visit and email correspondence of cancer support organisations*

An online scoping search was conducted, which resulted in 34 professional and charitable supportive cancer care organisations being identified; 11 of 34 are based in Scotland (since July 2023). Invitation letters and recruitment e-flyers were sent by email to each of the

organisations seeking collaboration and help to recruit participants. E-flyers were made with three language versions, including simplified Chinese, traditional Chinese and English (Appendix 6). Eight of the 11 organisations replied to the email within 2 weeks. Breast Cancer Now organisation granted permission to display the recruitment poster on their "Voice community", which is a network of people affected by breast cancer who share their experiences to help shape research, policy, and support services. Breast Cancer Now also agreed to promote the project through their monthly bulletin within their members' network in December 2023.

In addition, on-site visits were conducted to meet with managers of supportive cancer care organisations in Glasgow. Managers at Maggie's and Cancer Support Scotland approved the display of recruitment posters within their centres. A visit was conducted with Macmillan Cancer Support, the largest cancer support organisation in the UK. The Glasgow office, located within Gartnavel General Hospital, requested submission of ethical approval documents to the hospital managers for review. However, no response was received, and permission to display the poster at the Macmillan centre was not granted.

#### *6.3.2.2 Onsite visit and email correspondence of ethnic Chinese communities*

Community-based recruitment strategies were also explored. After searching online, twelve ethnic Chinese communities in Scotland were identified, of which five ethnic Chinese communities were based in Glasgow. These groups or communities were contacted by email. Only one ethnic Chinese community in Glasgow approved an in-person visit, and one community in Inverness agreed to put the poster at their centre. The remaining communities in Glasgow rejected the visiting request with the reason of cancer being a taboo subject.

#### *6.3.2.3 Collaborating with PPIE representatives*

As part of PPIE activity (Chapter 4), two PPIE representatives actively contributed to the organisation of public sessions aimed at promoting the project and building connections with Chinese communities. PPIE representatives liaised with ethnic Chinese churches in Scotland and their pastors gave permission to distribute e-flyer. The public sessions were held in Glasgow Chinese Christian Church (January 2024), community centre Dundee (February 2024), and Chinese Evangelical Church in Edinburgh (March 2024). These cities are the largest and most popular cities for ethnic Chinese immigrants living in Scotland as described in Chapter 2. The public sessions were chaired by a PPIE representative. During the sessions, the PhD researcher and the PPIE representative introduced and promoted this

PhD project. The PPIE representative also shared information about other initiatives related to ethnic Chinese health. Attendees were invited to ask questions and engage in discussion about the project. Supervisors attended the Glasgow session to support the PPIE activities. Approximately 70 ethnic Chinese attended the Glasgow session, with around 30 participants in Dundee and 20 in Edinburgh.

During these sessions, attendees who self-identified as meeting the inclusion criteria were invited to participate in the study by scanning the QR code displayed on the flyers. Attendees were also encouraged to take a flyer to share with others who might meet the inclusion criteria and interested in taking part.

#### *6.3.2.4 Recruiting from social media*

Online recruitment was conducted by sharing the e-flyers (Appendix 6) on social media platforms including X, Facebook, Red Note (a widely used Chinese social media platform), and WeChat. Potential participants who were interested could request to take part by clicking the link or scanning the QR code provided on the e-poster.

### 6.3.3 Data collection format – online survey

Phase 2 data were collected online using Qualtrics, a secure and University of Glasgow approved survey platform (https://www.qualtrics.com/en-gb/). The Qualtrics platform records all individuals who accessed the survey, providing transparency about recruitment flow and attrition. It can also detect duplicate entries based on repeated network address, thereby enhancing data quality. However, this feature also brings a limitation as the total number of responses may be inflated. Individuals who only opened the survey but did not proceed were also recorded, necessitating additional data cleaning.

Individuals without internet access or adequate digital literacy may be excluded from online survey participation, which potentially introduces sample bias (Dillman et al.2014). The response rate for online surveys are also often lower than those for face-to-face methods due to the absence of administration (Couper, 2017). However, an online survey was still considered a suitable option because it was cost-effective and could potentially reach a broad audience (Couper, 2017). Additionally, it also allows participants to complete the survey at their convenience and offers greater privacy, particularly when addressing sensitive topics such as health-related topics (Couper, 2017).

### 6.3.4 Data collection instruments

Selecting an appropriate patient reported outcome measure (PROM) requires consideration of study objectives, target population, treatment and resources (Osoba et al.2021). Following consultation with PPIE representatives, they advised that many ethnic Chinese immigrants have limited English proficiency, making it difficult for them to read and understand questionnaires provided only in English. Therefore, the selection of data collection instruments for this project needed to consider the availability of different language versions.

#### *6.3.4.1 Demographic questionnaire design*

The development of the demographic questionnaire was informed by the Social Determinants of Health Framework, with elaboration provided in Chapter 3. This framework highlights how the conditions in which people are born, grow, live, work, age, as well as money and resources, influence health inequalities for individuals (Marmot, 2005; Solar and Irwin, 2010). Therefore, it was essential to incorporate these social determinant factors into the design of the demographic questionnaire.

Additionally, the inclusion of these socioeconomic determinants was also informed by the evidence from the literature. Two systematic reviews reported that age, gender, education level and clinical factors such as the type of cancer was associated with patient reported outcomes (El Haidari et al., 2020; Zhang et al., 2025). Given that the target population of this project comprises participants with Chinese heritage, culturally specific elements were incorporated into the demographic questionnaire. For example, one response option under current treatment included the use of alternative therapies (e.g. traditional Chinese medicine), and this was also recommended during discussion with PPIE representatives. Finally, immigration-related questions were also incorporated. Lim et al. (2017) noted that although the Chinese population from mainland China, Hong Kong, and Singapore shared similar languages, they differ in cultural values due to varying degrees of modernisation and westernisation. The systematic review (Chapter 5) also found that higher acculturation was a positive factor associated with better care experiences. Therefore, demographic questions on place of birth and duration of residence in Scotland were included to explore whether levels of acculturation were associated with patient-reported outcomes.

The same questions were retained for the informal caregiver groups but with minor modifications, such as removing the question of type of cancer treatment to ensure relevance. The demographic questionnaire was reviewed by the supervisory team and PPIE

representatives prior to implementation to ensure it was understandable and aligned with the reading habits of ethnic Chinese immigrants. The demographic questionnaire included three language versions and an English version are presented in Appendix 7.

#### *6.3.4.2 Selection process of PROM for HRQoL*

There are three well validated PROMs for assessing HRQoL which are available in both Chinese and English versions. The McGill Quality of Life Questionnaire was first excluded as it is primarily designed for use in palliative care settings, focusing on patients at an advanced-stage cancer rather than being inclusive of all disease stages (Cohen et al., 1995). This reduced the decision to either the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (Aaronson et al., 1993), or the Functional Assessment of Cancer Therapy–General (FACT-G) (Brucker et al., 2005).

The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 instrument focuses on more objective aspects of functioning and is primarily symptom-oriented (Luckett et al., 2011). It is more commonly used in intervention studies that aim to evaluate functional outcomes and symptom burden after active cancer treatment (Kotronoulas et al., 2014). Conversely, the FACT-G encourages patients to reflect more deeply on their thoughts and feelings (Luckett et al., 2011). Therefore, the FACT-G was selected as the PROM for assessing HRQoL and wellbeing for this project, as it captures more subjective dimensions. This is consistent with the aim of this project to achieve an understanding of wellbeing for HRQoL rather than evaluating treatment outcomes.

In selecting the PROM for assessing HRQoL for the informal caregiver group, consideration was given to using instruments from the same measurement series. Employing PROMs that share a common theoretical foundation and domain structure enables consistency in the constructs measured and facilitates meaningful comparison across patient and caregiver groups (Beatty et al., 2020). The FACT series offers a validated caregiver version (Song et al., 2020), whereas the EORTC Quality of Life Group does not. This difference further supported the selection of the FACT series instruments for both the patient and informal caregiver group.

#### *6.3.4.3 Functional Assessment of Cancer Therapy–General (FACT-G)*

The FACT-G is a 27-item instrument comprising four subscales: Physical wellbeing, Social/Family wellbeing, Emotional wellbeing, and Functional wellbeing (Table 6-1) (Brucker et al., 2005).

Table 6-1 Overview of FACT-G subscales (Brucker et al., 2005)

| | **Number of items** | **Key focus** |
|---|---|---|
| Physical wellbeing | 7 | Physical symptoms and treatment side effects |
| Social /Family wellbeing | 7 | Relationship and social /family support |
| Emotional wellbeing | 6 | Psychological and emotional states after diagnosed with cancer |
| Functional wellbeing | 7 | Independence, roles, daily functioning |

The FACT-G was initially used with English-speaking patients with cancer in oncology trials and demonstrated strong convergent validity, showing a Pearson correlation of 0.79 with the Functional Living Index-Cancer in a sample of 845 patients (Cella et al., 1993). This instrument also showed good internal consistency, with a Cronbach's alpha of 0.89 for the total scale, and subscale alphas of 0.82 for physical wellbeing, 0.74 for emotional wellbeing, 0.69 for social/family wellbeing, and 0.80 for functional wellbeing (Cella et al., 1993).

The simplified Chinese version of the FACT-G was validated by Cheung et al. (2009), with 165 Chinese patients in Singapore. Cheung et al. (2009) reported that FACT-G demonstrated strong psychometric properties among Chinese patients, with high Cronbach's alpha ranging from 0.81 to 0.93. It also showed strong convergent validity with the Functional Living Index-Cancer (Cheung et al., 2009). In terms of the traditional Chinese version, Yu et al. (2000) assessing it in 1262 patients with cancer in Hong Kong. The results showed acceptable reliability, validity, and reasonable utility for Chinese populations familiar with traditional Chinese character (Yu et al., 2000). Functional Assessment of Chronic Illness Therapy group granted permission to use the questionnaires in all three language versions (Appendix 8).

#### *6.3.4.4 Functional Assessment of Cancer Therapy–General Caregiver (FACT-G Caregiver)*

The FACT-G Caregiver instrument was developed from the FACT-G for patients (Cella et al., 1993). FACT-G Caregiver instrument consists of 27 items across four subscales (Physical, Social/family, Emotional, Functional). The key focus of FACT-G Caregiver parallels the FACT-G domains (Table 6-1). The development of FACT-G caregiver was based on transactional theory of stress by Lazarus and Folkman (1984). Song et al. (2020)

examined psychometric properties of FACT-G Caregiver instrument among 263 partners of prostate cancer patients, and 484 caregivers of patients with advanced cancer from two randomised control trials. The FACT-G Caregiver was acceptable with high inter-factor correlations and internal consistency reliability (Cronbach's alphas range from 0.81 to 0.91) (Song et al., 2020). It also shows the strong convergent and discriminant validity through significant correlations with caregiver self-efficacy, social support, and psychological distress (Song et al., 2020).

The language consideration of data collection instruments was important for this project. However, there was only the English version of the FACT-G Caregiver available for use provided by the developer. This language limitation for caregivers was clearly explained in the Participant Information Sheet and further discussed in the limitation section of this chapter. Permission to use the FACT-G Caregiver instrument was obtained alongside the FACT-G licence (Appendix 8).

#### *6.3.4.5 Selection process of PROM for unmet needs*

The primary consideration when selecting PROMs to assess unmet needs was also the availability of validated Chinese versions. There are five well validated PROMs assessing unmet needs which have either a simplified or traditional Chinese version (Yan et al., 2022). The Advanced Cancer Patients Needs Questionnaire developed by Duan (2012) was firstly excluded, as it was developed in China but without a valid English version. Although most ethnic Chinese immigrants may prefer to read Chinese, it was also important to ensure the availability of an English version, given that this study was conducted in an English-speaking country and to accommodate participants who might prefer to complete the questionnaire in English. The Problems and Needs in Palliative Care Questionnaire developed by Osse et al. (2004) and Three Levels of Needs Questionnaire developed by Johnsen et al. (2011) were also excluded because both instruments were developed for patients with advanced-stage cancer and were therefore not suitable for assessing needs across all cancer stages.

Cancer Survivors' Unmet Needs Measure was developed by Hodgkinson et al. (2007) and was psychometrically tested with a traditional Chinese version by Xing et al. (2019). This instrument was further excluded because the simplified Chinese version was not available at the time this project started (November 2023) and was only recently translated and validated by Xu et al. (2024). Having a simplified and traditional Chinese version available was important as ethnic Chinese immigrants who come from mainland China and are

educated in simplified Chinese, may find traditional Chinese characters difficult or uncomfortable to read due to notable differences between two writing systems. Finally, the Supportive Care Needs Short Form (SCNS-SF 34) developed by Boyes et al. (2009) was selected to assess the unmet needs of the patient group. SCNS-SF 34 is an internationally used instrument designed to measure cancer patients' perceived needs and could be utilised as part of routine cancer care (Boyes et al.2009).

To minimise participant burden, the Phase 2 survey did not include a direct assessment of unmet needs among informal caregivers. Instead, informal caregivers' wellbeing was assessed using the FACT-G Caregiver instrument, which provides indirect indications of potential unmet needs. In the subsequent in-depth interviews (Chapter 7), informal caregivers were asked questions specifically exploring their unmet needs, which could alleviate the limitations for this project.

#### *6.3.4.6 Supportive Care Needs Short Form (SNCS-SF 34)*

SCNS-SF34 assesses cancer specific unmet needs across five domains (Table 6-2) (Boyes et al.2009). The English version of SCNS-SF 34 has high internal consistency with Cronbach's alpha of at least 0.86 for each subscale (Boyes et al.2009). Lyu et al. (2020) tested the simplified Chinese version with 206 patients in Chengdu, China, reporting satisfactory psychometric properties. Au et al. (2011) validated the traditional Chinese version with 348 women with breast cancer in Hong Kong, which demonstrated an appropriate factor structure and strong internal consistency, with Cronbach's alpha ranging from 0.75 to 0.92. The email correspondence granting permission to use the SCNS-SF 34 from its developer is provide in Appendix 8.

Table 6-2 Overview of SCNS-SF 34 subscales (Boyes et al. 2009)

| | **Number of items** | **Key focus of unmet needs** |
|---|---|---|
| Physical & Daily life | 5 | Impact of physical symptoms on daily functioning |
| Psychological | 10 | Emotional distress and psychological adjustment |
| Sexuality | 3 | Sexual health |
| Patient Care & Support | 5 | Quality of professional care and support received |
| Health System & Information | 11 | Access to clear information and communication with healthcare providers |

### 6.3.5 Data analysis

Data were initially entered onto a Microsoft Excel spreadsheet and then transferred into SPSS 26.0 for analysis. The original plan was to perform descriptive and inferential statistical analyses. Despite seven months of data collection efforts, the final sample size was too small to achieve statistical power for inferential analysis. Therefore, only descriptive analyses were conducted. Given that the demographic variables are categorical, frequency and percentage were used to describe the data.

Data analysis for FACT-G and FACT-G Caregiver followed scoring guidelines provided by the developer, with both instruments using the same scoring method (https://www.facit.org/scoring). The FACT-G and FACT-G Caregiver instruments use the five-point Likert-type scale ranging from 0 to 4 with the following response options: 0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, and 4 = very much (Brucker et al., 2005). Negatively worded items were reverse-scored, and scores were calculated by summing the items. The overall score for FACT-G and FACT-G Caregiver range of 0 to 108, with a higher score indicating better quality of life (Brucker et al., 2005). Response categories were collapsed for clarity in reporting. “Not at all” and “a little bit” were combined to indicate no problem affecting wellbeing; “somewhat” indicated a moderate problem; and “quite a bit” and “very much” were combined to indicate major problems affecting wellbeing.

SCNS-SF 34 was also a five point Likert scale, with the following response options: 1= no need, not applicable; 2= no need, satisfied; 3= low need; 4= moderate need; 5= high need (Boyes et al.2009). Scoring and analysing for SCNS-SF 34 followed the guidelines provided by the developers, with higher scores indicating greater levels of perceived supportive care needs (McElduff et al.2004; Boyes et al., 2012). In accordance with the developer’s analysis approach, the item responses of “4= moderate need” and “5= high need” were combined to represent unmet needs (McElduff et al.2004; Boyes et al., 2012).

In addition to following the scoring guidelines for FACT-G (Caregiver) and SCNS-SF 34, the frequency and percentage were also employed to describe the prevalence of identified unmet needs and problems affecting HRQoL. As the scores were continuous variables, mean and standard deviation (SD), median and minimum and maximum values were applied to assess the central tendency and variability of the data.

### 6.3.6 Ethical considerations

#### *6.3.6.1 Research ethics approval*

Ethical approval for this study was obtained from University of Glasgow, College of Medical, Veterinary and Life Sciences (MVLS) Ethic Committee (Project Number: 200220455, 16th October 2023) (Appendix 9).

#### *6.3.6.2 Informed consent*

The participant information sheet, privacy notice, consent form and questionnaires were uploaded onto Qualtrics. Potential participants were given sufficient time to review these before deciding to take part. If they agreed to participate, they responded by clicking the option "*Yes, I agree to take part in this study*" on the consent form page. If a participant chose "*No, I do not agree to take part in this study*", then the webpage closed automatically, and a "*Thank you*" message appeared. Only participants who agreed to consent were granted access to the questionnaire. This process ensured that ethical considerations regarding informed consent were appropriately addressed. On the first page of the questionnaire, participants identified their role as either "patient" or "family member". "Family member" was used instead of "informal caregiver" to improve understanding, as individuals were more likely to identify themselves in this way. This decision was informed by the cultural context discussed in Chapter 2 and consultation with the PPIE group.

All questions were non-mandatory, allowing participants to skip any items they did not wish to answer. Additionally, participants were informed that they could withdraw from the study at any time without providing a reason and without any penalty. This approach shows the ethical principles of voluntary participation, autonomy, and respect for participants' choices. The participant information sheet, privacy notice, and consent form were available in simplified Chinese, traditional Chinese and English. English versions of these documents are provided in Appendix 10.

#### *6.3.6.3 Data management plan*

The University of Glasgow serves as the data controller for this project. All data were held only for research purposes and will not be shared with or used by any third party for commercial purposes. This project involved collection of personal data, and the overall data management plan was developed in accordance with the General Data Protection Regulation and UK Data Protection Act 2018. These regulations and protection measures constitute the current data protection legislation governing the handling of personal data in

the UK (Medical Research Council, 2018). Additionally, the Data Protection Impact Assessment was reviewed by the Data Protection Office at the University of Glasgow, as a legal requirement for research involving human participants.

Phase 2 survey obtained identifiable and non-identifiable personal data. The identifiable personal data (email address) were used for communication purposes with potential participants who were interested in taking part in Phase 3 in-depth interviews (Chapter 7). Non-identifiable personal data (e.g. gender, age) were considered as 'research data' and helped to describe the sample. The Qualtrics platform was only employed during the active data collection period. Upon completion of data collection, all responses were securely downloaded and stored on the University of Glasgow's approved OneDrive system. Subsequently, all data were permanently deleted from Qualtrics. Identifiable personal data were also permanently deleted from OneDrive after the completion of participant recruitment.

## 6.4 Results

### 6.4.1 Questionnaire distribution and responses

Between November 2023 and June 2024, a total of 81 individuals clicked the survey invitation link. Of these, 24 patients and 13 informal caregivers completed the survey, resulting in 37 valid responses for analysis and an overall response rate of 45.7%. Figure 6-1 presents the details of participant attrition across the survey process.

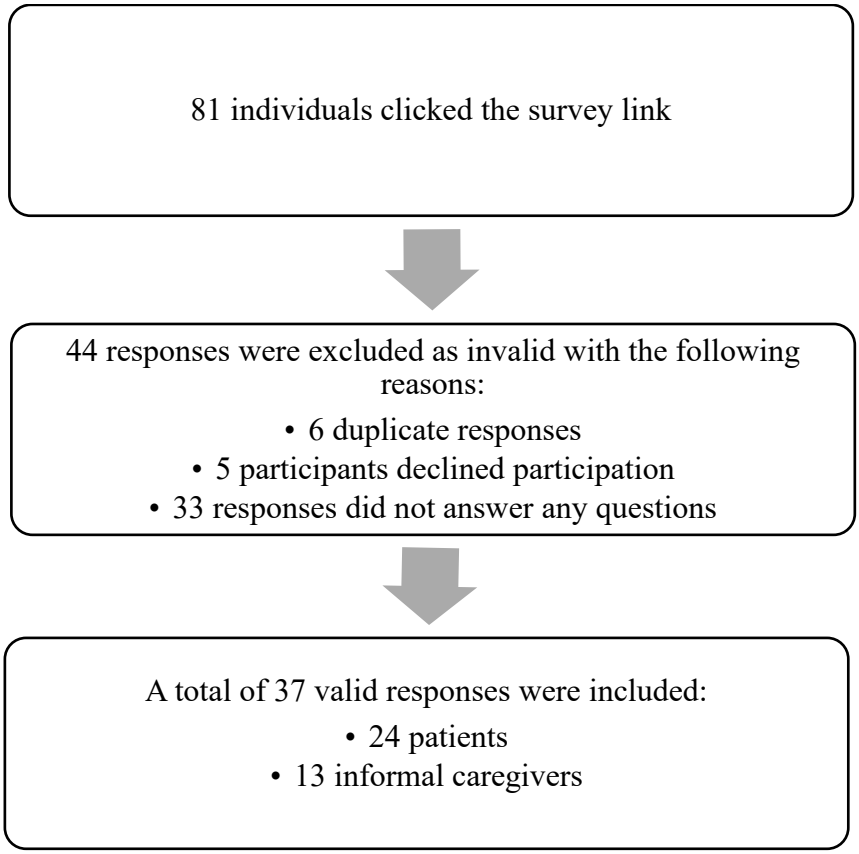



Figure 6-1 Phase 2 survey response flow chart

### 6.4.2 Demographic results for patients and informal caregivers

Most patients were female (n=16, 66.7%), aged under 50 years (n=14, 58.3%), born in mainland China (n=18, 75%) and had lived in Scotland for less than five years (n=13, 54.2%). Patients were generally well educated, with 87.5% (n=22) holding a bachelor's degree or higher. Seventeen patients were employed either part-or full-time, and 66% reported a monthly income between £2000 and £4000. In terms of family and faith, 79.1% were married or partnered, 70.8% had at least one child, and 70.9% identified a religion. In terms of cancer diagnosis, 62.5% of patients were newly diagnosed and had received chemotherapy. Breast cancer (37.5%) and lung cancer (33.3%) were the most common diagnoses. Half of the patients were in the early stages of cancer (Stages I–II), while 29.2% were in advanced or metastatic stages (Stages III–IV), and 20.8% were unaware of their stage. Details of sample characteristics for patient group can be found in Table 6-3.

Most informal caregivers were male (n=9, 69.2%), and nearly half (46.2%) of them age between 31 to 40. Five of them originated from mainland China (38.5%), followed by 30.8% from Hong Kong (n= 4). Most informal caregivers had been living in Scotland for either less than 5 years (n=6, 46.2%) or more than 10 years (n = 6, 46.2%). Ten informal

caregivers (77%) held a bachelor's degree or higher and were employed either full-time or part-time. Nine informal caregivers (69.3%) had less than one year of caregiving experience, and six informal caregivers (46.2%) were caring for their spouse or partner. Additional demographic details for informal caregivers group are shown in Table 6-3.

Table 6-3 Demographic characteristics of patients (n=24) and informal caregivers (n=13)

| **Variable** | **Category** | **Patients; N (%)** | **Informal caregivers; N (%)** |
|---|---|---|---|
| Age (years) | <30 | 2 (8.3) | 1 (7.7) |
| | 31–40 | 7 (29.2) | 6 (46.2) |
| | 41–50 | 5 (20.8) | 2 (15.4) |
| | 51–60 | 4 (16.7) | 4 (30.8) |
| | 61–70 | 4 (16.7) | – |
| | >70 | 2 (8.3) | – |
| Gender | Female | 16 (66.7) | 4 (30.8) |
| | Male | 8 (33.3) | 9 (69.2) |
| Place of birth | Mainland China | 18 (75.0) | 5 (38.5) |
| | Hong Kong | 4 (16.7) | 4 (30.8) |
| | Singapore | 1 (4.2) | 2 (15.4) |
| | Malaysia | 1 (4.2) | 2 (15.4) |
| Years in Scotland | <5 years | 13 (54.2) | 6 (46.2) |
| | 5–10 years | 6 (25.0) | 1 (7.7) |
| | >10 years | 5 (20.8) | 6 (46.2) |
| Education | Primary school | 1 (4.2) | – |
| | Junior high school | – | 2 (15.4) |
| | High school | 1 (4.2) | 1 (7.7) |
| | Bachelor's degree | 11 (45.8) | 4 (30.8) |
| | Master's degree | 10 (41.7) | 6 (46.2) |
| | Doctoral degree | 1 (4.2) | – |
| Employment | Retired | 2 (8.3) | 1 (7.7) |
| | Unemployed | 4 (16.7) | 2 (15.4) |
| | Employed full-time | 9 (37.5) | 6 (46.2) |
| | Employed part-time | 8 (33.3) | 4 (30.8) |
| | On sick leave | 1 (4.2) | – |
| Living area | City | 16 (66.7) | 7 (53.8) |
| | Suburb/town | 8 (33.3) | 4 (30.8) |
| | Remote/village | – | 2 (15.4) |
| Marital status (patients only) | Married | 14 (58.3) | – |
| | Partnered | 5 (20.8) | – |
| | Single | 4 (16.7) | – |
| | Divorced | 1 (4.2) | – |
| Relationship to patient (caregivers only) | Spouse/partner | – | 6 (46.2) |
| | Parents | – | 5 (38.5) |
| | Son/daughter | – | 2 (15.4) |
| Religion | Christianity | 13 (54.2) | 4 (30.8) |
| | Catholic | 3 (12.5) | 1 (7.7) |
| | Buddhism | 1 (4.2) | 2 (15.4) |

| | | | |
|---|---|---|---|
| | None | 7 (29.2) | 6 (46.2) |
| Monthly income | <£2000 | 4 (16.7) | 5 (38.5) |
| | £2000–£3000 | 8 (33.3) | 5 (38.5) |
| | £3000–£4000 | 8 (33.3) | 2 (15.4) |
| | >£4000 | 4 (16.7) | 1 (7.7) |
| Children | 0 | 7 (29.2) | 3 (23.1) |
| | 1 | 12 (50.0) | 7 (53.8) |
| | >1 | 5 (20.8) | 3 (23.1) |
| Cancer type (patients)/caring for (caregivers) | Breast | 9 (37.5) | 6 (46.2) |
| | Lung | 8 (33.3) | 2 (15.4) |
| | Thyroid | 4 (16.7) | – |
| | Prostate | 1 (4.2) | – |
| | Liver | 1 (4.2) | – |
| | Uterine | 1 (4.2) | – |
| | Gastrointestinal | – | 5 (38.5) |
| Years since diagnosis/ caregiving | <6 months | 7 (29.2) | 3 (23.1) |
| | 6–12 months | 8 (33.3) | 6 (46.2) |
| | 1–2 years | 3 (12.5) | 3 (23.1) |
| | 2–5 years | 1 (4.2) | 1 (7.7) |
| | >5 years | 5 (20.8) | – |
| Stage of cancer | Stage I | 8 (33.3) | 3 (23.1) |
| | Stage II | 4 (16.7) | 6 (46.2) |
| | Stage III | 6 (25.0) | 1 (7.7) |
| | Stage IV | 1 (4.2) | 1 (7.7) |
| | Don’t know | 5 (20.8) | 2 (15.4) |
| Current treatment (Multiple-choice question for patients only) | Chemotherapy | 15 (62.5) | – |
| | Radiotherapy | 3 (12.5) | – |
| | Hormone therapy | 3 (12.5) | – |
| | Alternative therapy | 3 (12.5) | – |
| | Targeted therapy | 2 (8.3) | – |
| | Immunotherapy | 1 (4.2) | – |
| | Palliative care | 1 (4.2) | – |
| | Don’t know | 1 (4.2) | – |

### 6.4.3 HRQoL of patients and informal caregivers

#### *6.4.3.1 Completeness of data*

For the patient sample, out of a total of 648 possible responses across 24 participants, only 9 responses were missing (1.4%). Missing responses were observed for an optional question related to sexual life. For the informal caregiver sample, out of 351 possible responses across 13 participants, 52 responses were missing (15%). Of the 15% missing data, 11% was concentrated in the emotional and functional wellbeing domains, whereas 4% was in the social/family wellbeing domain, primarily due to the optional question on sexual life. Table 6-4 presents the visual overview of missing data for patients and informal caregivers.

Table 6-4 Overall responses for FACT-G/ FACT-G (Caregiver)

| **Domains** | **Items** | **Patients (n=24)** | **Informal caregivers (n=13)** |
|---|---|---|---|
| Physical wellbeing | 1. I have a lack of energy | 24 | 13 |
| | 2. I have nausea | 24 | 13 |
| | 3. Because of my physical condition, I have trouble meeting the needs of my family | 24 | 13 |
| | 4. I have pain | 24 | 13 |
| | 5a. I am bothered by side effects of treatment (patient only) | 24 | 13 |
| | 5b: Are you currently taking any medication or receiving other medical treatments? If yes, I am bothered by side effects of treatment (informal caregiver only) | | 13 |
| | 6. I feel ill | 24 | 13 |
| | 7. I am forced to spend time in bed | 24 | 13 |
| Social/ Family wellbeing | 1. I feel close to my friends | 24 | 13 |
| | 2. I get emotional support from my family | 24 | 13 |
| | 3. I get support from my friends | 24 | 13 |
| | 4. My family has accepted my illness | 24 | 11 |
| | 5. I am satisfied with family communication about my illness | 24 | 11 |
| | 6. I feel close to my partner | 24 | 11 |
| | 7. I am satisfied with my sex life (optional) | 15 | 6 |
| Emotional wellbeing | 1. I feel sad | 24 | 10 |
| | 2. I am satisfied with how I am coping with my/ family member's illness | 24 | 10 |
| | 3. I am losing hope in the fight against my/family member's illness | 24 | 10 |
| | 4. I feel nervous | 24 | 10 |
| | 5. I worry about (my family member) dying | 24 | 10 |
| | 6. I worry that my/family member's condition will get worse | 24 | 10 |
| Functional wellbeing | 1. I am able to work (include work at home) | 24 | 10 |
| | 2. My work (include work at home) is fulfilling | 24 | 10 |
| | 3. I am able to enjoy life | 24 | 10 |
| | 4. I have accepted my/family member's illness | 24 | 10 |
| | 5. I am sleeping well | 24 | 10 |
| | 6. I am enjoying the things I usually do for fun | 24 | 10 |
| | 7. I am content with the quality of my life right now | 24 | 10 |

### *6.4.3.2 Patient data*

The scores of FACT-G ranged from 50 to 97 (Mean=66.9, SD=11.3). Subscale scores ranged from 11 to 28 for physical wellbeing (Mean=19.3, SD=4.7), 4 to 26 for social/family wellbeing (Mean=17.2, SD=5.4), 8 to 23 for emotional wellbeing (Mean=14.2, SD=4.9), and 7 to 24 for functional wellbeing (Mean=16.2, SD=5.1) (Table 6-5).

Table 6-5 Descriptive statistic results of FACT-G

| | N | | Number of items | Median | Mean (SD) | Min-max |
|---|---|---|---|---|---|---|
| | Valid | Missing | | | | |
| Physical wellbeing | 24 | 0 | 7 | 19 | 19.3 (4.7) | 11-28 |
| Social/family wellbeing | 24 | 0 | 7 | 18 | 17.2 (5.4) | 4-26 |
| Emotional wellbeing | 24 | 0 | 6 | 13 | 14.2 (4.9) | 8-23 |
| Functional wellbeing | 24 | 0 | 7 | 16 | 16.2 (5.1) | 7-24 |
| Total | 24 | 0 | 27 | 63 | 66.9 (11.3) | 50-97 |

In the physical wellbeing domain, 37% of patients reported lack of energy ranking as "quite a bit" to "very much". Other symptoms, such as pain (13%) and nausea (13%), were also reported as "quite a bit" to "very much" affecting physical wellbeing (Figure 6-2).

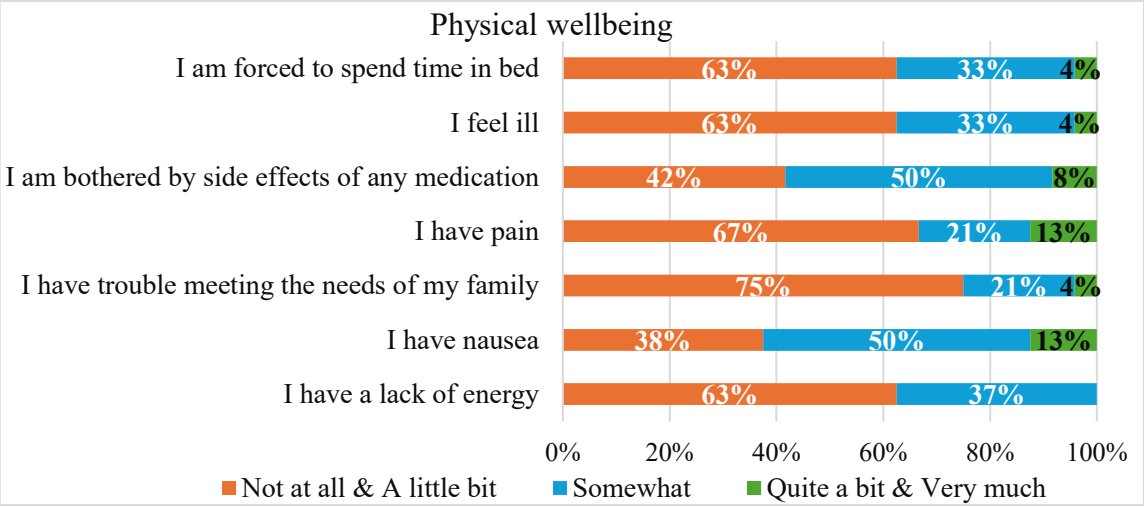



Figure 6-2 Physical wellbeing for patients

In social or family wellbeing domain, most patient samples reported feeling close to their partner (66%), receiving emotional support from their family (63%) and family accepting the illness (63%) ("quite a bit" or "very much"). In terms of family functioning, 54% of patient reported being satisfied with family communication, and 47% reported satisfaction with their sex life ("quite a bit" or "very much"). However, closeness to friends appeared more limited: 25% of patient samples reported feeling "not at all" or "a little bit" close to

their friends, and 38% reported feeling “somewhat” close. Similarly, when asked about support from friends, 17% reported received no support and 42% reported receiving support “somewhat” (Figure 6-3).

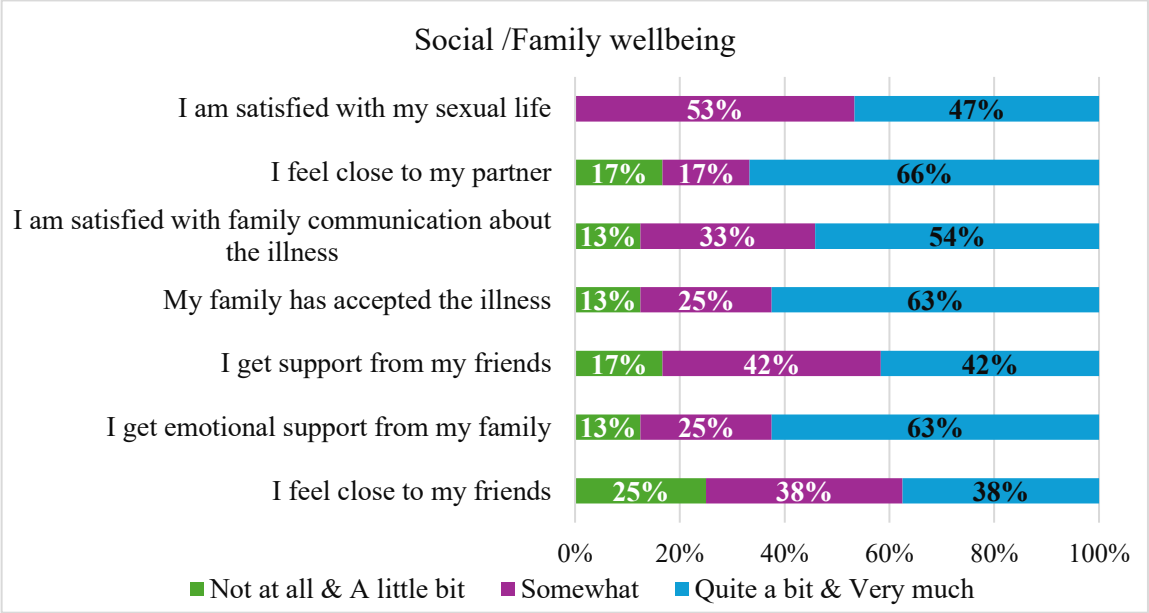



Figure 6-3 Social/Family wellbeing for patients

In the emotional wellbeing domain, 38% of patient samples reported worrying that their condition would worsen, 33% reported sadness, 29% reported worrying about dying, 25% reported feeling nervous, with responses of “quite a bit” or “very much”. However, 67% of patient samples reported that they had not lost hope in their fight against cancer, and 45% reported being satisfied with how they were coping with their illness “quite a bit” or “very much” (Figure 6-4).

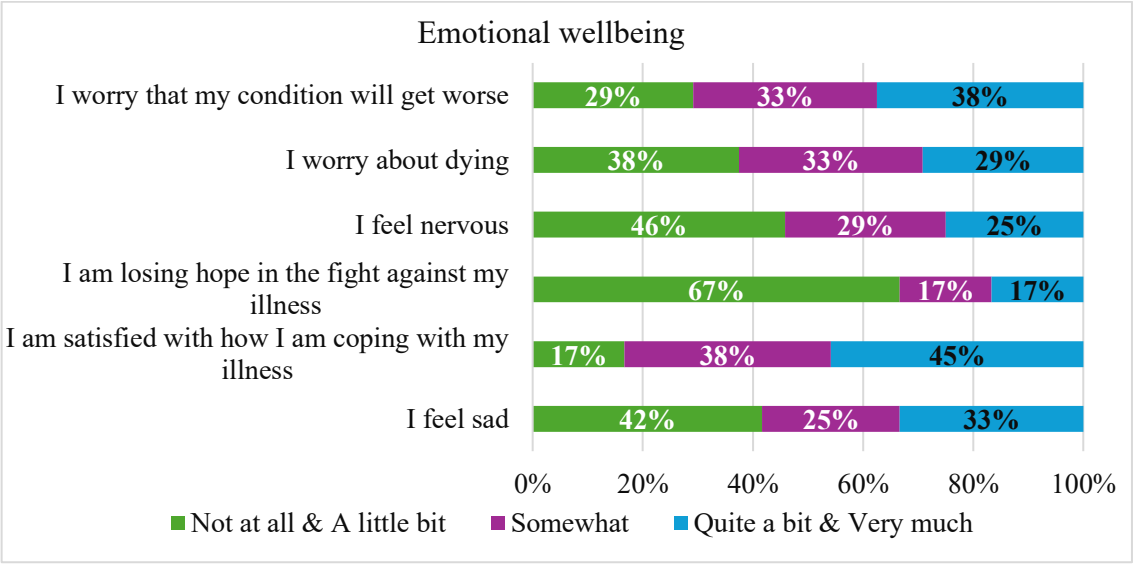



Figure 6-4 Emotional wellbeing for patients

In the functional wellbeing domain, 71% of patient samples reported accepting their illness, 50% reported enjoying activities they usually find pleasurable, 46% reported being able to work, and 42% reported being able to enjoy life, with responses of "quite a bit" or "very much". Additionally, 33% of patient samples reported being content with their quality of life, 29% reported sleeping well, and 25% reported that their work was fulfilling after the cancer diagnosis, with responses of "quite a bit" or "very much" (Figure 6-5).

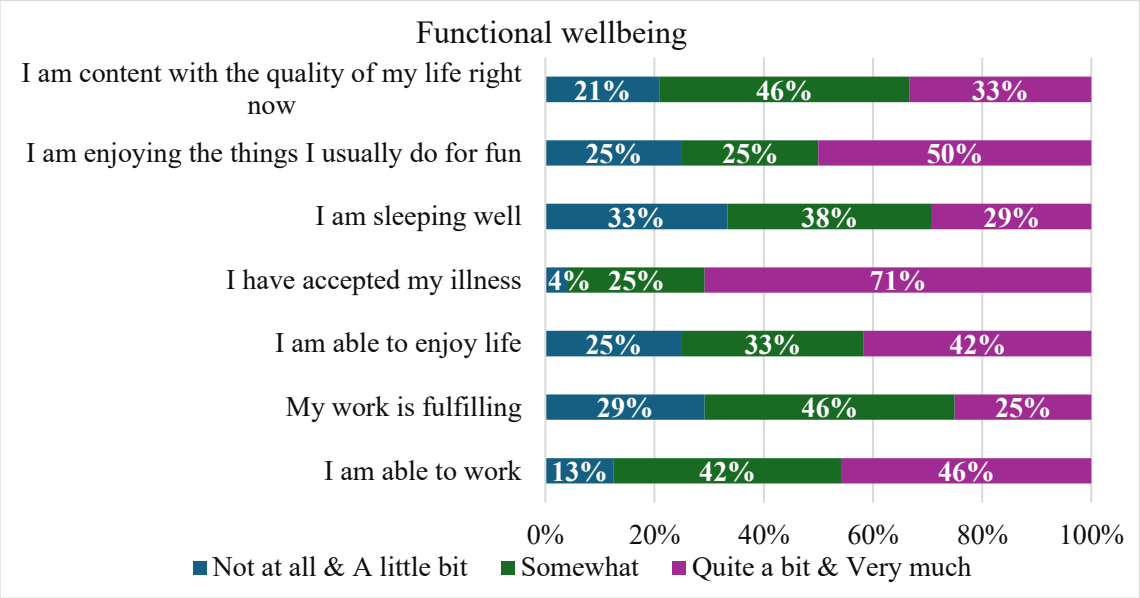



Figure 6-5 Functional wellbeing for patients

### *6.4.3.3 Informal caregiver data*

The scores for FACT-G Caregiver ranged from 37 to 85 (Mean=61.3, SD=13.8). Subscale scores ranged from 16 to 26 for physical wellbeing (Mean=20.1, SD=3.1), 7 to 21 for social/family wellbeing (Mean=13.5, SD=5.0), 4 to 21 for emotional wellbeing (Mean=13.2, SD=4.9), and 8 to 24 for functional wellbeing (Mean=13.6, SD=5.5) (Table 6-6).

Table 6-6 Descriptive statistics results of FACT-G Caregiver

| | N | | Number of items | Median | Means (SD) | Min-max |
|---|---|---|---|---|---|---|
| | Valid | Missing | | | | |
| Physical wellbeing | 13 | 0 | 7 | 20 | 20.1 (3.1) | 16-26 |
| Social/family wellbeing | 11 | 2 | 7 | 11 | 13.5 (5.0) | 7-21 |
| Emotional wellbeing | 10 | 3 | 6 | 14 | 13.2 (4.9) | 4-21 |
| Functional wellbeing | 10 | 3 | 7 | 12 | 13.6 (5.5) | 8-24 |
| Total | 10 | 3 | 27 | 62 | 61.3 (13.8) | 37-85 |

In the physical wellbeing domain, informal caregiver samples reported minimal physical symptoms, with the majority responding “not at all” or “a little bit” to items such as nausea (100%), medication side effects (92%), spending time in bed (77%), feeling ill (69%) and pain (62%). Nevertheless, a proportion of informal caregiver samples reported lack of energy (38%) and 8% of them reported difficulty meeting the family needs as “quite a bit” to “very much” extent (Figure 6-6).

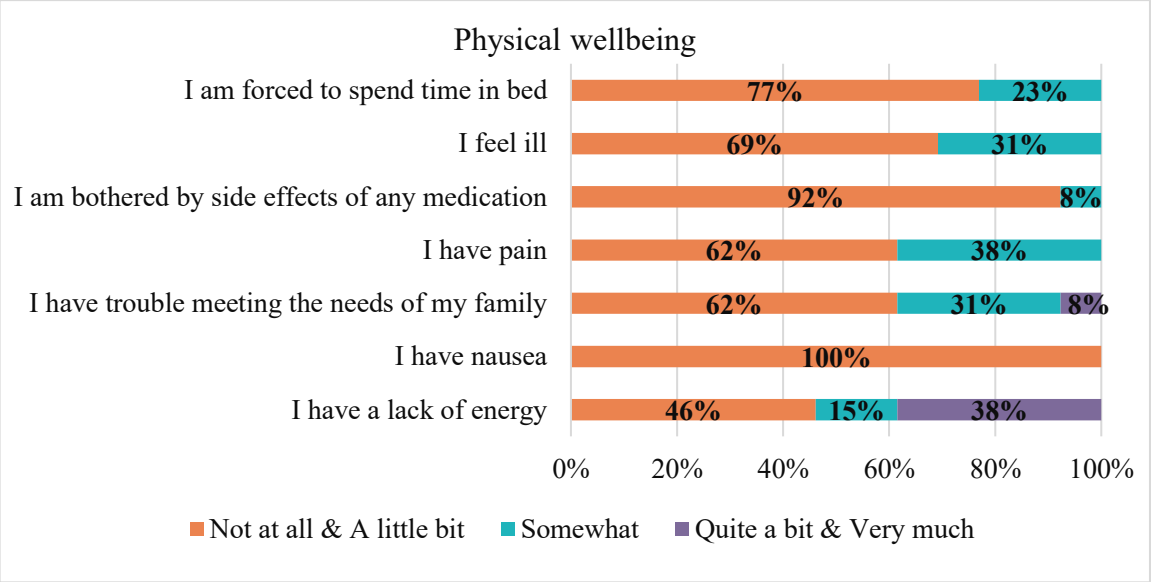



Figure 6-6 Physical wellbeing for informal caregivers

In the social or family wellbeing domain, only 38% of informal caregiver samples reported receiving emotional support from their family, with the responses of “quite a bit” or “very much”. 27% of the sample reported feeling close to their partner, being satisfied with family communication, and perceiving that their family had accepted the patient’s illness to a “quite a bit” or “very much”. In terms of external social wellbeing, only 31% of informal caregiver samples reported they received or felt close to their friends (“quite a bit” to “very much”). Finally, limited informal caregiver samples (17%) reported being satisfied “quite a bit” to “very much” with their sexual life after taking on their caregiver role (Figure 6-7).

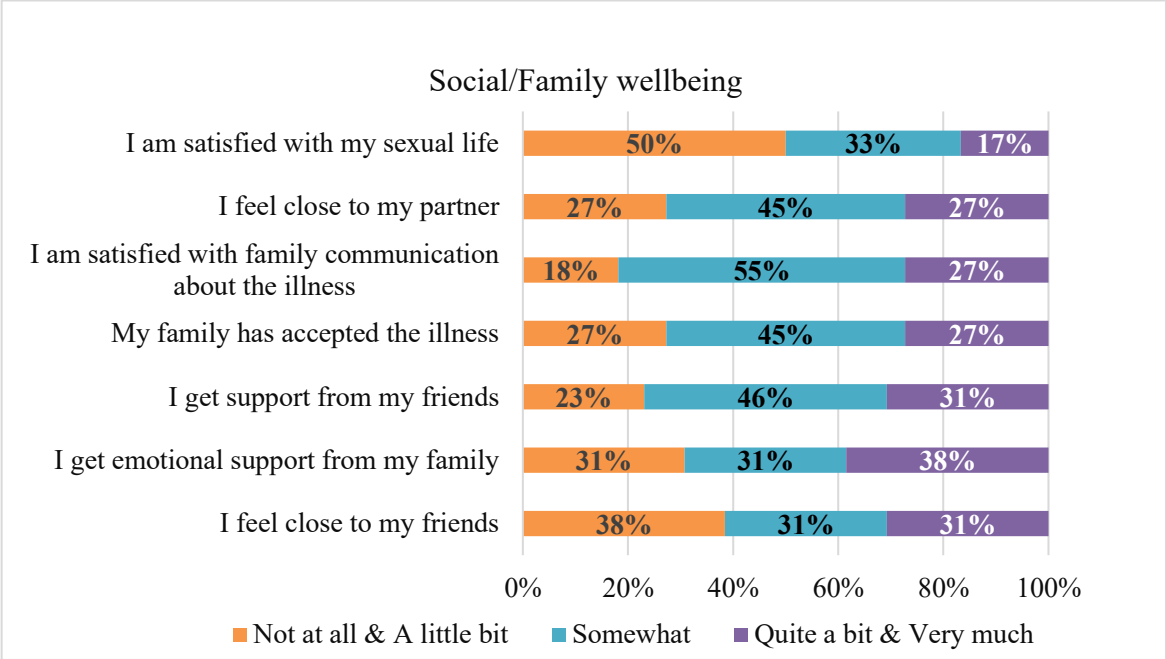



Figure 6-7 Social/Family wellbeing for informal caregivers

In the emotional wellbeing domain, 50% of informal caregivers reported worrying about the patient dying, and 40% were concerned that the patient's condition would worsen, rating these items as "quite a bit" or "very much". Thirty per-cent of them reported satisfaction with their family's current coping strategies, while 20% reported losing hope in fighting cancer, from "quite a bit" to "very much". Despite these concerns, only 20% of informal caregivers reported feeling sad, and 10% reported feeling nervous "quite a bit" to "very much" extent (Figure 6-8).

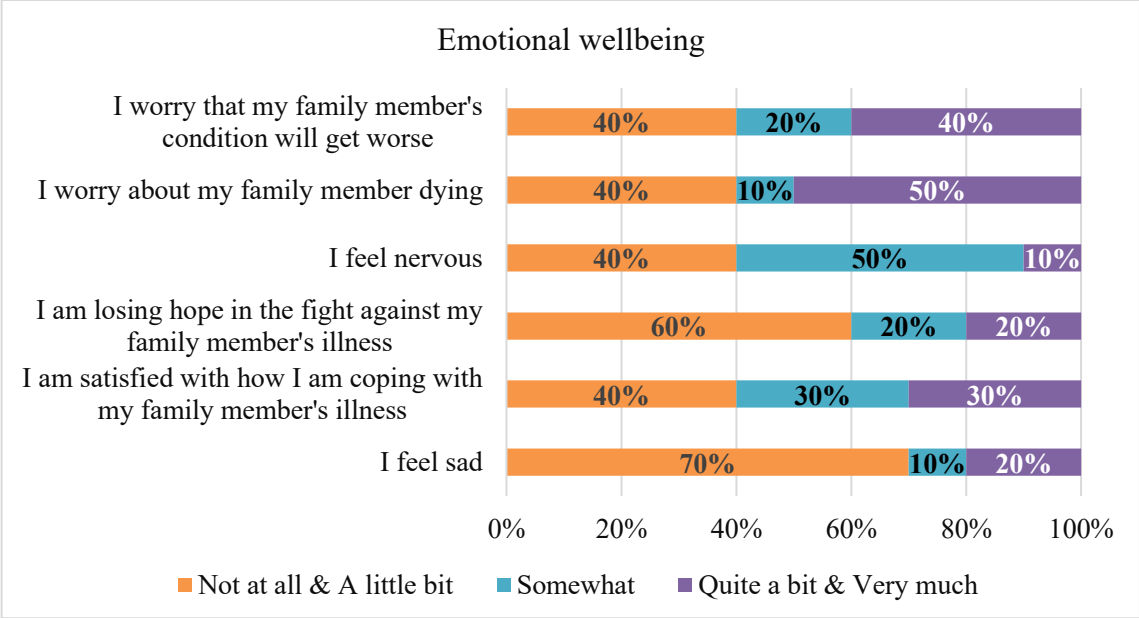



Figure 6-8 Emotional wellbeing for caregivers

In the functional wellbeing domain, half of the informal caregiver samples reported poor sleep, reduced enjoyment of activities they usually find pleasurable, and low satisfaction with their quality of life. Only 20% of them reported accepting their family member's illness "quite a bit" or "very much". 40% of informal caregivers reported being able to work and enjoy their life, while only 20% felt that their work was fulfilling "quite a bit" or "very much" (Figure 6-9).

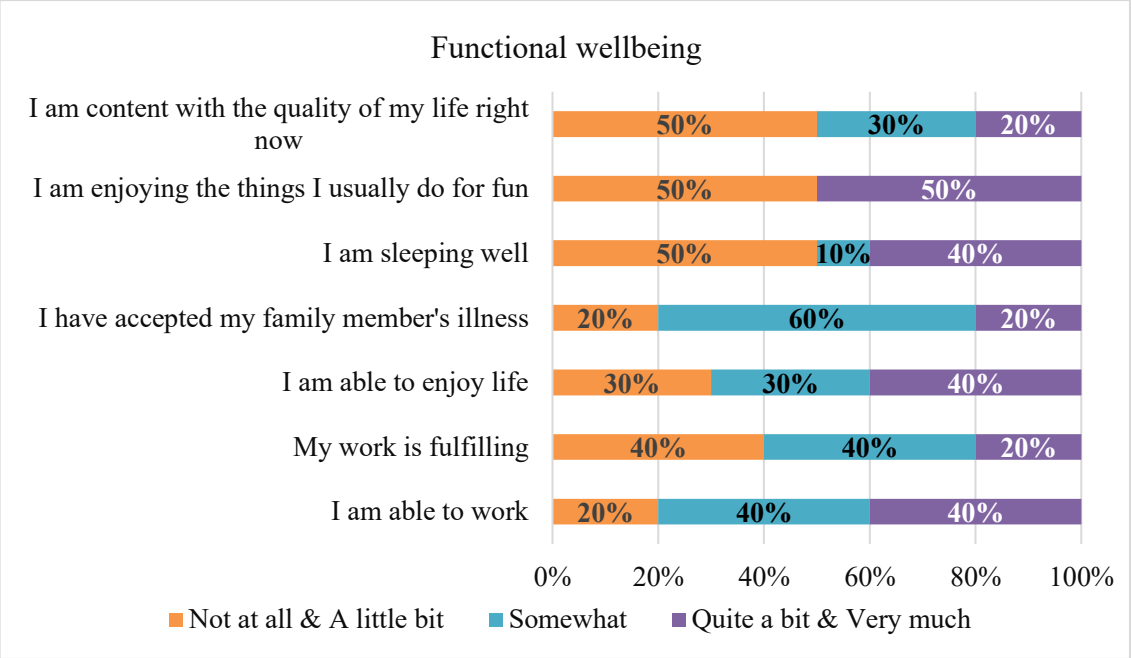



Figure 6-9 Functional wellbeing for informal caregivers

### 6.4.4 Unmet needs of patients

The healthcare system and information domain included 11 items, with scores ranging from 14 to 54 (Mean=35.9, SD=10.4). The psychological domain consisted of 10 items, with scores ranging from 14 to 47 (Mean=32.3, SD=8.9). The "physical and daily living" and "person care and support" domains each contained five items, with score ranges of 6 to 21 (Mean=14.7, SD=3.7) and 5 to 22 (Mean=15.5, SD=4.4), respectively. Finally, the sexuality domain included three items, with scores ranging from 3 to 13 (Mean=7.9, SD=3.5). The detailed results for the SCNS-SF 34 are presented in Table 6-7.

Table 6-7 Descriptive statistics results of SCNS-SF 34

| **Domain** | **Number of items** | **Minimum** | **Maximum** | **Median** | **Means (SD)** |
|---|---|---|---|---|---|
| Physical and Daily Life | 5 | 6 | 21 | 15 | 14.7 (3.7) |
| Psychological | 10 | 14 | 47 | 33 | 32.3 (8.9) |
| Sexuality | 3 | 3 | 13 | 8 | 7.9 (3.5) |
| Person care and Support | 5 | 5 | 22 | 17 | 15.5 (4.4) |
| Healthcare system and Information | 11 | 14 | 54 | 36 | 35.9 (10.4) |

Among these 34 items, the highest prevalent needs were reported in the healthcare system and information domain, with 62.5% of patients indicating a need for information to help them manage their condition. The other top four healthcare system and information needs were: needing to be treated in a physically comfortable hospital environment (54.2%); needing information about the progress of cancer (50%); needing to be treated as a person (50%); and needing access to counselling services for their family (50%). The second most prevalent unmet needs among the 34 items were found within the psychological domain, with 58.3% of patients needing support in managing anxiety and 54.2% of patients needing help coping with uncertainty about the future. In terms of the needs related to person-centred care and support, 54.1% of patients desired greater choice in the cancer specialists they saw, followed by 50% needing healthcare providers to acknowledge their feelings and emotional needs. In the physical and daily life domain, 50% of patients reported the need of dealing their lack of energy. Finally, fewer unmet needs were reported in the sexuality domain, and the main needs related to the informal needs related to sexual relationship (41.9%). Detailed results on patients' unmet needs are presented in Table 6-8.

Table 6-8 Frequency of unmet needs of patient samples

| **Domain** | **Item** | **N (%)** |
|---|---|---|
| Physical and Daily life | Lack of energy/tiredness | **12 (50.0)** |
| | Work around the home | 8 (33.3) |
| | Feeling unwell a lot of the time | 7 (29.2) |
| | Not being able to do the things you used to do | 4(29.2) |
| | Pain | 3 (12.5) |
| Psychological | Anxiety | **14 (58.3)** |
| | Uncertainty about the future | **13 (54.2)** |
| | Feeling down or depressed | 12 (50.0) |
| | Fears about the cancer spreading | 11 (45.8) |
| | Worry that the results of treatment are beyond your control | 11 (45.8) |
| | Feelings of sadness | 11 (45.8) |
| | Keeping a positive outlook | 11 (45.8) |
| | Feelings about death and dying | 10 (41.7) |
| | Learning to feel in control of your situation | 8 (33.3) |
| | Concerns about the worries of those close to you | 6 (25.0) |
| Sexuality | Being given information about sexual relationships | **10 (41.9)** |
| | Changes in sexual feelings | 7 (29.2) |
| | Changes in your sexual relationships | 6 (25.0) |
| Patient care and Support | More choice about which cancer specialists you see | **13 (54.1)** |
| | Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs | **12 (50.0)** |
| | Reassurance by medical staff that the way you feel is normal | 11 (45.8) |
| | More choice about which hospital you attend | 10 (41.7) |
| | Hospital staff attending promptly to your physical needs | 9 (37.5) |
| Healthcare system and Information | Being informed about things you can do to help yourself to get well | **15 (62.5)** |
| | Being treated in a hospital or clinic that is as physically pleasant as possible | 13 (54.2) |
| | Being informed about cancer which is under control or diminishing (that is, remission) | 12 (50.0) |
| | Having access to professional counselling if you, family or friends need it | 12 (50.0) |
| | Being treated like a person not just another case | 12 (50.0) |
| | Being given information about aspects of managing your illness and side effects at home | 11 (45.8) |
| | Being given explanations of those tests for which you would like explanations | 10 (41.6) |
| | Being informed about your test results as soon as possible | 10 (41.6) |
| | Being given written information about the important aspects of your care | 10 (41.6) |
| | Being adequately informed about the benefits and side effects of treatments before you choose to have them | 9 (37.5) |
| | Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up | 8 (33.3) |

## 6.5 Discussion

### 6.5.1 Patient sample

#### *6.5.1.1 Summary of main findings*

In this survey, ethnic Chinese immigrant patients reported greater concerns related to emotional wellbeing (Mean=14.2, SD=4.9), with 38% of participants identifying fear of cancer progression as a major problem. Patients also reported that their main source of emotional support came from family networks (63%), whereas only 38% felt close to their friends following a cancer diagnosis. In addition, patients generally appeared to retain relatively good functional ability, including acceptance of their cancer diagnosis (71%), enjoyment of leisure activities (50%), and ability to work (46%). In terms of unmet supportive care needs, information needs (62.5%), support for managing anxiety (58.3%) and uncertainty about the future (54.2%) were the most prevalent among ethnic Chinese immigrant patients with cancer in Scotland.

#### *6.5.1.2 Contextualising the findings within the systematic review and existing literature*

Ethnic Chinese immigrants with cancer reported lower emotional wellbeing (Mean = 14.2) compared with UK cancer survivors registered at Maggie's Cancer Centres (Mean = 16.4) (Hulbert-Williams et al., 2021). This may be because people with cancer from culturally and linguistically diverse communities face language barriers and have limited access to supportive cancer care services, and consequently report greater emotional difficulties (Barrett et al., 2017). Consistent with the systematic review (Chapter 5), fear of cancer progression emerged as the main psychological problem affecting HRQoL. In this survey, 62.5% of ethnic Chinese patients had received chemotherapy, and a systematic review by Yang et al. (2017) reported that receiving chemotherapy is associated with fear of cancer progression. The side effects of chemotherapy may persist for months or even years after treatment, and the presence of bodily symptoms may act as a trigger for fear of cancer progression (Warrington et al., 2024). Additionally, within the current survey, 66.7% of the patient sample were female and 58.3% were younger than 50 years. Being younger is associated with moderate to high levels of fear of cancer recurrence (Vandraas et al., 2023). Finally, within the current survey, patients reported receiving less support from their wider social networks, such as friends. This finding is consistent with the content presented in the background chapter, which suggests that, within Chinese culture, informal caregiving roles are more commonly undertaken by family members. This also supports the decision in the

present project to include only informal caregivers who had a family relationship with the patient.

Consistent with the findings of the Phase 1 systematic review (Chapter 5), information needs were prevalent among ethnic Chinese patients in Scotland. Unmet information needs can intensify patients' uncertainty and concerns about their illness, which in turn are positively associated with psychological anxiety (Hoang et al., 2020). Unfamiliarity with the host country's healthcare system, combined with language barriers, may contribute to these needs by hindering patients' ability to seek, access, and comprehend health-related information (Simard et al., 2013; Luigjes-Huizer et al., 2022). However, sample characters may also contribute to this result. Firstly, more than 90% of ethnic Chinese patients in this survey held at least a bachelor's degree. Previous research shows that patients with higher educational attainment may be more proactive in seeking information to better manage their health conditions (Halbach et al., 2016). Secondly, in this survey, 62.5% of patients were newly diagnosed with cancer (within one year), which is a group that has been shown to have heightened information needs (Halbach et al., 2016). Apart from information needs, dealing with anxiety was reported as the second most prevalent unmet need. The systematic review (Chapter 5) identified fear of cancer progression as a contributor to anxiety, which was frequently reported as an issue affecting psychological wellbeing in these survey findings.

### 6.5.2 Informal caregiver sample

#### *6.5.2.1 Summary of main findings*

In this survey, informal caregivers reported the poorest wellbeing in the emotional domain (Mean = 13.2, SD = 4.9) relative to the other three domains. Like the patient sample, fear of cancer progression (40%) was also frequently reported as affecting informal caregivers' emotional wellbeing. Some informal caregivers reported receiving support from their families (38%) or friends (31%). Only 20% of informal caregivers reported satisfied with quality of life. While 40% indicated that they were able to enjoy life and continue working, only 20% felt that their work was fulfilling.

#### *6.5.2.2 Contextualising the findings within existing literature*

Similarly to the patients, fear of cancer recurrence was frequently reported affecting emotional wellbeing among ethnic Chinese informal caregivers. Fear of cancer progression among informal caregivers has often been described as intrusive and may be triggered by cancer-related stimuli or by physical symptoms reported by patients (Webb et al., 2024). A

systematic review by Webb et al. (2022) highlighted that fears of cancer progression among caregivers are distinct from those experienced by patients, including worries about the potential loss of a loved one and the perceived need to adopt a protective role in supporting their family member. Additionally, another finding of this survey is consistent with a systematic review by Wang et al. (2018), which found that informal caregivers of Chinese heritage frequently experienced insufficient listening and encouragement from family members.

In this survey, informal caregivers reported lower levels of satisfaction with their quality of life and reduced ability to work, which is consistent with previous findings on the experiences of informal caregivers caring for patients with dementia (Yang et al., 2021). Existing literature reported that informal caregivers of patients with cancer are prone to deterioration of their quality of life due to caregiving burdens (Murong et al., 2023). Fulfilling dual responsibilities as both caregiver and breadwinner places substantial pressure on them and reduces the time available for their own social activities (Liu et al., 2020). However, as the breadwinner for the family, informal caregivers in this survey reported reduced working ability. A systematic review on the economic impact of cancer diagnosis to individuals and their families reported that caregivers in countries such as the USA, UK, and Canada experienced loss of income, reductions in working hours, or unemployment (Alzehr et al., 2022).

### 6.5.3 Strengths and limitations

The strengths of this survey were mainly related to data collection instruments. Firstly, the use of PROMs allowed participants to report their own wellbeing and unmet needs directly, without interpretation by healthcare professionals. Secondly, the detailed description of the PROM selection process enhanced methodological transparency and enabled readers to understand the rationale for selecting these measures. Thirdly, the demographic questionnaire was theoretically informed and based on relevant literature, which strengthened its content validity. Finally, following consultation with PPIE representatives and consideration of ethnic Chinese participants' English proficiency, the data collection instruments were provided in different language versions, making the survey more accessible and easier to complete. This consideration of language also reflected the person-centred care principles underpinning this project.

The limitations of this survey also needed to be acknowledged. The sample of this survey included some demographic variation, however, it was not sufficiently diverse. Despite

extensive recruitment efforts, the overall sample size was small, which posed limits to external validity of this evidence and prevented meaningful inferential statistics. The use of convenience sampling and advertising the research through social media may have favoured individuals who were more digitally connected and socially engaged. The online survey may have restricted participation among individuals with limited digital proficiency, such as older adults. Consequently, the result of patient sample was skewed towards individuals with a relatively high socioeconomic position, including comparatively high levels of education, income and living area. Therefore, the findings for patients may have limited generalisability to individuals with lower socioeconomic positions or those living in rural areas. Moreover, the sample of informal caregivers was relatively young and well educated. Most participants were caring for patients with early-stage cancer. Therefore, the findings may have limited generalisability to older or less educated informal caregivers and to those caring for individuals with advanced cancer.

In addition to these sampling limitations, the FACT-G Caregiver questionnaire also has several limitations. First, it was only available in English, which may have limited the recruitment of informal caregivers and excluded those with limited English proficiency. Secondly, the psychometric testing of the FACT-G Caregiver was conducted primarily among partners of individuals with cancer (Song et al., 2020). Although 6 of the 13 informal caregivers in this survey were caring for a spouse or partner, the remaining participants were caring for a parent (n = 5) or a child (n = 2). Therefore, the results for participants caring for a parent or child should be interpreted with caution.

### 6.5.4 Recommendations

Future research using a community-engaged approach is needed to replicate these results with a larger and more diversity sample of ethnic Chinese patients and informal caregivers in Scotland. With an adequate sample size, inferential statistical analyses can investigate how demographic characteristics are associated with differences in unmet needs and wellbeing. Flexible and inclusive options to data collection should also be considered, e.g. by offering postal questionnaires or telephone-based options alongside online data collection. This may help recruit participants from a wider range of social backgrounds and improve the inclusiveness of future studies.

## 6.6 Chapter summary

The survey found unmet information needs among patients that were similar in prevalence to existing literature synthesised in the systematic review in Chapter 5. As patients and informal caregivers completed HRQoL instruments from the same measurement series (FACT-G and FACT-G Caregiver), comparisons between the two groups were possible. The average HRQoL score for informal caregivers was lower than that of the patient group, with the largest difference observed in the social/family wellbeing domain. For both groups, emotional wellbeing had the lowest scores, and fear of cancer progression was frequently reported by both patients and informal caregivers. The findings from the Phase 2 survey required in-depth explanation. Chapter 7 presents insights from ethnic Chinese patients and informal caregivers to provide a deeper understanding of their lived experiences and to further explain the underlying reasons for the identified unmet needs and wellbeing challenges.

# Chapter 7 : Phase 3: A qualitative exploration of the care experiences of ethnic Chinese immigrants affected by cancer in Scotland

## 7.1. Introduction

Chapter 7 introduces the third phase of the thesis and represents a key explanatory stage within the hybrid multistage mixed-methods design. Building directly on the findings from Phase 1 (Chapter 5) and Phase 2 (Chapter 6), this chapter provides rich contextual insights into how ethnic Chinese immigrants affected by cancer experience cancer care in Scotland and how the unmet needs identified in the Chapter 6 survey could be better addressed. Chapter 7 presents the methods, results, and key considerations of this exploratory descriptive interview.

## 7.2 Objectives

- To understand the lived experiences of receiving care and interacting with care services from the perspective of ethnic Chinese immigrants affected by cancer in Scotland.
- To better understand how unmet needs and problems affecting HRQoL are experienced by ethnic Chinese immigrants affected by cancer in Scotland.

## 7.3 Methods

Interviews are the most commonly used method of gathering qualitative data, with semi-structured interviews considered particularly useful for guiding researchers to obtain specific information and direct the conversation towards the problem of interest (Cyr and Goodman, 2024). Semi-structured interviews offer flexibility and enable the moderator to adapt the flow of the discussion based on the participants' responses (Denzin and Lincoln, 2011). This qualitative study employed semi-structured, in-depth interviews. The consolidated criteria for reporting qualitative research (COREQ) framework was used to guide reporting of the interviews (Tong et al.2007) (Appendix 5).

### 7.3.1 Eligibility and recruitment

Participants were recruited during the Phase 2 survey. The sampling method, eligibility criteria, and recruitment method were the same as the Phase 2 survey (Chapter 6).

### 7.3.2 Sample size

The prevailing concept for sample size in a qualitative study is "*saturation*", which is defined as the point at which no new information of themes emerge from the data (Denzin and Lincoln, 2011). The concept of saturation originated as a specific element of constant comparison within grounded theory and has since been widely applied across qualitative studies using diverse analytic approaches (Malterud et al., 2016). However, there has been limited clarity regarding how saturation should be operationalised to justify participant numbers when qualitative studies employ analytic approaches other than grounded theory (Malterud et al., 2016). To address this limitation, Malterud et al. (2016) proposed the concept "*information power*" to guide adequate sample size for qualitative studies, which means that the more information the sample holds, relevant for the actual study, the lower amount of participants is needed. In this qualitative study, information power was used to guide decisions regarding sample size. As the first qualitative study in Scotland to explore the cancer care experiences of ethnic Chinese immigrants, this work is exploratory in nature, while also serving an explanatory function within the overall mixed-methods design. When a study is expected to generate novel insights, consideration of information power is recommended to inform sample size adequacy (Malterud et al., 2016).

### 7.3.3 Data collection format – online/telephone semi-structured interview

Interviews were conducted using either an internet-based platform or via telephone, depending on participants' preference. Offering both options aimed to enhance accessibility, inclusivity and accommodate participants' varying levels of comfort with digital technologies. Aligning with advice from the University of Glasgow MVLS Ethics Committee, Microsoft Teams was used for online interviews, which can provide high-quality video and audio recording. All the interviews were audio-recorded. A remote interview format can facilitate access to geographically dispersed populations and make data collection more cost-effective (Woodyatt et al.2016). For interviewees, remote interviews may be more appealing than face-to-face interviews due to convenience and flexibility (Woodyatt et al.2016). Despite advantages for both researchers and participants, remote interviewing comes with common challenges, such as dropped calls, unstable internet connection, and reduced ability to observe body language (Weller, 2017). Consistent with the language considerations applied to the Phase 2 survey instruments (Chapter 6), the interviews were available to be conducted in English, Mandarin, and Cantonese (interpreter assistance).

Using convenience sampling by distributing e-flyers on social media may introduce risks to data quality. In this project, during the early stage of data collection, one lady who identified herself as ethnic Chinese chose to undertake the interview in English. However, during the interview, concerns arose regarding the credibility of this participant's eligibility, as she was unable to respond meaningfully to questions related to Chinese cultural issues. Following discussion with the supervisors, this interview was excluded from the study. To maximise confidence that interviewees belonged to the intended target population for the following interviews, an additional verification step was subsequently introduced. At the beginning of each interview, the PhD researcher delivered a brief greeting in Mandarin to help confirm whether participants were ethnic Chinese immigrants. Through this process, two further potential interviewees were excluded, as they were unable to respond and subsequently withdrew from the interview. This procedure helped to enhance the appropriateness and overall quality of the data collected.

### 7.3.4 Interview schedule

The first section of the interview guide for the patient sample focused on healthcare experiences, with questions addressing their perceptions of current cancer care services, care preferences, and perceived needs. Moreover, Phase 1 systematic review (Chapter 5) and Phase 2 survey (Chapter 6) identified a high prevalence of unmet information needs, and the systematic review (Chapter 5) highlighted difficulties in accessing the healthcare system. Accordingly, the second section of the interview guide focused on participants' information needs and their views on how the healthcare system could be made easier for them to navigate. Overall, the interview guide was designed to further explain and integrate the findings from the Phase 2 survey (Chapter 6). The English version full interview guide for the patient sample is presented in Appendix 11.

The interview guide for the informal caregiver sample comprised two sections. The first section explored informal caregivers' experiences, including the challenges encountered in their caregiving roles, the impact of caregiving on their daily lives, and their perceived unmet needs. Including these topics in the interview guide enabled a more in-depth interpretation of the problems reported in the Phase 2 survey (Chapter 6) and helped to explain and integrate those findings. Consistent with the interview guide used for the patient sample, the second section focused on informal caregivers' access to supportive cancer care services, including their preferences for information provision and support

services. The English version of full interview guide for the informal caregivers is provided in Appendix 11.

The interview guides for both the patient and informal caregiver samples were piloted with colleagues, supervisors, and PPIE representatives to identify any issues related to clarity, comprehensiveness, and to ensure that the questions were well understood. This piloting process aligns with established recommendations for enhancing the credibility of qualitative research (Cyr and Goodman, 2024).

### 7.3.5 Data analysis

Thematic analysis, as developed by Braun and Clarke (2022), was employed for the qualitative analysis. NVivo 14 was used for the coding process. The methodological considerations in underpinning the inductive and relativist approach to thematic analysis were discussed in Chapter 4. This section outlines the practical steps of the thematic analysis applied to the qualitative components of this project. The thematic analysis process for each theme in the Phase 3 in-depth interviews is presented in Appendix 12.

- Phase 1 *(Familiarising with the dataset)*: The first step was to become familiar with the data through a process of immersion. This involved working through the transcript, listening and re-listening to the audio recordings, and simultaneously making brief notes to capture initial analytical ideas. For interviews conducted in Mandarin or Cantonese, the transcripts were translated into English as part of the familiarisation process.
- Phase 2 *(Coding)*: Systematic and rigorous coding was undertaken using a line-by-line inductive approach in NVivo 14. Codes were generated at both the explicit (semantic) and conceptual (latent) levels.
- Phase 3 *(Generating initial themes)*: Based on multiple rounds of coding, codes were clustered around shared ideas that could provide meaningful answers to the research questions. Following the collation of all coded data, a set of "candidate themes" were generated.
- Phase 4 *(Developing and reviewing themes)*: The "candidate themes" were assessed and reviewed during the supervisory meetings. In this phase, all "candidate themes" were reviewed to ensure they accurately reflected both the coded extracts and the full dataset. The "candidate themes" were collapsed or split or retained after the reviewing process.

- Phase 5 *(Refining, defining and naming themes)*: A brief synopsis of each theme was written to ensure that it was clearly defined and built around a strong core concept. During this phase, the names of the themes were discussed and agreed upon in supervisory meetings. Although preliminary theme names were defined, the analytical process remained open, allowing for further refinement of the themes as deeper insights continued to emerge.
- Phase 6 *(Writing up)*: This final and integral phase of the reflective thematic analysis involved weaving together the narrative themes to construct a coherent account of how the dataset addressed the research questions, supported by vivid and illustrative data extracts.

Given that some of the interviews were conducted in Mandarin or Cantonese, special consideration was given to the nuances of translation and its impacts on the research's trustworthiness. The back-translation approach was employed as a quality assurance strategy to ensure that translated content accurately reflected the original intent (Chan and Pollard, 2001). The bilingual PhD researcher, fluent in Mandarin and English, undertook the initial translation of interview transcripts from Chinese into English. In line with ethical considerations and data protection requirements, full back-translation of all interview transcripts was not undertaken. Instead, a targeted and reflexive approach was adopted, whereby final codes were back-translated into Chinese by an independent bilingual researcher with no conflict of interest of this project at the University of Glasgow. This approach balanced translation accuracy with participant confidentiality, as no identifiable or sensitive participant information was shared during the back-translation process. The back-translated Chinese versions were then compared with the original transcripts to identify any discrepancies or potential loss of meaning. No major inconsistencies were identified, and minor discrepancies were resolved through discussion between the researcher and the translator, ensuring that the final English interpretations accurately reflected participants' intended meanings.

### 7.3.6 Ethical considerations

#### *7.3.6.1 Research ethics*

Ethical approvals were similar as the Phase 2 survey and are reported in Chapter 6.

#### *7.3.6.2 Informed consent*

At the end of the Phase 2 survey, participants were asked to consider taking part in an interview. Those who expressed interest, by providing their email address, were

subsequently contacted via email. These potential participants were sent a link to the Qualtrics survey, which included the participant information sheet, privacy notice and consent form of this interview (Appendix 10). Participants were given sufficient time to read and understand these documents. After reviewing these documents, they were asked to provide consent by providing a digital signature, followed by indicating their convenient time, language, and interview format. For those who preferred a telephone interview, they were asked to leave their phone number for communication purposes.

A reminder email was sent one week later to those who had not responded. If no action was taken after the reminder, the potential participant was not contacted further. Upon receiving the completed consent form, the researcher proceeded to arrange the interview based on the participant's preferred format. For those who selected Microsoft Teams, a calendar invitation containing the Microsoft Teams link was sent in advance. Participants could then join the interview at the scheduled time by accepting the invitation. For those who preferred a telephone interview, a reminder email was sent one day before the scheduled date, and the researcher phoned the participant at the agreed time.

The rights, dignity, and welfare of individuals were fully respected throughout the interview process. Each interview began with the PhD researcher providing an overview of the study and the purpose of the interview. Participants were reassured about the confidentiality of their data and informed of their rights, including the voluntary nature of participation. They were also notified that the interview would be audio-recorded and were reminded that they could withdraw from the interview at any point. Additionally, the interviewees received a £20 Amazon voucher as a token of appreciation for their time.

#### *7.3.6.3 Data management plan*

Interviews obtained identifiable and non-identifiable personal data. In addition to email addresses, participants who provided digital consent were also required to sign their name. For those who preferred to conduct the interview by phone, their phone number was also collected as personal data. Identifiable personal data were permanently deleted from Qualtrics and local downloads upon completion of data collection.

For participants who chose to take part via Microsoft Teams, the interviews were recorded using the platform's recording function. After the interview, the researcher downloaded the recording and securely stored it on OneDrive. If the participants chose to take part by telephone, the interview was recorded using an audio recorder device and upload onto OneDrive. Recording was permanently deleted from Microsoft Team and the audio

recorder device once data analysis was complete. The transcripts were securely stored on OneDrive and NVivo on the office desktop with password protection. Access to all files was restricted to the research team to ensure data confidentiality.

#### *7.3.6.4 Confidentiality and anonymity*

As the consent form required participants to provide an electronic signature and email address, these identifiable data were subsequently pseudonymised for confidentiality and protection purposes. Patients were assigned a unique fictional name and cancer. Informal caregivers were also given fictional name, their relationship to the patients, and the patient's cancer type. This ensured that participants could not be identified from the final written reports and on any publication.

The PhD researcher is originally from mainland China and speaks Mandarin. PPIE representatives noted that many ethnic Chinese immigrants in Scotland are from Hong Kong and mainly speak Cantonese. Therefore, language needs were considered during the interview process. For participants who preferred to be interviewed in Cantonese, a trained Cantonese-speaking interpreter was recruited to assist with the interview process. The interpreter received prior training in qualitative interviewing and data confidentiality. The interpreter's role was limited strictly to facilitating communication during interviews and the interpreter was not granted access to any research data. The presence of the interpreter was clearly outlined when participants choose the language format.

## 7.4 Results

Data collection for Phase 3 followed the same timeline as the Phase 2 survey (Chapter 6), taking place between November 2023 and June 2024. Sixteen patients and 8 informal caregivers expressed interest in participating in the interview. A total of six patients and five informal caregivers eventually consented and took part in the interviews. The mean duration of the interviews was around 1 hour.

Regarding the language of the interviews, only one patient (Lily) chose to be interviewed in English, while the remaining five patients opted for Mandarin. Among the informal caregiver group, informal caregiver (David) chose to be interviewed in Cantonese with interpreter assistance, while the remaining four interviews were conducted in English.

### 7.4.1 Participant characteristics

#### *7.4.1.1 Patient sample*

All patients were female and held at least a bachelor's degree. Four were diagnosed with breast cancer (three at early stage), one with thyroid cancer and one with lymphoma. Three patients had been diagnosed within the past 6 months, one between 6 and 12 months, and two between 1 and 2 years. One participant was experiencing a recurrence of cancer. In addition, four patients were mothers with one or more children. Details of demographic information for patient sample is presented in Table 7-1.

#### *7.4.1.2 Informal caregiver sample*

Among the informal caregiver samples, four of five participants were male. Three of the male informal caregivers were caring for their wife who has diagnosed with early-stage breast cancer within the past 1 year. One male caregiver was caring for his mother with lung cancer. The only female caregiver was a mother who had cared for her daughter with lymphoma for over 5 years, and her daughter has since passed away. Except for David, the remaining four had at least on child. Details of demographic information for informal caregiver sample is presented in Table 7-2.

Table 7-1 Demographic information for patient sample

| **Patient pseudonym** | **Age** | **Gender** | **Place of birth** | **Years of immigration** | **Education level** | **Employment status** | **Marital status (number of children)** | **Religion** | **Type and stage of cancer** | **Years of diagnosis** |
|---|---|---|---|---|---|---|---|---|---|---|
| Anna | < 30 | Female | mainland China | < 5 | Master | Unemployed | Single (0) | None | Lymphoma, Do not know | 1-2 Years |
| Mary | 30-40 | Female | mainland China | >10 | Master | Part-time | Married (>1) | Catholic | Breast cancer, Stage I | < 6 Months |
| Lily | < 30 | Female | Hong Kong | 5-10 | Bachelor | Full time | Partnered (1) | Christianity | Breast cancer, Stage III | 1-2 Years |
| Kelly | 30-40 | Female | mainland China | 5-10 | Master | Full time | Married (0) | None | Breast cancer, Stage I | <6 Months |
| Emma | 41-50 | Female | Malaysia | > 10 | Master | Sick leave | Married (>1) | Christianity | First time: Thyroid cancer, Stage I; Second time: Breast cancer, Stage I | < 6 Months |
| Sarah | 41-50 | Female | mainland China | < 5 | Doc-toral | Full time | Married (1) | None | Thyroid cancer, Stage II | 6-12 Months |

Table 7-2 Demographic information for caregiver sample

| **Caregiver pseudonym** | **Age** | **Gender** | **Place of birth** | **Years of immigration** | **My ____ with cancer** | **Number of children** | **Education level** | **Religion** | **Type and stage of cancer** | **Years of care** |
|---|---|---|---|---|---|---|---|---|---|---|
| James | 30-40 | Male | mainland China | < 5 | Wife | > 1 | Bachelor | Catholic | Breast cancer, Stage I | 6-12 Months |
| David | 51-60 | Male | Hong Kong | <5 | Wife | 0 | Junior high school | Christianity | Breast cancer, Stage II | 6-12 Months |
| Daniel | < 30 | Male | Malaysia | > 10 | Mother | 1 | Bachelor | Christianity | Lung cancer, Stage II | 1-2 Years |
| Tom | 41-50 | Male | Hong Kong | > 10 | Wife | > 1 | Master | Christianity | Breast cancer, Stage II | 6-12 Months |
| Susan | 51-60 | Female | mainland China | > 10 | Daughter | >1 | High school | Christianity | Lymphoma, Stage III | > 5 Years; died |

### 7.4.2 Experiencing illness and care – patients

Five main themes were constructed from the data. Firstly, patients described personal factors that contributed to psychological distress during their cancer care. These included the impact of the maternal role, feelings of unfairness following a cancer diagnosis, and a tendency towards social isolation. Secondly, patients described suboptimal interactions with healthcare professionals. Some ethnic Chinese patients appeared to have limited understanding of patient autonomy and were less likely to actively seek help, which could make it difficult for healthcare professionals to determine how best to respond. Thirdly, patients described the challenges of being immigrants and living with cancer without support from extended family and social networks. Fourthly, patients reported some positive experiences of cancer care in Scotland, including feeling respected and fully informed about their diagnosis. Finally, patients described their perceived unmet needs and their preferred ways of addressing them (Figure 7-1).

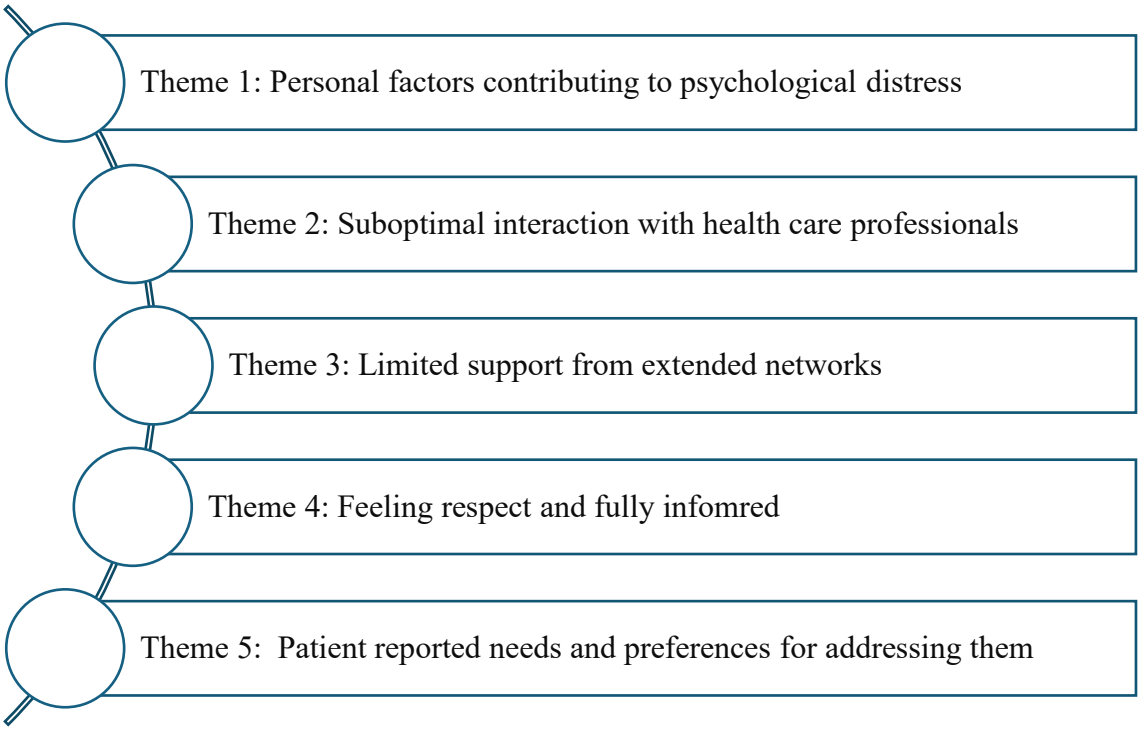



Figure 7-1 Experiencing illness and care as an ethnic Chinese immigrant with cancer in Scotland

#### 7.4.2.1 Theme 1: Personal factors contributing to psychological distress

The first personal factor contributing to psychological distress during the cancer journey was related to gendered personal circumstances. All participants in this interview were

female. Among those with children, patients reported a deep sense of guilt and emotional distress arising from their perceived inability to fulfil female family roles:

> *I'm not able to do what I am supposed to do, for my husband and for my children. Sometimes I feel that I was a burden for the whole family, and this led me to have emotional issues, I could not accept that now I am a cancer patient.*
>
> *(Lily: Breast cancer)*

> *I have been diagnosed with cancer twice. The biggest difference is that the mental pressure is much greater, and I feel more anxiety for my second diagnosis. As when I was first diagnosed, I didn't have children, but now I am a mother of two, and my children are still young, so I worry about who will take care of them."*
>
> *(Emma: Breast cancer)*

The second personal factor contributing to psychological distress was patients' self-imposed social isolation. Participants described different reasons for choosing to isolate themselves. Lily anticipated experiencing social discrimination. Kelly described feelings of unfairness related to her cancer diagnosis and explained that watching others' everyday lives acted as a trigger for sadness, prompting her to distance herself from others. In addition, Kelly also chose to conceal her cancer diagnosis from their parents as a protective strategy, intended to shield ill or vulnerable family members from emotional distress.

> *I do not want my colleagues to know that I was diagnosed with cancer, so I keep it a secret and isolate myself because I do not want to feel a sense of rejection.*
>
> *(Lily: Breast cancer)*

> *During my most depressed moments, I withdrew from all social activities. No-one knows my cancer diagnosis except my husband. And I didn't want to see people's vibrant lives while I was dealing with cancer. I felt like life is unfair for me.*
>
> *(Kelly: Breast cancer)*

> *At the beginning time, I isolated myself, even didn't tell my parents about my cancer diagnosis. My mother found out about my diagnosis from one of my friends. As of now, only my mother knows about my condition. She hasn't told my father or the rest of the family, as my father had serious hypertension.*
>
> *(Kelly: Breast cancer)*

#### 7.4.2.2 Theme 2: Suboptimal interaction with health care professionals

Poor communication with healthcare providers was identified as a barrier during cancer survivorship. Both patients and healthcare professionals contributed to this. From the

patients' aspect, limited self-disclosure meant that healthcare professionals often assumed patients were satisfied with their care.

> *After I knew that I had cancer. The doctor asked me if I had any questions, I said no, and then the specialist nurse wrote I handled very well! But that was not the case, because I was in a state where I was not in the mood to ask questions.*
>
> *(Mary: Breast cancer)*

Mary and Emma described their experiences of communicating with their breast care nurses. They reported that the nurses seldom actively checked on their condition.

> *My breast nurse gave me her contact details. The main purpose of contacting her was to help me make an appointment with a doctor. In fact, I had very little contact with her. Because she would not proactively tell me anything.*
>
> *(Mary: Breast cancer)*
>
> *I have a breast cancer nurse, and I can call her if I feel unwell, but she doesn't proactively check my condition. Maybe it's because they are very busy with many patients.*
>
> *(Emma: Breast cancer)*

Emma further mentioned that cultural differences may contribute to this, as patients may have limited understanding of patient autonomy and what kind of help they need.

> *So, as a patient, you must take the initiative to ask questions before they respond. This is quite the opposite of the culture in Asia, where doctors and nurses will actively inquire about your condition.*
>
> *(Emma: Breast cancer)*
>
> *Within many Asian cultural, patients may be less inclined to express their needs or challenge healthcare professionals. They are less likely to actively communicate, often passively accepting the care arrangements proposed by doctors or nurses.*
>
> *(Emma: Breast cancer)*

From the aspect of healthcare professionals, Anna reported that when healthcare professionals attempted to address her psychological concerns, they were often unsure how to respond or what actions to take. Sarah also mentioned that her doctor provided her with limited information. Then, both Anna and Sarah expressed that suboptimal interaction with healthcare professionals contribute to feelings of mistrust towards them.

*Sometimes I felt anxious, but the nurse didn't know how to respond, it creates a disconnect. It made me feel misunderstood or even feeling of not being treated equally.*

*(Anna: Lymphoma)*

*My doctor only answered my questions with 'yes or 'no', without giving any detailed explanations. Maybe he thought I wouldn't understand if he explained more, but in reality, I needed more information about my condition. Because of this, I didn't feel I could fully trust him. I even started to doubt whether he had enough knowledge or experience about my disease.*

*(Sarah: Thyroid cancer)*

#### 7.4.2.3 Theme 3: Limited support from extended networks

The final barrier came from the reality of being an immigrant and having limited support from family. Mary highlighted the importance of parental support, although her parents were far away from Scotland and travelling was not easy for them. In the end, her mother was able to come and care for her, which made Mary feel greatly comforted.

*My mum came from China to support me, even though travelling to Scotland was not easy for her. The love and care from my family made me feel very comforted.*

*(Mary: Breast cancer)*

Emma, Sarah and Kelly had each studied in Scotland before marrying and settling there. With no extended family living nearby, their husbands became their only source of support. In addition to the absence of extended family, Kelly and Emma also reflected on the loss of friendships over time, which they attributed to the nature of immigrant life.

*My family was in Malaysia. I was studying in Scotland, then working in here, meeting with my husband then we get married. Actually, I did not receive any support from my parents or siblings. Most of my close friends had back to Malaysia after graduation, so I had no one to help expect my husband during that time. This is one of the biggest issues immigrants face: once you fall ill, there is no family to help you.*

*(Emma: Breast cancer)*

*I am married to a Scottish person, and my family are still in China, far away from me. After I was diagnosed with cancer, my husband became my main source of emotional and spiritual support.*

*(Sarah: Thyroid cancer)*

> *My parents living in China, in here, only my husband take care of me. Most of my close friends are no longer here because I've been living in the UK for many years, and most of them have returned to China.*
>
> *(Kelly: Breast cancer)*

#### 7.4.2.4 Theme 4: Feeling respect and fully informed

Lily, Kelly and Emma reported that they were fully informed about their cancer diagnosis and were given the opportunity to decide on their treatment, which contributed to their sense of involvement in treatment decision-making.

> *My doctor directly told me my diagnosis, and I was fully informed about it and the treatment decision was made by myself.*
>
> *(Lily: Breast cancer)*
>
> *I received my diagnosis directly from my doctor, and my husband accompanied me. The doctor directly explained to me about each treatment and gave me time to make the decision.*
>
> *(Kelly: Breast cancer)*
>
> *I had the chance to ask questions and think about the treatment options, instead of just being told what to do. I felt that my opinion mattered.*
>
> *(Emma: Breast cancer)*

Lily and Sarah mentioned how they felt respected when they received care from healthcare professionals.

> *I was feeling of being respect, and my doctors and nurses do not have discriminate to me. They don't say "these kind of people". They treat everyone with equity.*
>
> *(Lily: Breast cancer)*
>
> *The better thing is the humanistic care, and the healthcare professionals are very kind. There is no sense of nerves when talking with doctors.*
>
> *(Sarah: Thyroid cancer)*

Specifically, Anna described how healthcare professionals helped her parents to apply for a visa during COVID-19. Anna described being single in Scotland when she was diagnosed with cancer at the beginning of the COVID-19 pandemic. As her parents were unable to travel to Scotland to support her, she lacked family support, and the main support she received came from healthcare professionals.

> *I was diagnosed with cancer and got treatment when the COVID-19 was start. Scotland was locked down at that time. I was here alone, and my parents in China were unable to apply for a visa, and they couldn't come even if they wanted to. The nurses who take good care for me and come every day to ask whether my parents plan to come. They helped my parents provide proof of faster visas, and this makes me feel very credible. At times when my parents were not around, the care provided by healthcare professionals made me feel that I was still being well cared for.*
>
> *(Anna: Lymphoma)*

Additionally, Kelly specifically mentioned that she was very satisfied with the care she received especially from nurses.

> *The medical team was very responsible and caring. My doctor was great, but he was very busy, so I did not have many chances to meet with him. My care nurses, on the other hand, took very good care of me. I felt that they were very professional. Each time I met my nurse, she explained my condition in detail.*
>
> *(Kelly: Breast cancer)*

#### 7.4.2.5 Theme 5: Patient reported needs and preferences for addressing them

Information-related needs were most frequently expressed. The absence of clear guidance to support navigation of the healthcare system contributed to feelings of frustration during the diagnosis process. Patients reported ongoing information needs, including advice on diet and insights drawn from the lived experiences of peers. Patients expressed a preference for bilingual information, particularly in written formats such as brochures provided by hospitals. Beyond information needs, patients also expressed a desire to connect with other patients who shared similar cultural and linguistic backgrounds.

##### 1) Ongoing information needs

Mary, Lily and Sarah described information needs arising during diagnosis and treatment. Adapting to life in a new country while undergoing cancer treatments required them to navigate an unfamiliar healthcare system. The diagnosis and treatment period was recalled as particularly overwhelming, with patients expressing confusion and uncertainty about the process involved.

> *There was no guidance in the entire diagnosis and treatment process, to guide me on what I needed to do in every step. I know the procedure at the GP, but I don't know the procedure at the hospital.*

*(Mary: Breast cancer)*

*I struggled with the healthcare process too many times. I often don't know what steps to take, who to contact, or how long things will take. Without clear guidance, I sometimes feel lost and overwhelmed.*

*(Lily: Breast cancer)*

*From the beginning of my diagnosis, I didn't really know what was going on. I even went back to my GP, but he just told me I'd been referred and that the medical team would contact me. But no one actually explained anything, and I just received a letter at home. I didn't realise that the letter was actually confirming my surgery appointment.*

*(Sarah: Thyroid cancer)*

Following the completion of treatment and returning home, patients emphasised the need to improve the informational brochures provided by hospitals upon discharge. In particular, Mary and Anna expressed a strong preference for brochures to be available in Chinese, as many reported limited motivation to engage with material written in English during the early stages of recovery.

*Because the amount of information is too large, I do receive the brochures from hospital but it is all in English, there is no Chinese translation. If there is a Chinese version of brochures, I would like to read it.*

*(Mary: Breast cancer)*

*If it is impossible to communicate with the doctor, at least a translated version of the information leaflet can help patients with language barriers understand some basic information after their treatment.*

*(Anna: Lymphoma)*

Regarding the content of information related to self-care, patients expressed a specific need for dietary guidance, with Mary and Sarah noting that this need was closely linked to their Chinese cultural beliefs.

*In Chinese culture, patients need to pay attention to their diet. But I didn't receive any diet-related information. For example, how much protein should I take every day to help my body recover?*

*(Mary: Breast cancer)*

*Because under the Chinese cultural background, especially for people who have had surgery, there is actually a big taboo on their diet. However, in the UK, the nurses and doctors did not tell me any dietary precautions. Under traditional Chinese culture, after thyroid surgery, I cannot eat foods with particularly high iodine content, but my doctor never told me about it.*

*(Sarah: Thyroid cancer)*

In addition to the dietary information, Mary, Anna and Kelly expressed a strong interest to receive information from the real-life survivorship experience of peers with cancer. They valued that these shared experiences were practical and meaningful.

*I am a mother, so I especially want to know how mothers in other families take care of their families after suffering from cancer.*

*(Mary: Breast cancer)*

*I am more interested in patients like me who are in survival situations, their prognosis and living conditions. Real life experiences are more helpful than numbers and words to refer.*

*(Anna: Lymphoma)*

*I also looked up a lot of information online to learn about other people's experiences, especially those in the early stages of cancer. And I believe that it is very necessary, and I wish the brochures could include some cases of others' experiences.*

*(Kelly: Breast cancer)*

### 2) Peer support networks with Chinese cultural background

During the cancer survivorship period, peer support networks within the Chinese community in Scotland was recognised as important. Sarah and Kelly expressed that communicating with individuals who did not share similar cancer experiences often felt less supportive and, in some cases, burdensome rather than helpful.

*My friends and neighbours also give me a lot of care and buy gifts for me, which makes me very touched. But this is not what I need most at the moment. What I need is someone to understand this disease with me. The help from my friends and neighbours give me sometimes becomes a burden.*

*(Sarah: Thyroid cancer)*

*The most important thing is that friends who haven't experienced cancer can't fully empathise. They sympathise with me, but they don't truly understand. However,*

*communicating with someone who has been through cancer means they can better relate to me.*

*(Kelly: Breast cancer)*

Two patients highlighted that peer support could serve as a platform for encouragement and empowerment. Emma emphasised that this was particularly important within the Chinese community, where role modelling was perceived as highly influential.

*Interacting with peers means that we can exchange, encourage, and support. Chinese community needs a role model to share their experiences and let others know that having cancer doesn't make us different from anyone else. After treatment, we can live a normal life.*

*(Emma: Breast cancer)*

*I know it is difficult to find the peer, but if we can share our thoughts with each other, it means that we can learn from each other.*

*(Lily: Breast cancer)*

Sarah shared her experience of receiving peer support and described it as particularly valuable in relieving anxiety during her cancer journey.

*I met a Chinese aunt who also suffered from cancer in my living city. We chat a lot after I diagnosed. She was very helpful. To be honest, this was my first time being hospitalised in Scotland and I had no idea what the process was like. This Chinese aunt told me a lot and relieved my anxiety. Therefore, I hope to know which channels have patient groups or peer support. We really need this organisation.*

*(Sarah: Thyroid cancer).*

When discussing the future development of peer support groups, Kelly emphasised the importance of language considerations, noting that communicating in English did not always allow them to fully express their feelings.

*Communicating in my mother tongue would help me express my feelings more clearly, even though I don't have any issues with English.*

*(Kelly: Breast cancer).*

Additionally, Kelly further emphasised the importance of considering age differences when developing peer support groups, as their needs and priorities differed from those of older patients.

> *Patients of different ages have different needs. For instance, I'm relatively young, and there can be a communication gap between me and older patients. So, it might be helpful to group patients by age. Younger patients, like me, worry about balancing life with work and fertility issues.*
>
> *(Kelly: Breast cancer)*

### 7.4.3 Experiencing illness and care – informal caregivers

Four themes were identified from the informal caregiver sample. Informal caregivers described how their lives were reshaped after assuming the caregiving role and how this role influenced their wellbeing. They also expressed the practical challenges they encountered and the unmet needs they experienced (Figure 7-2).

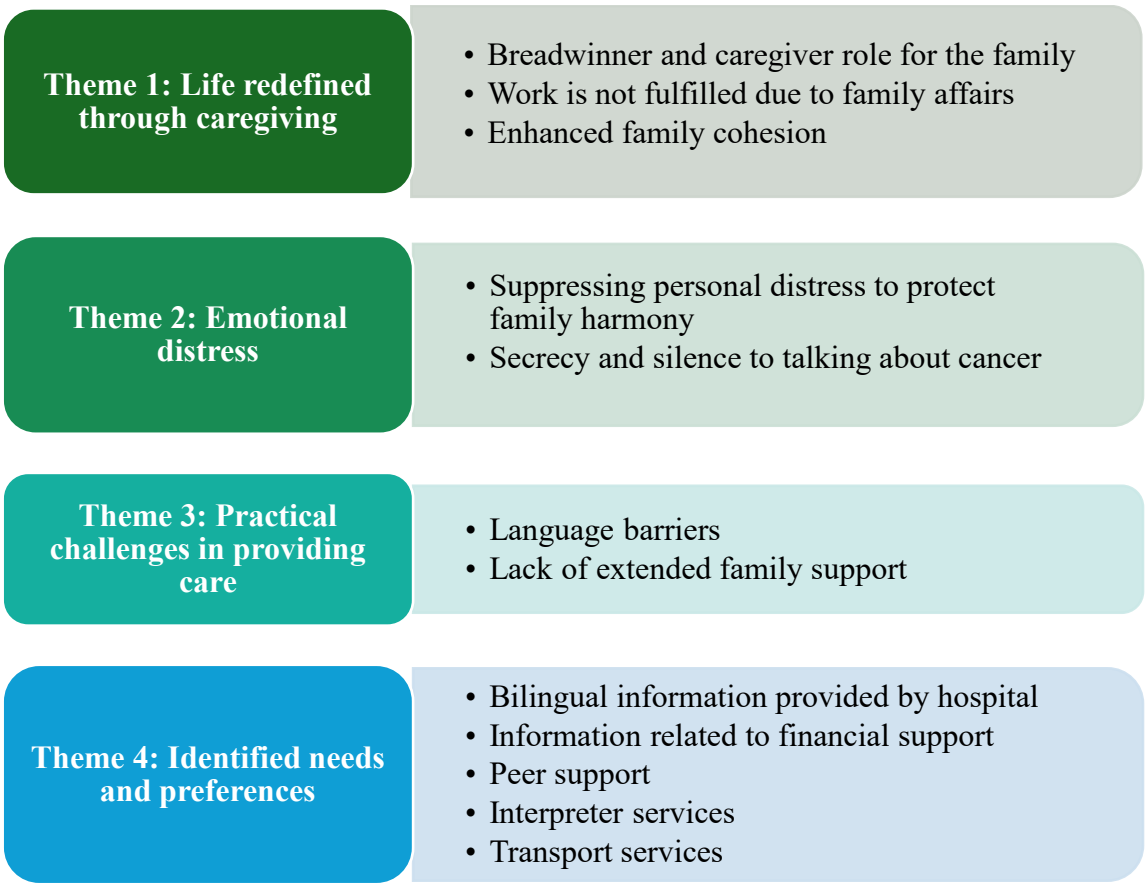



Figure 7-2 Experiencing illness and care as a caregiver of an ethnic Chinese immigrant with cancer in Scotland.

#### 7.4.3.1 Theme 1: Life redefined through caregiving

"Life redefined through caregiving" reflected how caregiving reshaped informal caregivers' lives across personal, family, and social domains. They described losing

personal time, taking on additional family responsibilities, and experiencing employment disruption, while also fostering stronger family cohesion.

### 1) Breadwinner and caregiver role for the family

Husbands (James and Tom) and son (Daniel) described their caregiving experiences as involving the need to earn income for the family while simultaneously caring for their wife or mother following a cancer diagnosis. These combined family responsibilities led to significant changes in their lives, with participants reporting little time for personal activities or social engagement.

> *My wife is a patient with cancer, and I need to earn money and care for the whole family. My life has been changed, and I do not have time for myself. There is no way I can go to any parties or take part in social activities.*
>
> *(James: Husband for wife with breast cancer).*
>
> *My wife's physical situation could not make money and we have two children, so all the things was on my side. I was almost working like a daddy and mom.*
>
> *(Tom: Husband for wife with breast cancer)*
>
> *I tried to keep working as usual but needed to spend more time for my parents. That meant my schedule was completely filled with family, leaving no time for friends or hobbies.*
>
> *(Daniel: Son for mother with lung cancer)*

### 2) Work is not fulfilled due to family affairs

As both the primary breadwinner and caregiver for the family, husbands were required to balance employment demands with caregiving responsibilities; however, this balance was often difficult to maintain, leading some to reduce their working hours.

> *The hospital is far, and I have to drive her there. I try to arrange things so I can go with her to the doctor's appointments, but sometimes they clash with my work. In the end, I had no choice but to give up my job.*
>
> *(James: Husband for wife with breast cancer)*
>
> *Right now, she needs me to spend more time at home to take care of her, and that means I need to reduce my working time.*
>
> *(David: Husband for wife with breast cancer)*
>
> *Since October last year, I had to take at least six months off from my work. I don't even have time to do part time.*
>
> *(Tom: Husband for wife with breast cancer)*

Susan as mother of a daughter diagnosed with lymphoma reported that she had to give up her job to take on full caregiving responsibilities for the family, while her husband assumed sole responsibility for earning income.

> *I cannot work, and my husband needs to work and taking this responsibility. We have heavy financial pressure because we need to pay the mortgage and pay the bills. You need to work. But if I go to work, who takes care of my child?*
>
> *(Susan: Mum for daughter with lymphoma)*

#### 3) Enhanced family cohesion

In addition to the negative impact of caregiving on their daily lives, Daniel and Tom also described positive aspects associated with taking on this role. They specifically noted that caregiving allowed them to spend more time with their families and contributed to a deeper sense of connection:

> *After I graduated and started to work, actually, I do not have time to spend with my parents. Until my mum got cancer, I know the importance of the family relationship. In a way, I now treasure this time together.*
>
> *(Daniel: Son for mother with lung cancer)*
>
> *I've been able to spend more time with my family, which is something I didn't have before. I used to be focused on work a lot, but now I'm more involved in my kids' lives. I've been able to take on more of my wife's responsibilities, and I can see the benefits of spending more time with the kids.*
>
> *(Tom: Husband for wife with breast cancer)*

### 7.4.3.2 Theme 2: Emotional distress

In the second theme, informal caregivers reported the emotional impact of assuming the caregiving role on their wellbeing. This theme illustrates how cultural values, such as collectivist beliefs and Confucian principles emphasised family harmony. Informal caregivers' emotional wellbeing was also influenced by their observations of cancer-related taboos within ethnic Chinese communities.

#### 1) Suppressing personal distress to protect family harmony

Informal caregivers put the patients' feelings as a priority rather than considering themselves, they suppressed their own emotional distress to protect their family member from further emotional suffering.

*My wife always got emotional crying and this influenced me a lot. But I still need to provide her with mental support. These things really bother me the most. Sometimes I do not know how to comfort her.*

*(James: Husband for wife with breast cancer)*

*The first time when I know my mum was diagnosed with lung cancer, I cried in a corner. I should be more confident and positive toward her with her disease. If my mum knew I was upset, then she will worry about me.*

*(Daniel: Son for mother with lung cancer)*

*My mum is always overthinking about her current situation. She is so worried that she will die soon and always asked me how long she can still live. This really breaks me down and makes me emotional as well. Although I feel anxious after hearing her say these things, I do not express my own distress. Instead, I continue to encourage her, as I want to keep her happy.*

*(Daniel: Son for mother with lung cancer)*

### 2) Secrecy and silence to talking about cancer

Informal caregivers described how discussions about cancer were considered a highly private matter and were often kept secret. They reported that cancer diagnoses were perceived within the community as bringing bad luck, which contributed to feelings of stigma among individuals affected by cancer.

*In the Chinese community, cancer is often seen as something very negative, and people don't want to talk about it. They don't want others to know they have cancer because it's seen as unlucky or shameful.*

*(Tom: Husband for wife with breast cancer)*

*People do not want to tell if someone is sick in their family. They try to avoid the cancer topic as much as possible. If there was someone diagnosed with cancer, they think it is the bad thing in your family. People do not want their neighbour and friend to know this. They just hiding on that.*

*(Susan: Mother for daughter with lymphoma)*

Followed by their observation, Susan as a mother of daughter diagnosed with lymphoma further described how openly sharing her daughter's diagnosis led to social avoidance by others, which further intensified her emotional distress.

*I didn't know anything like the sensitivities to chat about cancer in the Chinese community. So I told them that my daughter was diagnosed with cancer and in hospital, and everybody knows this. But nobody coming to visit and even ask 'How are you?' to me. They even avoid contacting me.*

*(Susan: Mother for daughter with lymphoma)*

#### 7.4.3.3 Theme 3: Practical challenges in providing care

The third theme highlighted the practical challenges encountered in providing care, with language barriers identified as a primary obstacle to understanding health-related information and seeking help. The other practical challenge concerns limited support, as there is no extended family member living in their host country.

##### 1) Language barriers

Limited English proficiency restricted informal caregiver's ability to understand information and communicate effectively with healthcare providers.

*The biggest difficulty is to understand and communicate with the doctor. Sometimes the professional terms make me frustrated and it was hard to understand.*

*(David: Husband for wife with breast cancer)*

*Sometimes I lack confidence about my English level, some complicated medical terms I do not understand, so I always ask doctor to repeat or ask write down and Google by myself.*

*(Daniel: Husband for wife with breast cancer)*

*In the hospital, the language barrier makes it more difficult. You do not know what's going on. When they explain to me, I still do not understand. This makes me feel like I cannot trust them.*

*(Susan: Mother for daughter with lymphoma)*

Beyond limited understanding of information, language barriers also restricted informal caregivers' ability to seek support from cancer care organisations, as they felt uncomfortable expressing deeper emotions in a second language.

*I know about the cancer support centre, but I haven't been because it's all in English. Expressing deep emotions in English is difficult for me. I can handle everyday conversations, but finding the right words to express my feelings in English is hard.*

*(David: Husband for wife with breast cancer)*

*So far, my mum's situation is worse than before, I do need support from professional staff, but I am not comfortable to speak English when I express my heart feeling. Maybe my English level does not allow me to do this.*

*(Daniel: Son for mother with lung cancer)*

### 2) Lack of extended family support

Informal caregivers described the absence of extended family in Scotland as a significant challenge. Although friends sometimes offered help, informal caregivers were reluctant to rely on them too often, fearing they might become a burden or cause inconvenience. As a result, they were often left to manage caregiving responsibilities largely on their own.

*We came to Scotland for work or study and ended up staying, but our families are still back in China.. So, we can only ask friends for help, but even friends have their own commitments. Without close family support, making it harder.*

*(Tom: Husband for wife with breast cancer)*

*We do not have any other family members in Scotland, we have to do everything by ourselves. The first time, I asked help from my friend to translate for me, as I would like to know what the disease of my child. But everyone is busy, and they have their own things, they cannot go to hospital with me every time.*

*(Susan: Mother for daughter with lymphoma)*

Additionally, for families with more than one child and without extended family support, caregiving arrangements often required one parent to continue working while the other assumed full responsibility for caring for the child with cancer. In such situations, mothers had no choice but to bring their other child to the hospital during caregiving visits, which left parents feeling that this arrangement was unfair to the child without cancer.

*I have two children, dad had to work, so I had to take over our sick child and the whole family. I had no choice, most of the time, I had to bring the younger one with me to the hospital. No one can take care of our second child, I felt very depressed during that time."*

*(Susan: Mother for daughter with lymphoma)*

#### 7.4.3.4 Theme 4: Identified needs and preferences in supportive cancer care

The final theme captured several key needs to support informal caregivers in their role. They highlighted the need for accessible bilingual information, peer support, improved quality of interpreter services to overcome language barriers, and better transport support to ease the burden of hospital visits.

##### 1) Bilingual information provided by hospital

The most frequently expressed need was related to the information. Limited English proficiency restricted informal caregiver's ability to engage with English documents. They needed bilingual information related to the patient's disease from hospital. James and David emphasised that information provided by hospitals was a trusted source and expressed willingness to read brochures if these were available in Chinese.

> *I need information in Chinese to help my wife deal with the side effects of her treatment and to guide the care I give her. If the hospital could provide this, it would really help.*
>
> *(James: Husband of wife with breast cancer)*
>
> *If there were brochures in Chinese, I would definitely read them to ensure that the treatment is correct and to prepare for the next stage of care. I believe the information that I got from the hospital is definitely correct.*
>
> *(David: Husband for wife with breast cancer)*

In the absence of bilingual information provided by hospitals, Daniel and Tom reported turning to alternative sources, such as online searches and personal networks, to obtain information. However, they also expressed concern about the accuracy of this information.

> *Reading English is not easy to every Chinese patient and family members. I have received brochures, but all those are in English, I know they are helpful, but I do not have motivation to read. So most of time I search information on Chinese website, but not 100% sure that was correct."*
>
> *(Daniel: Son for mother with lung cancer)*
>
> *As the absence of bilingual information from hospital, I think a lot of Chinese patients rely on what they hear from friends or family or what they read on Chinese social media. But that's not always accurate. It would be better if hospital have bilingual documents for us to read.*
>
> *(Tom: Husband for wife with breast cancer)*

Tom further explained that these bilingual sources of information can help to alleviate anxiety and fear.

> *If there was more written information available in Chinese, that explains the treatments and what to expect, it might reduce some of the fear.*
>
> *(Tom: Husband for wife with breast cancer)*

### 2) Information related to financial support

David and Susan expressed that they need information to manage their life, especially for financial support.

> *After we had just settled everything in Scotland, my wife was diagnosed with cancer. We don't even have a stable income at that time, and we do not know what kind of financial support we could apply for from the government.*
>
> *(David: Husband for wife with breast cancer)*
>
> *Our family needed financial support at that time, but I didn't have any information about that.*
>
> *(Susan: Mother of daughter with lymphoma)*

### 3) Peer support

Informal caregivers expressed a strong need for peer support, emphasising that talking with others who had shared similar experiences provided understanding, emotional relief, and practical advice that made the caregiving journey feel less isolating.

> *I need to talk to someone who truly understands how I feel and can offer advice based on their own experience. Having someone who's been through it makes a big difference.*
>
> *(David: Husband for wife with breast cancer)*
>
> *It can be hard to talk about the stress and challenges you face when you're taking care of someone with cancer. Sometimes, just knowing that someone else understands what you're going through can make a big difference. It's good to have people to talk to who can offer advice and emotional support.*
>
> *(Tom: Husband for wife with breast cancer)*
>
> *People around me don't really understand what I'm going through and the pressure I'm under. That's why I need someone to talk to who truly understands how difficult it is to care for my daughter with cancer.*
>
> *(Susan: Mother for daughter with lymphoma)*

David shared his experience of receiving peer support and highlighted its importance and value.

> *One day, me and my wife met another couple at the hospital who shared a similar cultural background and also had breast cancer. We had a nice chat. It was comforting to talk with someone who understood.*
>
> *(David: Husband for wife with breast cancer)*

### 4) Interpreter services

Informal caregivers called for reliable interpreter services, ideally with interpreters trained in medical terminology, and expressed frustration when doctors assumed such support was unnecessary. David emphasised that interpreter services were essential for individuals with limited English proficiency, not only for patients but also for their family members.

> *I haven't experienced discrimination, but the language barrier is definitely an issue. Having better translation services would help a lot. When we first met the doctor, we asked for a translator. Sometimes the doctor arranged one, but sometimes not. Maybe the doctor assumed my wife's English was good enough, but my English is not, and I still need to fully understand the treatment and everything.*
>
> *(David: Husband for wife with breast cancer)*
>
> *I think having more language support would be a start. Maybe more translators who are trained in medical terminology.*
>
> *(Tom: Husband for patient with breast cancer)*

### 5) Transport services

This need was reported only by caregivers in spousal relationships with patients. David and Tom as husband for their wife with breast cancer highlighted that access to hospital transport services could help reduce the burden of balancing employment, childcare, and caregiving responsibilities.

> *I think the government could consider transportation services to help patients get to the hospital. And this can help alleviate the burden for family member, as we have to earn money and take care for family member at the same time. For immigrants like us, we have to rely on ourselves for everything.*
>
> *(David: Husband for patient with breast cancer)*
>
> *Sometimes transportation is an issue. For example, my wife had an appointment in Glasgow, but I had to pick up my kids at the same time. So, having someone to help*

*with transport or transport service would be really helpful. It's hard to be in two places at once, I need to care for my wife but my children are also waiting for me.*

*(Tom: Husband for patient with breast cancer)*

## 7.5 Discussion

### 7.5.1 Summary of main findings

One overlapping issue reported by both patients and informal caregivers is the reality of being immigrants with limited support from extended family members. In addition, several shared preferences and needs were identified in these in-depth interviews. Both patients and informal caregivers reported that:

- Healthcare professionals and information provided by hospitals as the most reliable sources of information;
- Preferred bilingual information in written formats;
- Valued peer support from individuals who shared similar cultural backgrounds.

### 7.5.2 Integration with survey results – patients

The Phase 3 in-depth interviews helped to provide a deeper and richer understanding of the Phase 2 survey findings. Patients in the interviews expressed a need for greater guidance to help with navigating the pathway from GP referral to treatment. This finding is consistent with the information needs related to navigating the healthcare system identified in the systematic review (Chapter 5). Previous research reported that difficulties in navigating the healthcare system of the host country can contribute to uncertainty and anxiety (Son et al., 2018). This may partly explain why dealing with anxiety emerged as the second most prevalent unmet need among patients in the Phase 2 survey (Chapter 6). It also suggests that the factors contributing to anxiety may extend beyond fear of cancer recurrence, as discussed in survey (Chapter 6), to include the challenges associated with navigating the healthcare system, which may in turn contribute to health inequalities among ethnic Chinese immigrant patients with cancer.

All patient participants in the Phase 3 in-depth interviews were female, and those with children described feelings of guilt towards their families because they were unable to fulfil expected family responsibilities. In Chinese families, females are traditionally expected to serve as the primary caregivers due to the patriarchal structure of Chinese society (Kwok and White, 2014). Younger female cancer survivors may have greater competing life responsibilities, such as caring for children, which may contribute to greater

fear of cancer progression (Vandraas et al., 2021). Combined with the demographic findings from the Phase 2 survey (Chapter 6), in which more than half of the patient sample were female and under 50 years of age, it is important to consider that gender and age may contribute to differences in psychological issues and cancer care experiences. Additionally, some patients described actively concealing their cancer diagnosis and socially isolating themselves from friends. This finding helps to integrate the Phase 2 survey result (Chapter 6) that patients reported receiving less support from friends, as these friends may not have been aware of the patients' cancer diagnosis.

### 7.5.3 Integration with survey results – informal caregivers

Several experiences described by informal caregivers in the Phase 3 interviews may help explain the lower HRQoL observed among informal caregivers, compared with patients, in the Phase 2 survey (Chapter 6). The reality of immigration meant that other family members were not available to provide support or share caregiving responsibilities. Ethnic Chinese informal caregivers assumed multiple roles following a family member's cancer diagnosis, and this was often at the expense of their employment, personal time, and social lives. Gender may contribute to this result, as 80% of informal caregivers in Phase 3 interviews and 69.2% in the Phase 2 survey were male. Male caregivers face challenges shaped by gender identity and notions of masculinity (Longo et al., 2020). This sense of duty frequently leads them to alter their lifestyle and careers pursuits, often resulting in neglecting their own care and support needs (Rosdiana and Afiyanti, 2022).

In the Phase 3, informal caregivers reported unmet information needs primarily related to the patients' treatment-related information and to financial support for the family. Informal caregivers expressed less concern about their own wellbeing and needs. This neglect may help to explain the lower levels of satisfaction with current quality of life reported in the Phase 2 survey (Chapter 6). Additionally, previous research has shown that limited access to appropriate and adequate information about patients' conditions can increase psychological distress among caregivers (Wang et al., 2021). The high prevalence of unmet information needs relating to patients' conditions may also have contributed to the prominent psychological issue of fear of cancer progression reported among informal caregivers in the Phase 2 survey (Chapter 6).

Notably, the experiences of ethnic Chinese informal caregivers reported in Phase 3 in-depth interviews may be subject to bias. Four of the five informal caregivers were interviewed in English. This should be considered when interpreting the findings.

Nevertheless, it is notable that even those informal caregivers who were able to participate in English still described difficulties in expressing complex emotions in a second language, which may discourage them from seeking support from cancer support organisations. This suggests that access to supportive services may be even more challenging for ethnic Chinese informal caregivers with more limited English proficiency.

### 7.5.4 Positive experiences-being informed about their cancer diagnosis

As introduced in Chapter 2 (Background) about the Chinese culture of healthcare, family-centred disclosure of cancer diagnosis was often highlighted. This practice refers to information about the patient's condition being communicated primarily to family members rather than directly to the patient, with the intention of protecting the patient from distress (Nielsen et al., 2015). This action was not reported by patients or informal caregivers in the Phase 3 in-depth interviews. Instead, patients indicated that they felt respected and well informed about their cancer diagnosis, which appeared to facilitate a more positive care experience. Additionally, informal caregivers also did not report attempting to withhold information or request limited disclosure of cancer-related information to patients. A possible reason for this may be related to the age of the patient; family controlling disclosure of information is frequently associated with older patients, underlying the filial piety culture and maintaining collective wellbeing (Nielsen et al., 2015). However, patients and informal caregivers in these in-depth interviews were relatively young.

### 7.5.5 Strengths and limitations

The Phase 3 in-depth interviews were not conducted independently but were interconnected with the Phase 2 survey (Chapter 6). The strengths of Phase 3 were reflected in the use of development and connecting purposes within the mixed-methods design. For the development purpose, the interview guide was informed by findings from the preceding phases, which helped ensure the relevance and contextual appropriateness of the interview topics. For the connecting purpose, participants in the Phase 3 in-depth interviews were recruited from the Phase 2 survey, resulting in a more targeted sample. Additionally, participants were given a choice of interview language and format (telephone or online), reflecting the person-centred care principles underpinning this project. Participants who chose to complete the interviews in Mandarin were able to express their experiences and emotions in their first language, which may have facilitated richer and enhanced the depth of the qualitative data. Although the PhD researcher was not fluent in

Cantonese, participants were also given the option of using a Cantonese interpreter, allowing them to complete the interview in their first language.

Despite the strengths, limitations from the Phase 2 survey (Chapter 6) were also carried forward. The availability of the FACT-G Caregiver questionnaire only in English may have influenced the characteristics of informal caregivers for the qualitative interviews. Four of the five informal caregivers completed their interviews in English, suggesting that most had relatively strong English proficiency. This may limit the transferability of the informal caregiver findings to those with limited English proficiency. Although Phase 3 offered participants the option of completing interviews by telephone, the resulting sample of both patients and informal caregivers were still relatively young. This may have been influenced by the fact that participants were recruited from the Phase 2 online survey. Additionally, most patients had been diagnosed with early stage cancer, and most informal caregiver were caring for patients with early stage cancer. These characteristics may limit the transferability of findings to individuals with advanced cancer and to informal caregivers caring them. Finally, the use of snowball sampling allowed patients and informal caregivers nominate one another for participation. Potential patient–informal caregiver dyadic relationships were not explicitly recorded in this phase. If such dyadic relationships existed, Confucian values emphasising family harmony may have influenced participants to withhold or minimise sensitive issues relating to their family relationships.

### 7.5.6 Recommendations

It is recommended that future research include participants from more diverse backgrounds, particularly older patients and informal caregivers with limited English proficiency. Including more older patients may provide a more in-depth understanding of whether family-controlled communication with healthcare professionals occurs in Scotland and, if so, how healthcare professionals manage and respond to such situations. The next recommendation is to consider recruiting and clearly identifying patient–informal caregiver dyads. This would enable researchers to explore shared and differing experiences within families and better understand how family relationships and cultural values may influence communication, caregiving, and experiences of cancer care.

## 7.6 Chapter summary

Chapter 7 offered in-depth understanding of cancer care experiences among ethnic Chinese patients and informal caregivers in Scotland as surveyed before. The intensity of burden experienced could provide reason as to why the informal caregivers as a group reported

lower general wellbeing than the patients in the survey. Patients and informal caregivers described needs for information related to disease management, support in navigating the healthcare system, and opportunities to talk with others who had shared experiences and could understand them. Both patients and informal caregivers explained that living with cancer as immigrants was particularly difficult because of the absence of support from extended family members.

Informal caregivers in the Phase 3 interviews described their observations of secrecy and silence surrounding discussions of cancer within ethnic Chinese communities. The PhD researcher encountered similar challenges during data collection for Phase 2 survey and Phase3 interviews. Some community leaders declined engagement based on beliefs that discussing cancer could bring bad luck. These findings and experiences prompted further consideration of whether such patterns reflect a broader cultural phenomenon. They also highlight the need to examine whether health and social care professionals encounter similar issues in providing care. Chapter 8 subsequently presents the insights from health and social care professionals when caring for ethnic Chinese immigrants affected by cancer.

# Chapter 8 : Phase 4: A focus group with health and social care professionals to understand their experiences of providing cancer care in Scotland

## 8.1 Introduction

Building on the findings from the first three phases and the challenges encountered during Phase 2 and 3 data collection, Phase 4 employed a focus group with health and social care professionals to explore their experiences of caring for ethnic Chinese immigrants affected by cancer. Understanding experiences of receiving and providing cancer care was considered important to help identify shared challenges that should be prioritised for future improvement. Including perspectives from health and social care providers helped enrich the findings by bringing in additional viewpoint. This Phase 4 focus group provided further explanation of the results for Phase 2 survey (Chapter 6) and Phase 3 in-depth interview (Chapter 7). Chapter 8 presents the methods, results, and key considerations of this focus group study.

## 8.2 Objectives

- To bring together different perspectives and understand the experiences of health and social care professionals in interacting with and providing care to ethnic Chinese immigrants affected by cancer in Scotland.

## 8.3 Methods

Phase 4 employed a focus group design. A focus group is a facilitated discussion involving a group of participants, designed to explore their perceptions, experiences, and opinions (Liamputtong, 2016). The focus group design was chosen over in-depth interviews for this phase because it allows participants to build on each other's responses, fostering interactive dialogue and group dynamics that can reveal deeper insights (Liamputtong, 2016). The consolidated criteria for reporting qualitative research (COREQ) framework (Tong et al.2007) was used as a guide for the focus group (Appendix 5).

### 8.3.1 Sample

Convenience, purposive, and snowball sampling methods were employed. Purposive and snowball sampling were chosen because they are commonly used recruitment techniques in qualitative studies and offer flexibility to select participants who are most likely to

provide relevant insights and contribute meaningfully to addressing the study's pragmatic aims (Kim et al.2017). Moreover, a convenience sampling method was also employed via recruitment from social media.

#### *8.3.1.1 Eligibility criteria*

The inclusion criteria were as follows:

- 18 years of age or older.
- Staff members within any health or social care or community service in Scotland.
- Self-identify as having experience in providing care to ethnic Chinese people affected by cancer who live in Scotland.

There were no specific exclusion criteria beyond not meeting the inclusion criteria outlined above.

#### *8.3.1.2 Sample size*

Hennink et al. (2019) proposed a range of parameters for estimating data saturation in focus group studies, including study purpose, type of codes, group stratification, number of groups per stratum, type of saturation, and degree of saturation. For this focus group, considerations of saturation were primarily informed by the study purpose and the overall project timeline. Within this project, this focus group was designed to provide further explanation and to gather health and social care professionals' perspectives to inform improvements in healthcare services, rather than to function as an independent or standalone inquiry. In line with the concept of information power (Chapter 7), a smaller sample size was considered sufficient to address the study objectives. Moreover, given the PhD timeline, only one month was allocated for recruitment for this focus group study, which constrained the achievable sample size.

### 8.3.2 Recruitment procedures

An e-flyer containing recruitment details (Appendix 6) was disseminated via social media platforms, including X, Facebook, Red Note (a widely used Chinese social media platform), and WeChat. PPIE representatives also assisted in liaising with ethnic Chinese community leaders to identify individuals who might be interested in participating. Subsequently, potential participants were asked whether colleagues might also be willing to take part.

### 8.3.3 Data collection format – online focus group

The online focus group by Microsoft Teams was selected as the most appropriate option for this focus group, as the health and social care professionals were based across Scotland. Their wide geographic distribution made it impractical to conduct a face-to-face focus group. After the interview guide was finalised, a list of available dates and times was distributed to participants who has signed the consent form. Once the preferred time slot was confirmed by the majority, the remaining participants were contacted to negotiate adjustments and explore whether they could accommodate the agreed time. The focus group interview was conducted in English, as it was the only common language shared by all participants.

### 8.3.4 Interview schedule

In line with the objectives of this focus group, the interview guide was consistent with two parts. The first part focused on health and social care professionals' experiences in interacting with ethnic Chinese patients and informal caregivers. As the first three phases (Chapter 5 to 7) reported on prevalent unmet information needs, the first session for this focus group included a question about the observations of information seeking behaviour among ethnic Chinese immigrants. The second part focused on health and social care professionals' perspectives on which areas of current healthcare services should be improved to better care for ethnic Chinese immigrants. The interview guide was also informed by a review of relevant literature. These studies were conducted in countries with the same HDI level as Scotland and the UK (Sarpel et al., 2018; Møen et al., 2018; Claeys et al., 2023). The interview guide was reviewed by the supervisory team and PPIE representatives to ensure its relevance and readability. The final version of the interview guide is provided in Appendix 11.

### 8.3.5 Data analysis

The focus group data were analysed using inductive relativist thematic analysis developed by Braun and Clarke (2022). NVivo 14 was used for the coding process. The methodological consideration underpinning the inductive and relativist approach to thematic analysis are discussed in Chapter 4. The practical steps for analysing the focus group data followed the same procedures used in the Phase 3 in-depth interviews, as detailed in Chapter 7. The thematic analysis process for each theme in the Phase 4 focus group is presented in Appendix 12.

### 8.3.6 Ethical considerations

#### *8.3.6.1 Ethical approval*

An amendment covering the focus group was submitted to the University of Glasgow, College of MVLS Ethics Committee on 20th December 2023 and was subsequently approved on 3rd January 2024 (Appendix 9).

#### *8.3.6.2 Informed consent*

Potential participants who scanned the QR code on the recruitment flyer were directed to the participant information sheet, privacy notice, and consent form for the focus group (Appendix 10). After reviewing these documents, participants provided electronic consent by completing a digital signature on the consent form. A brief set of demographic questions, including professional role, years of work experience, and nationality, was collected following consent. Participants were also asked to provide an email address for communication purposes. Following a one-month recruitment period, participants who had provided consent and contact details were contacted by email to arrange a suitable time for the focus group. A reminder email was sent one week later to those who had not responded. If no response was received after the reminder, no further contact was made. Once participation confirmed a suitable time, a Microsoft Teams calendar invitation containing the meeting link was sent, allowing participants to join the focus group at the scheduled time. At the start of the focus group, an overview of the study was provided. Participants were reassured about data confidentiality and informed of their rights, including the voluntary nature of participation. They were also notified that the focus group would be audio-recorded and reminded that they could withdraw at any time.

#### *8.3.6.3 Data management plan*

The data management plan followed the same procedures outlined in Chapter 7.

#### *8.3.6.4 Confidentiality and anonymity*

All data from the focus groups were pseudonymised. Each participant was assigned the fictional name and their professional role. This ensures that participants cannot be identified from final written reports and any publication.

## 8.4. Results

Five potential participants initially expressed interest in taking part in this focus group. However, one later withdrew due to personal reasons. As a result, a single focus group was

conducted with four participants in April 2024. The duration of focus group was around 1.5 hours.

### 8.4.1 Participants' characteristics

The focus group comprised one oncology nurse representing healthcare professionals and three social care workers. The characteristics of participants were presented in Table 8-1.

Table 8-1 Characteristics of participants in focus group

| **Number** | **Nationality** | **Healthcare position** | **Years of experience** |
|---|---|---|---|
| Jane | British Overseas | Oncology Nurse | 5-10 |
| Helen | British | Social Worker | > 10 |
| Linda | Chinese | Social Worker | 5-10 |
| Emily | Chinese | Social Worker | <5 |

### 8.4.2 Theme 1: Experiences of interacting with ethnic Chinese immigrants affected by cancer

The first theme of the focus group reflected health and social care professionals' experiences of interacting with ethnic Chinese immigrants affected by cancer. Theme 1 summarised the identified barriers, their underlying reasons, and their wider influences (Figure 8-1).

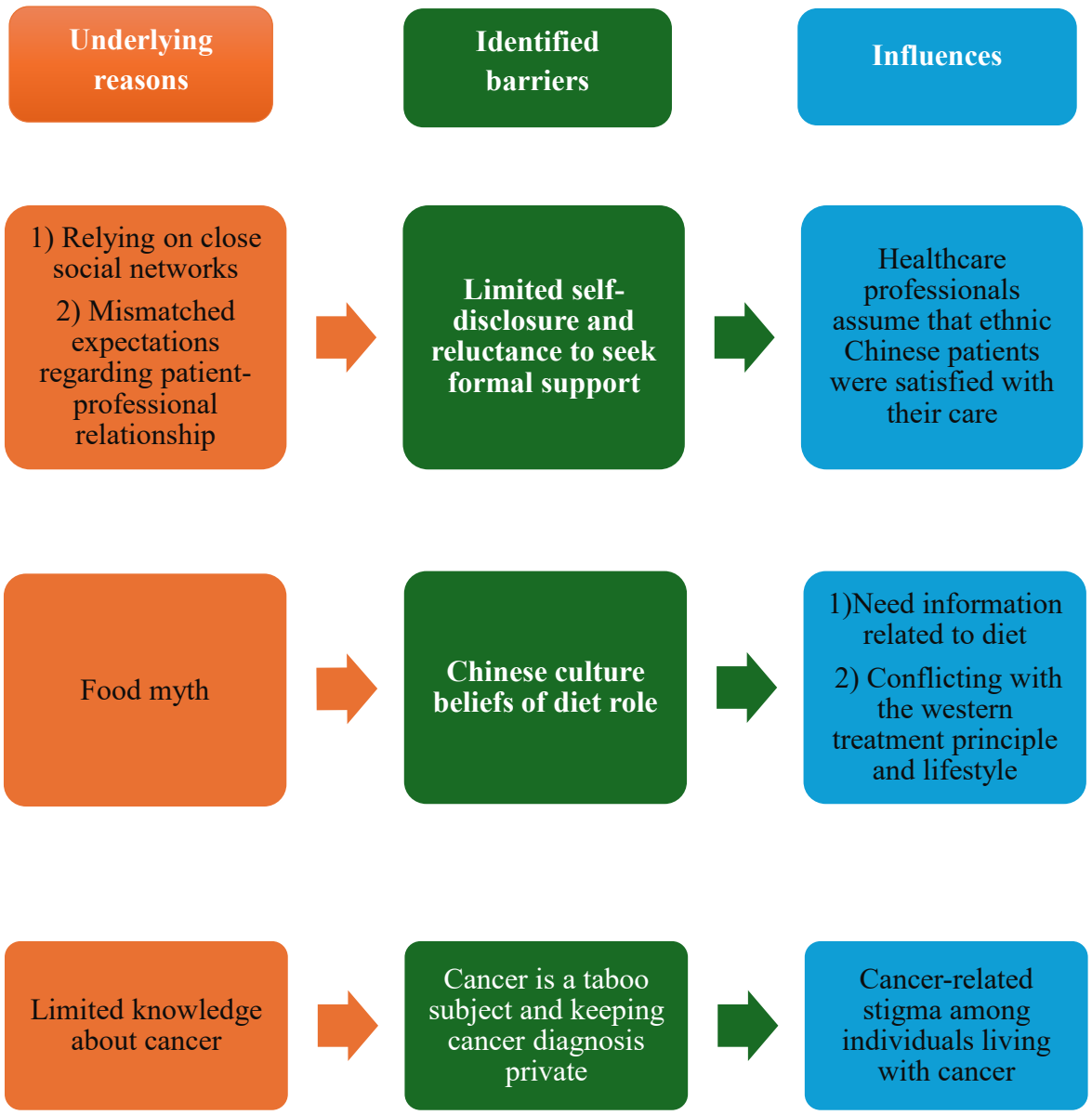



Figure 8-1 Barriers affecting cancer care experiences with underlying reasons and influences: perspectives of health and social care professionals

#### *8.4.2.1 Limited self-disclosure and reluctance to seek formal support*

Health and social care professionals discussed their observations of help-seeking behaviours of ethnic Chinese immigrants affected by cancer. They noted that ethnic Chinese immigrant patients hold a strong preference for managing health independently or relying on close social networks, rather than engaging with formal supportive care services.

> *Chinese people don't feel comfortable to seek formal help. Even if they know about the service, they prefer to deal with things themselves. No matter how good the service is, they would rather rely on family members or close friends for support.*
>
> *(Jane, Oncology Nurse)*

> *I've found that they rely on their own knowledge or things they've heard from family or friends to help them. If their networks can't provide the information, they might look things up online using Google. But even with limited sources, they're still not willing to reach out for external support.*
>
> *(Linda, Social care worker)*

Without adequate disclosure of their needs, healthcare professionals were more likely to assume that ethnic Chinese patients were satisfied with their care, when in fact, this was not the case.

> *Chinese patients are less disclosive themselves, they do not ask their questions and just wait. And this makes the treatment team feel like they are satisfied with everything. However, the truth is that they bring their questions back to home.*
>
> *(Emily, Social care worker)*

Helen as a social care professional further noted that mismatched expectations regarding patient–professional relationships influenced ethnic Chinese immigrants' willingness to seek formal support services.

> *In Western style the relationship between the patient and healthcare provider is totally different, from the Chinese expectation. In Western healthcare, the relationship between doctors and patients is more distant. It's a professional relationship, and there's a clear boundary. But in Chinese culture, patients want a closer, warmer relationship with their healthcare providers. They want to feel cared for, not just as patient.*
>
> *(Helen, Social care worker)*

### *8.4.2.2 Chinese culture beliefs of diet role*

Linda, Emily and Helen highlighted the important views of diet among ethnic Chinese immigrant patients and how traditional Chinese dietary beliefs contribute to this. Many patients modified their diets based on culturally rooted understandings of food, but some of which were based on unverified or non-evidence-based beliefs.

> *There are a lot of dietary myths in Chinese culture, especially around what patients can and cannot eat. One of my patients, who was diagnosed with breast cancer, told me she couldn't eat chicken because it contains hormones.*
>
> *(Jane: Oncology Nurse)*
>
> *Many patients adjust their diets based on traditional Chinese beliefs, particularly those from the older generation. They are very careful about what they eat after treatment, but some of these dietary beliefs are not based on any evidence and are simply followed because others do the same or have told them to.*
>
> *(Linda: Social care worker)*
>
> *People don't know the science behind those myths. They follow cultural beliefs about what they should and shouldn't eat, but they might not have accurate information about what's healthy.*
>
> *(Helen: Social care worker)*

These food myths and preferences sometimes directly conflict with Western lifestyle, but clinical healthcare professionals often overlook this point.

> *I think professionals should be aware of some Chinese cultural habits. For instance, Chinese people always drink hot water instead of cold water, which is completely different from the Western style. Not just water, but also food. In Western culture, they eat salads, but Chinese people don't like to eat cold food. They believe cold food is bad for their health.*
>
> *(Helen: Social care worker)*

Western healthcare professionals believed that these dietary myths sometimes conflict with Western treatment principles, leaving patients uncertain about whether to follow their traditional beliefs or medical advice.

> *I also came across a case where a Chinese patient believed certain foods are good for specific organs. However, when they talk to doctors or nurses, they're told not to follow those traditional ideas because there's no research to support them. So,*

*they're confused. Should they trust the doctors, or should they follow what their culture tells them? In Chinese culture, everyone says certain foods are healthy, but in here, the doctors say no, so they don't know what to do."*

*(Helen: Social care worker)*

#### *8.4.2.3 Cancer is a taboo subject and keeping cancer diagnosis private*

Helen as social care professionals found that there was a cultural silence surrounding the discussion of cancer in ethnic Chinese communities, particularly among older adults.

*Normally, the Chinese because age-wise, whoever has cancer tends to be from the older generation. And I think it's a taboo in the Chinese community; they don't talk about it.*

*(Helen: Social care worker)*

The cancer taboo within ethnic Chinese communities further influenced patients' willingness to disclose their diagnosis, with many choosing to share this information only with those they trusted closely.

*I found that my community members don't want to talk about cancer straight away. It seems like a 'big secret' topic, they don't want to tell you anything at all about their cancer diagnosis. They try to withhold, unless you are familiar with them.*

*(Linda: Social care worker)*

*They won't really let you know their cancer diagnosis until you have a good relationship with them."*

*(Helen Social care worker)*

This cancer taboo may stem from limited knowledge about cancer, which contributes to fatalistic perceptions and, in turn, reinforces the stigma surrounding patients with cancer. Such fatalistic beliefs can contribute to delays in seeking diagnosis and treatment, ultimately affecting health outcomes.

*Many people lack understanding of what cancer is. They always associate cancer with death. You got cancer, you are going to die. They have a very negative perspective, and it affects their mental health. Even when they understand that early detection and early treatment can be helpful. But in their mind, they still think that cancer is a penalty for people. They don't see it as something they can fight.*

*(Linda: Social care worker)*

### 8.4.3 Theme 2: Room for improvement

Health and social care professionals identified four areas in cancer care services that needed improvement and proposed corresponding solutions (Figure 8-2). These areas for improvement were primarily related to cultural and language barriers, and further extended to the specific needs of older patients.

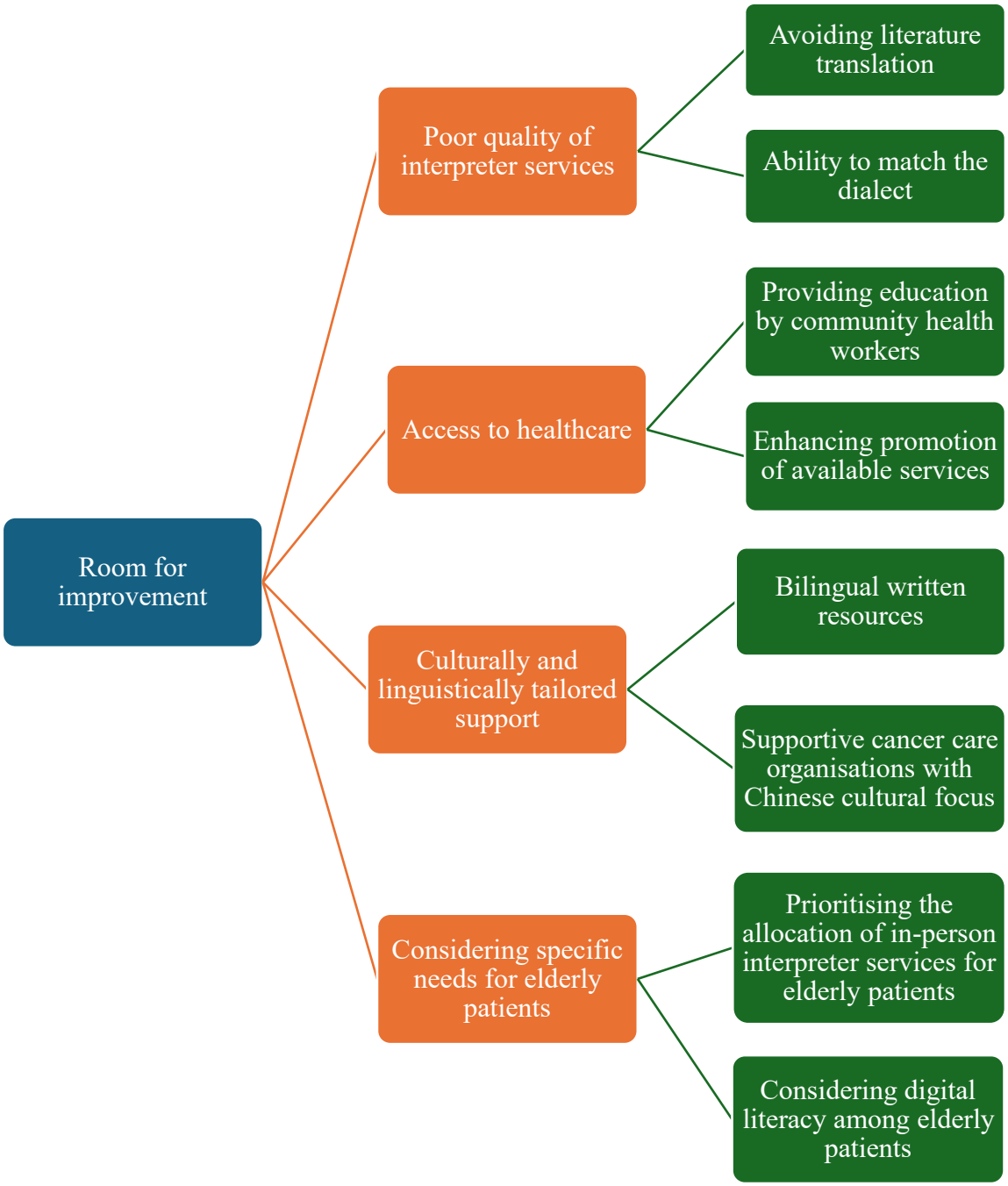



Figure 8-2 Room for improvement to cancer care services and proposed strategies

#### *8.4.3.1 Poor quality of interpreter services*

Linda, Helen and Jane observed issues related to the use of interpreter services. Firstly, elderly patients often felt uncomfortable using telephone-based interpretation, as they struggled to hear clearly. This, in turn, discouraged them from attending their medical appointment.

> *At our centre, the elderly sometimes complain that they don't want to go to their appointments because the interpreters aren't good. Sometimes, the interpreter is on the phone, and they can't hear them clearly, so it's difficult for the elderly to understand.*
>
> *(Linda: Social care worker)*

Secondly, when allocating interpreters for each case, dialect matching between the patients and interpreter was often overlooked.

> *Some patients speak Cantonese or Hakka, but the interpreter is Mandarin speaking, so it does not help. As a result, patients feel that interpreter is not doing it properly.*
>
> *(Linda: Social care worker)*

Finally, the interpreters did not translate the emotional and personal experiences of patients, as they were providing a literal translation of what was being said, without being able to convey the emotion behind it:

> *Interpreter might just translate words and can't always transfer patient's emotions properly, so patients feel unsupported.*
>
> *(Helen, Social care worker)*
>
> *Interpreters often struggle to convey the emotions or personal experiences behind patients' words. But these are exactly sometimes patients want to express and share with their feelings of treatment to doctors.*
>
> *(Jane: Oncology Nurse)*

#### *8.4.3.2 Access to healthcare*

Health and social care professionals discussed the challenges they observed among ethnic Chinese immigrant patients in accessing the healthcare system and available services. Patients often struggled to navigate the healthcare system and were unaware of the supportive options available, which in some cases led them to consider returning to their place of birth for further treatment.

> *Some patients they prefer to go back to Hong Kong because they find it hard to navigate the NHS system when diagnosed with cancer. They don't understand what it means and what help is available.*
>
> *(Helen: Social care worker)*

Low health literacy was also reported as a key barrier contributing to this issue, and health and social care professionals recommended developing tailored educational strategies to enhance patients' and public's understanding of healthcare system and awareness of available services.

> *The literacy and understanding are the biggest issue to getting access to healthcare services. Because they do not know what it is, how it is worthy. You need somebody give you some guided direction, what's going on.*
>
> *(Helen: Social Worker)*
>
> *Patients do not know what the services are, where to find help and what resources are available. Therefore, we need experts who know their culture and language to navigate patients to go to the right place to seeking cancer help services.*
>
> *(Jane: Oncology Nurse)*

Jane recommended establishing a Chinese speaking healthcare professional position, as such position would be well suited to providing relevant education.

> *If NHS have the related position like Chinese speaking community nurse that would be helpful to let patients be familiar with the healthcare system and raise cancer awareness for the public.*
>
> *(Jane: Oncology nurse)*

A notable point of discussion was that the low awareness of supportive cancer care services was not only attributable to the above-mentioned individual factors but was also linked to insufficient promotion and outreach by healthcare organisations. The experience shared by Jane further suggested that nurses may be ideally positioned to raise awareness of and actively promote these services.

> *I've been volunteering with a charitable cancer organisation for around four months. I remember when I handing out a Cantonese version of our leaflet to members of my local community, they were so surprised and eager to take it. They told me they had no idea such material even existed. Their reaction made me*

*realise that the promotion of supportive cancer services may not have been sufficient in the past.*

*(Jane: Oncology nurse)*

#### *8.4.3.3 Culturally and linguistically tailored support*

The absence of culturally appropriate services was reflected in two key points. Firstly, Helen emphasised the importance of establishing a supportive cancer care organisation rooted in Chinese heritage within Scotland. Jane also highlighted the potential benefit of such an organisation. This organisation could enable patients to communicate in their native language and connect with others who share a similar cultural background and cancer treatment experience.

*I think in Scotland, we need cancer organisations specific for Chinese background patients. England has this kind of organisation, but this is an absence for Scottish cancer care service.*

*(Helen: Social care worker)*

*Scotland needs to offer peer support groups specifically for Asian people. If there were peer support groups where people could use their first language and share their experiences with others who understand their culture, it would help a lot.*

*(Jane: Oncology nurse)*

Secondly, Emily pointed out the concern that was the lack of official bilingual written resources for patients. Currently all the official information about cancer was in English only.

*If their English isn't good, it's hard for them to find official information. I haven't seen any official publications about cancer in Chinese from NHS website.*

*(Emily: Social care worker)*

Helen further highlighted the lack of reliable Chinese-language information, may leading patients and public to access inaccurate information, in turn, resulting delayed treatment.

*Most official information is in English, but many patients from the Chinese community don't understand it. So, when they experience symptoms, some search for Chinese information online. But they often cannot distinguish whether this information is reliable then leading to delays in seeking appropriate treatment.*

*(Helen: Social care worker)*

#### *8.4.3.4 Considering specific needs for elderly patients*

The discussion between the Jane and Helen highlighted a specific concern for elderly patients, with the current supportive cancer care services lacking consideration for their digital literacy.

> *My volunteered charity supportive cancer care organisation has a station in the library with information like leaflets and booklets that they can read. Onsite booklet just shows the English version. But online, we do provide resources in Cantonese. The staff can also email them Cantonese version or even send hard copies by mail to the patients.*
>
> *(Jane: Oncology nurse)*
>
> *But the reality is how many elderly Chinese people have an email address? Elderly people with cancer don't feel comfortable using technology. I guess that the elderly people are preferring to find the Chinese version booklet onsite at supportive cancer care organisations.*
>
> *(Helen: Social care worker)*

## 8.5 Discussion

### 8.5.1 Summary of main findings

The main findings from the Phase 4 focus group included explanations for why ethnic Chinese immigrants expressed a desire for dietary information, which appeared to be influenced by the prevalence of food-related myths. Health and social care professionals also explained how cancer was a taboo subject within ethnic Chinese communities and was an important factor contributing to the silence surrounding cancer-related discussions. Health and social care professionals suggested that this taboo may be linked to limited health literacy.

Suggested areas for future improvement included enhancing the quality of interpreter services, developing ethnic Chinese cancer support organisations, and taking the digital literacy of older adults into greater consideration. Furthermore, health and social care professionals confirmed that unmet information needs and difficulties in navigating the healthcare system were common concerns and proposed the introduction of an ethnic Chinese community health worker role as a potential strategy to address these issues.

### 8.5.2 Connection with previous phases and literature

Findings from the Phase 4 focus group suggest that food myths rooted in Chinese culture may partly explain the prevalent unmet dietary information needs reported in the previous phases (Chapter 5 to 7). Within traditional Chinese health concepts, illness is often perceived as the result of an imbalance between "Yin and Yang", and maintaining an appropriate diet is viewed as a means of restoring balance, supporting health, and promoting recovery (Wu and Liang, 2018; Liu et al., 2025).

Health and social care professionals described their observations of "silence and secrecy" surrounding discussions of cancer diagnoses within ethnic Chinese communities and identified the presence of cancer-related taboos. Similarly, Shang et al. (2015) in a grounded theory study conducted in England among Chinese women exploring views of breast cancer, reported that negative attitudes towards cancer persist within ethnic Chinese communities, where cancer is often perceived as a fearful disease and is rarely discussed openly. These observed cancer taboos can perhaps explain in part why there were challenges collecting data for Phase 2 and Phase 3 (Chapter 6 and 7).

This focus group study highlighted inequalities in access to information and the healthcare system. This focus group proposed that these inequalities in access were partly attributed by inadequate promotion their supportive activities by cancer care organisations in Scotland. The data collection process of Phase 2 and 3 (Chapter 6 and 7) directly supports this. Initially, the recruitment approaches for this project were by social media dissemination and engagement with English-speaking cancer organisations. However, these strategies had limited reach and impact. Over time, more effective engagement was achieved through community collaboration, including the organisation of public information sessions, which proved more successful in raising awareness of available services.

### 8.5.3 Ageing generations and access to healthcare

In this focus group, health and social care professionals specifically mentioned the inequality to accessing healthcare services among elderly people. The inequality identified among elderly people related to phone-based interpreter services, which the health and social care professionals felt made older adults uncomfortable using them. This finding aligns with experiences reported among Chinese American patients with cancer, who described difficulties expressing themselves clearly over the phone and characterised such interactions as "inconvenient" (Sarpel et al., 2018). Secondly, information is currently

provided primarily in digital formats, such as email and online platforms. However, older adults may prefer printed materials that can be collected on site from supportive cancer care organisations. The limited availability of information in alternative formats may restrict older adults' access to healthcare services. It should be noted that one of the social care professionals worked mainly with ethnic Chinese elderly people, and is the likely reason why this emerged as a key theme.

### 8.5.4 Strengths and limitations

This focus group was embedded within the hybrid multistage mixed-methods design and served a further explanatory purpose within the overall project, rather than functioning as an independent study. Phase 4 focus group provided a complementary perspective by incorporating insights from health and social care professionals on how ethnic Chinese immigrants affected by cancer experience and receive cancer care in Scotland. These professionals had a good understanding of ethnic Chinese communities and were well positioned to act as key informants. In addition, through the development purpose of the mixed-methods design, the focus group guide was informed by evidence and experiences from the preceding phases. This helped ensure that the discussion topics were clearly focused and relevant to the objectives of the focus group.

The limitations of this focus group were mainly related to the fact that only one focus was conducted and participants served a limited geographical area. With the time constrains of this project, conducting a single focus group limited opportunities to compare and corroborate findings across groups, which may have reduced the trustworthiness of the findings. Additionally, all participants mainly served communities in the Greater Glasgow area. This limited the opportunity to capture the experiences and perspectives of health and social care professionals working in remote and disadvantaged areas of Scotland.

### 8.5.5 Recommendations

Only one oncology nurse participated in this focus group as a healthcare professional, while the remaining three participants were social care professionals. Future research should recruit a more diverse range of healthcare professionals, including those from different clinical roles, such as oncologists, to provide a broader range of perspectives. Although the aim of this focus group was to involve participants from across Scotland, most participants mainly served communities in the Greater Glasgow area. It is recommended that future research conduct multiple rounds of focus groups involving health and social care professionals from across Scotland and, where possible, the wider

UK. Conducting multiple focus groups with health and social care professionals from different UK nations could allow findings to be compared and corroborated across groups.

## 8.6 Chapter summary

Findings from focus group explained and contextualised the results from the previous three phases. At this stage, the explanatory component of the study was complete. The challenges in recruiting ethnic Chinese patients and informal caregivers in Phases 2 and 3 also became more understandable, with a tendency to keep cancer a secret, having limited cancer-related knowledge and cancer being considered a taboo subject. The issues identified within ethnic Chinese communities in the public context warranted further exploration in a larger sample, as these beliefs may influence intention to engage in cancer prevention. Therefore, to promote equality in cancer care among ethnic Chinese communities, it is essential to understand the prevalence of cancer-related taboos, knowledge about cancer, and intentions to engage in cancer prevention among the ethnic Chinese public. Accordingly, this project was extended to include a subsequent survey with ethnic Chinese members of the public, which is presented in Chapter 9.

# Chapter 9 : Phase 5: An exploratory survey on beliefs, knowledge about cancer and intention to engage in cancer prevention among ethnic Chinese communities without a cancer diagnosis

## 9.1. Introduction

As outlined in the Chapter 2 (Background), cancer screening plays a crucial role in cancer prevention, but cancer screening rates remain lower among ethnic minority groups (Scottish Government, 2023b). Previous research shows that cultural differences influence perceptions of cancer diagnosis (Badanta et al., 2022; Meng et al., 2024). For example, in some Asian cultures, cancer is believed to be an 'incurable disease', which subsequently influences health behaviours (Badanta et al., 2022; Meng et al., 2024).

Findings from Phase 3 and 4 indicated that ethnic Chinese immigrants affected by cancer in Scotland often experience the cancer as taboo within their communities, which fostered silence and impaired help-seeking for cancer related needs (Chapters 7 and 8). Therefore, it was hypothesised that cancer-free ethnic Chinese immigrants might have gaps in cancer knowledge or hold unhelpful beliefs. These could affect their experiences if they were later diagnosed with cancer and received cancer care. It was therefore considered important to explore the magnitude of beliefs, knowledge and intention to engage in cancer prevention among cancer-free ethnic Chinese immigrants that might be considered problematic, and explore any possible variation in responses across demographic groups. The Phase 5 survey was then undertaken, and this chapter presents the methods, results, and key considerations of that study.

## 9.2 Objectives

- To explore knowledge and beliefs about cancer among ethnic Chinese immigrants without a cancer diagnosis in Glasgow.
- To explore intention to engage with cancer prevention among ethnic Chinese immigrants without a cancer diagnosis in Glasgow.
- To explore variation in responses among different demographic subgroups.

## 9.3 Methods

An exploratory, cross-sectional design was employed, using an on-site data collection approach. Reporting of this survey is in line with the Consensus-Based Checklist for Reporting of Survey studies (CROSS) (Sharma et al., 2021) (Appendix 4).

### 9.3.1 Sample

The survey employed convenience sampling and adopted a community-collaborative approach to data collection. Given the availability of community networks, as well as cost and time constraints, the main data collection sites were ethnic Chinese communities in the Greater Glasgow area. The pool of potential participants mainly included Glasgow-based individuals, although it may also have included people who were permanently living in other regions of Scotland but were visiting Glasgow when the survey was conducted.

#### *9.3.1.1 Eligibility criteria*

The criteria for participation in the survey were:

- Over 18 years of age.
- Born in mainland China, Hong Kong, Macao, Taiwan, Malaysia, Singapore or other regions with Chinese heritage.
- No prior cancer diagnosis.

There were no specific exclusion criteria beyond not meeting the inclusion criteria outlined above.

#### *9.3.1.2 Sample size*

There were five accessible ethnic Chinese communities in Glasgow, and around twelve ethnic Chinese communities in Scotland. Following consultation with the local PPIE representative, it was estimated that these communities comprised approximately 1700 members, representing the anticipated accessible population. Sample size estimation was conducted using an online sample size calculator provided by Qualtrics (https://www.qualtrics.com/blog/calculating-sample-size/). With a confidence level of 95% and a margin of error of 7 -10 %, the sample size was 91-176 participants.

### 9.3.2 Recruitment procedures and data collection

Earlier phases in this project indicated that establishing relationships with ethnic Chinese communities was important before inviting this population to discuss cancer related topics. This survey adopted a community collaborative and face to face approach for data collection, whereby surveys were administered to potential participants during educational "Cancer Talk" sessions. The community groups participating in data collection included an elderly centre, a women's association, and two general community organisations.

The recruitment procedures and data collection processes involved clear allocation of responsibilities. The PhD researcher was responsible for preparing the slides and content for the "Cancer Talk" session and delivering it. The Glasgow-based PPIE representative primarily acted as a community coordinator, drawing on strong connections with various ethnic Chinese communities in Glasgow to support recruitment for this study. As the PPIE representative was primarily Cantonese-speaking and the PhD researcher was primarily Mandarin-speaking, both played important roles in organising activities and maintaining community engagement. The community coordinator approached community leaders to obtain permission for participant recruitment in four predominantly Cantonese-speaking communities. Access to the Mandarin-speaking Glasgow Chinese School was facilitated through the PhD researcher's personal networks, specifically through liaison with a senior Chinese teacher who had more than 10 years of experience at the school.

The date and time of the "Cancer Talk" sessions were coordinated collaboratively between the PPIE representative, community leaders, and the PhD researcher. To maximise attendance and participant convenience, the sessions were scheduled to coincide with the communities' regular weekly activities. Each "Cancer Talk" session was held either at the relevant community centre or in a lecture room at the Glasgow Chinese School. After agreement with the date and time, the content of the "Cancer Talk" sessions was also coordinated between the groups. The PPIE representative consulted with four Cantonese speaking community leaders about what area of cancer they would want to learn about during the session. Two community leaders expressed a particular interest in stomach and pancreatic cancers. Two communities preferred general cancer knowledge. At the Glasgow Chinese School, the session specifically focused on paediatric cancer to address the unique needs of parents. The flyer for the "Cancer Talk" sessions (Appendix 6) was designed by the PPIE representative and reviewed by the PhD researcher.

The PhD researcher prepared the slides based on the interests identified within each community. The overall content of the session was designed by the PhD researcher and included: (1) what cancer is; (2) common myths about cancer; (3) how to maintain a healthy lifestyle for cancer prevention; (4) the importance of cancer screening and the screening programmes available in Scotland; (5) a community-specific topic of interest; and (6) a Question & Answer session. The first two sections were included in response to findings from the earlier phases of this project, which highlighted cancer as a taboo subject and highlighted the need to improve the public's basic understanding of cancer. The third and fourth sections were informed by previous phases showing the importance of diet

within ethnic Chinese communities and evidence of lower uptake of cancer screening among ethnic Chinese populations. The slides were shared with the community for review one week before the “Cancer Talk” session took place. To meet language preferences, the PhD researcher prepared slides in Traditional Chinese for the Cantonese-speaking communities and in Simplified Chinese for the Glasgow Chinese School. During delivery of the “Cancer Talk” sessions, the PhD researcher acted as the main speaker, while the PPIE representative served as an interpreter for the Cantonese-speaking communities. The overall preparation and organisation process is visualised in the flow chart in Figure 9-1.

Survey data collection was weaved in the “Cancer Talk” sessions, with participants asked to complete each session of the questionnaire before the corresponding segment of the “Cancer Talk” began (Figure 9-2). This approach ensured that the data accurately reflected participants’ baseline knowledge of cancer, without being influenced by the information provided during the session. Participants were encouraged to ask questions both during the Question and Answer part and at any point throughout the presentation. Volunteers were contacted by the community coordinator, and each “Cancer Talk” session was supported by two to three volunteers, depending on the number of registered participants. Where necessary, volunteers provided assistance to support participants in completing the questionnaire. Each “Cancer Talk” session lasted approximately 60 minutes. Figure 9-1 provides a visual overview of the overall data collection process.

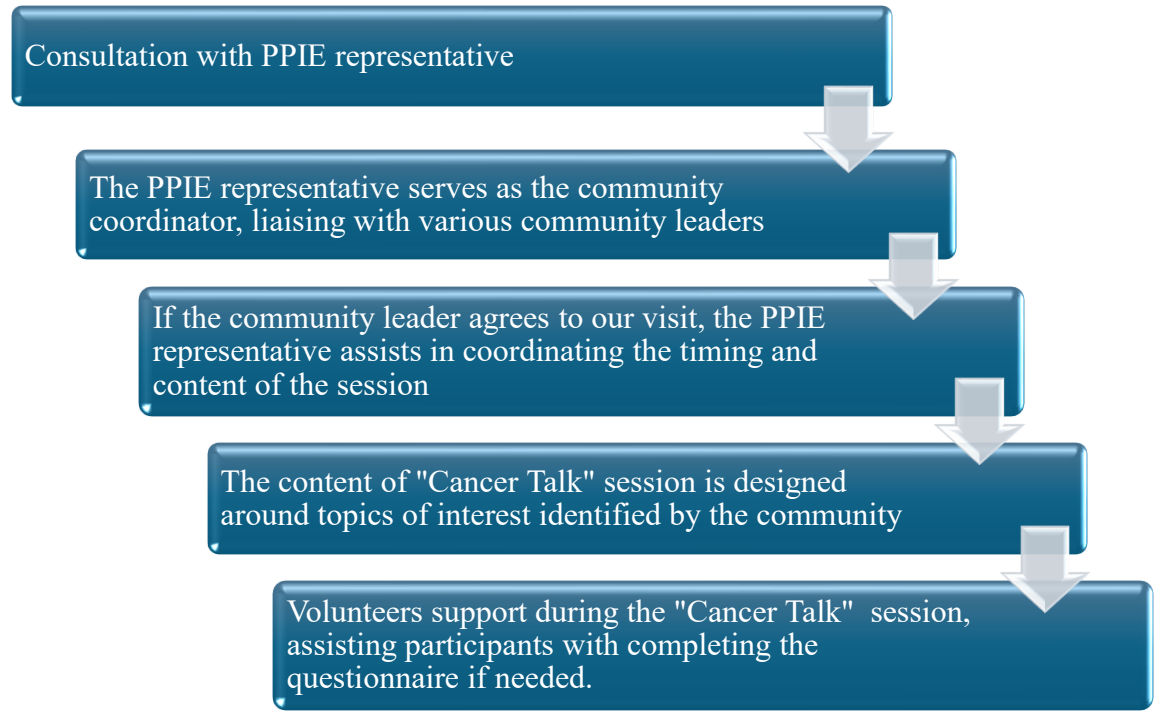



Figure 9-1 Flow chart of the preparation and organisation process for the Phase 5 survey

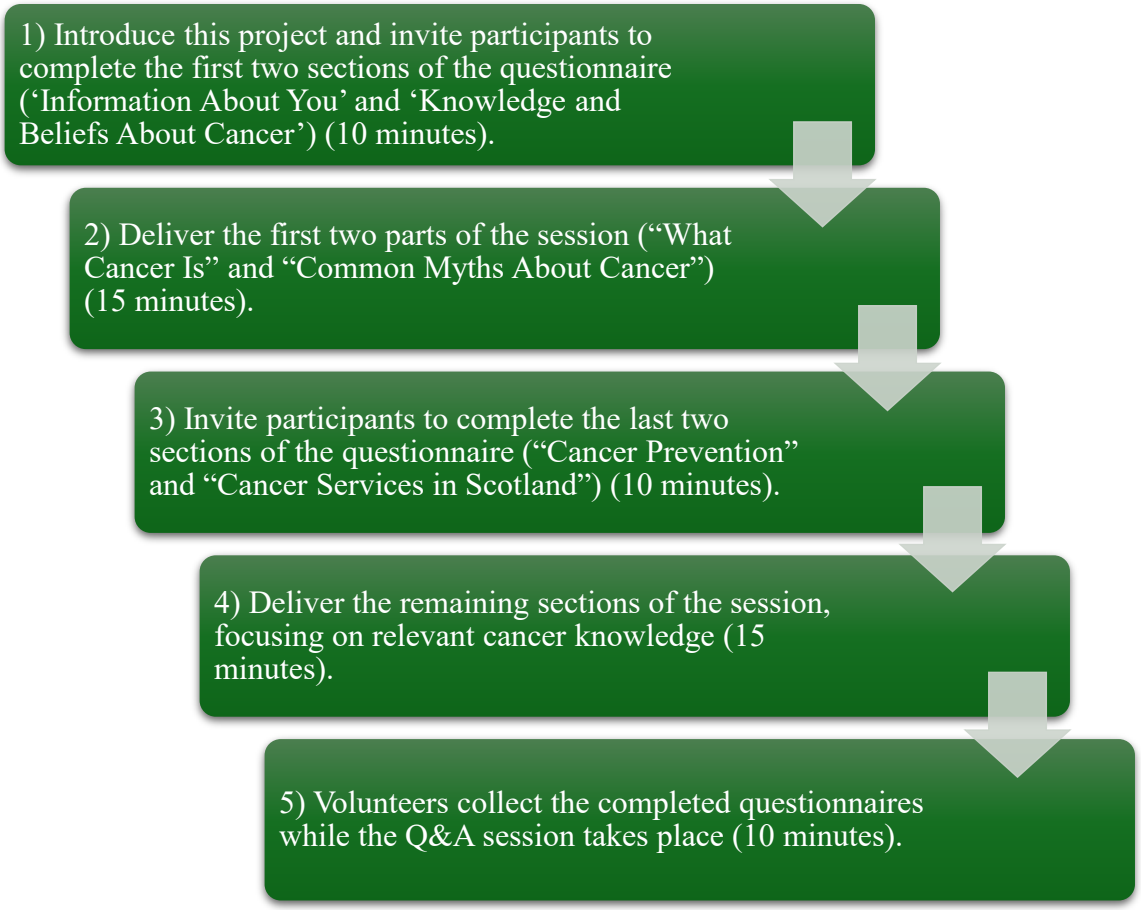



Figure 9-2 The flow chart of data collection process for Phase 5 survey

### 9.3.3 Data collection instrument

Currently, no validated instrument exists that specifically measures cancer awareness among ethnic Chinese immigrants. The name of this self-designed questionnaire was called "Cancer Awareness Questionnaire for the Ethnic Chinese Community". It was designed by the literature informed approach, which could enhance the content validity (Bruce et al., 2018). The overall questions in the questionnaire were close-ended, which offers the advantages of being easy to administer and enabling efficient data collection, however it restricts participants with freedom to express their responses in their own words (Polit and Beck, 2022). Questions developed from English literature were translated into Chinese using a back-translation approach to ensure translation accuracy and quality (details of the back-translation technique for qualitative transcripts, Chapter 7). The questionnaire comprised 19 items, which were categorised into four sections. The overall questionnaire was available in Simplified Chinese, Traditional Chinese and English versions. The completed English version is provided in Appendix 7, and the rationale for the design of each section is explained in detail in the following:

**Section 1–"Information about you" (7 items):** The first section gathered the demographic information. Demographic variables covered age and sex were designed in line with recommendations for demographic survey design (Chen and Gardner, 2022). Items relating to education, occupation, and income were informed by the social determinants of health framework (Chapter 3). In addition, items on place of birth and years of immigration were included to account for differences in acculturation (see Chapter 5 demographic questionnaire design). This section concluded with an item about participants' confidence in their knowledge of cancer.

**Section 2–"Knowledge and beliefs about cancer" (2 items):** Item 8 assessed participants' knowledge of cancer symptoms, and was informed by the Cancer Awareness Measure annual report for Scotland (Cancer Research UK, 2024). Item 8 included 6 sub items, each requiring a yes/no response to indicate whether the symptom listed could be a sign of cancer. Item 9 examined participants' beliefs about cancer and consisted of 9 sub items, each rated on a four-point Likert scales. The four-item Likert scale allows respondents to indicate their level of agreement or disagreement (Polit and Beck, 2022). Item 9 was partly adapted from a questionnaire developed by the Korean National Cancer Centre, which had been informed by a literature review and semi-structured interviews

(Cho et al., 2013). It was further refined through consultation with the PPIE representative, informed by their knowledge and by findings from the earlier phases of this project.

**Section 3 – "Cancer Prevention" (8 items):** This section included three parts. Part 1 (Item 10 and 14) aimed to understand the self reported participation rate of attending cancer screening programmes and was informed by National Health Service Scotland guidance (National Health Service Scotland, 2020). Part 2 (Item 11 and 15) explored participants' preferred ways of receiving reminders about cancer screening and cancer-related information, to identify public preferences. Part 3 (Items 12, 13, 16, and 17) aimed to understand intentions to engage in cancer prevention behaviours and drew on the theory of planned behaviour to inform interpretation of the findings. The content of items 12, 13, and 17 were informed by the Cancer Awareness Measure annual report for Scotland (Cancer Research UK, 2024). Item 16 was informed by the World Health Organisation's recommendations on ways to prevent cancer (World Health Organiszation, 2023).

**Section 4 – "Cancer Services in Scotland" (2 items):** Findings from Phases 3 and 4 suggested that ethnic Chinese immigrants had relatively low awareness of available supportive cancer care services. This section was intended to examine whether the public had limited knowledge of available supportive cancer care services in Scotland.

After the initial development of the instrument, the final version was pre-tested with PPIE representatives. This process ensured that the questions were easy for the public to understand and follow. No concerns were raised during this pre-test process, confirming the questionnaire's clarity and usability. Although the validity and reliability of this self-developed instrument were not formally established, its primary purpose was to generate initial insights and guide further inquiry, rather than to serve as a fully validated measurement tool.

### 9.3.4 Data analysis

All data were collected in the form of hard-copy questionnaires. The data were initially entered into a Microsoft Excel spreadsheet by the PhD researcher and subsequently double-checked by a colleague who did not have a conflict of interest with this project. Overall data analysis was conducted using SPSS version 26.0. Descriptive statistics summarised the data and described the characteristics of the sample with frequency (n) and percentage (%). Inferential statistics included Chi square or Fisher's Exact test, Cramér's V test and logistic regression model.

#### *9.3.4.1 Preparation of variables for inferential analysis – Collapsing*

The dependent variables related to cancer beliefs were dichotomised, with "agree/strongly agree" versus "disagree/strongly disagree". Independent variables were also re-categorised by collapsing categories with similar patterns to ensure adequate group size for valid inferential analysis. Age was grouped into three groups: <50, 50-70, >70. This classification was informed by the commonly accepted definitions of younger adults, middle-aged adults, and older adults (National Health Service, 2024). Education level was dichotomised into below bachelor's degree and bachelor's degree or higher. This threshold was selected as university level education is associated with health outcomes (Willetts, 2023). Considering ethnic Chinese immigrant patterns in the UK (Chapter 2), place of birth was collapsed into three groups: mainland China, Hong Kong, and other regions with Chinese heritage.

#### *9.3.4.2 Chi square or Fisher's Exact test*

Both the dependent and independent variables were categorical, Chi square tests or Fisher's Exact tests (applied when expected cell counts were less than 5) were used to assess significant relationships between variables (Polit, 2014). These non-parametric bivariate tests served as the first step in addressing the third objective of this survey to identify and estimate the likelihood of cancer-related misconceptions among different demographic subgroups.

#### *9.3.4.3 Logistic regression model*

Logistic regression models were applied in addition to the Chi square or Fisher Exact tests, as it allows adjustment for potential confounders and enables the identification of predictors that remain statistically significant after controlling for other variables (Polit, 2014). Only variables that showed statistical significance in the Chi-square or Fisher's exact tests were included in the logistic regression model. This approach provided a more in-depth means of addressing the third objective of this Phase 5 survey.

Given the potential influence of age on years of immigrant and employment status, Cramér's V was applied as a step to identify potential overlap among independent variables and thereby minimise the risk of multicollinearity, ensuring stability in the subsequent logistic regression model. Cramér's Values between 0.10 and 0.30 suggest a weak association, 0.30 to 0.50 indicate a moderate association, and values above 0.50 reflect a strong association (Polit, 2014). Finally, age was included as the primary

independent variable in the inferential statistics, whereas years of immigration and employment status were considered affiliated variables and excluded for further analysis.

For the logistic regression, all covariates were treated as binary, expect for age, which was analysed as a categorical variable with " >70 years" used as the reference category in the SPSS analysis. For gender and education level, the default SPPS coding was applied, whereby the category with smaller numeric code was used as the reference group. The codes of dependents and covariates in the logistic regression model presented in Table 9-1.

Table 9-1 Codes of dependent and independent variables in logistic regression model

| Variable | Category | Code |
|---|---|---|
| Dependent variable | | |
| | Disagree | 0 |
| | Agree | 1 |
| Covariates | | |
| Age (Ref: >70) | < 50 years | 1 |
| | 50–70 years | 2 |
| | > 70 years | 3 |
| Gender | Female | 1 |
| | Male | 2 |
| Education level | Below bachelor's degree | 1 |
| | Bachelor's degree or higher | 2 |

#### *9.3.4.4 P Value*

Inferential statistical tests generate a probability value (P value), indicating the likelihood that the null hypothesis is true (Kotronoulas et al., 2023). The P value < 0.05 shows that there is strong evidence to reject the null hypothesis and suggests a plausible association between the variables, otherwise, P > 0.05 has no difference to conclude an association (Polit, 2014). The threshold of P=0.05 was considered as failure to reject null hypothesis in this survey.

### 9.3.5 Ethical considerations

#### *9.3.5.1 Ethics approval*

The amendment for Phase 5 survey was submitted on 23rd May 2024 and approved by University of Glasgow College of MVLS Ethic Committee on 31st May 2024 (Appendix 9).

#### *9.3.5.2 Informed consent*

Attendees attending the "Cancer Talk" sessions were provided with printed copies of the participant information sheet and privacy notice (Appendix 10) in either traditional,

simplified Chinese or English version upon arrival. Attendees were instructed to read these documents and confirm their consent to participate by selecting a checkbox on the top of the questionnaire before the “Cancer Talk” session started. Returning the completed questionnaire was taken as an indication of informed consent to participate in the survey.

#### *9.3.5.3 Data management plan*

In contrast to the previous three phases, which were conducted online, the Phase 5 survey used a face-to-face and paper-based data collection approach. The completed paper questionnaires were securely stored in a locked cabinet in the office, while the electronic dataset was stored in Excel and SPSS files on OneDrive. The paper questionnaires were retained for one month and were permanently destroyed upon completion of this study.

#### *9.3.5.4 Confidentiality and anonymity*

This was an anonymous survey with no identifiable information gathered. Participants were instead assigned unique identification numbers, which were used in study documentation and for dataset development for analysis purposes.

## 9.4 Results

### 9.4.1 Questionnaire distribution and response

Data were collected from four ethnic Chinese communities between June and July 2024 and from parents at the Glasgow Chinese School in November 2024. A total of 142 questionnaires were returned: 29 from the elderly centre, 41 from the women’s association, 20 from Glasgow Chinese School and 52 from two general communities. One respondent was under the age of 18, and this response was excluded. Therefore, 141 responses were considered valid. Because of the customised approach to invite people to participate and complete the survey as part of attending an educational session, the response rate was 100% across all communities.

### 9.4.2 Demographic profile of the respondents

Among the 141 participants, 84.4% were women, 43.2% were aged 50–70 years, and 58.9% were retired. Over than half (59.6%) were born in Hong Kong, and 65.2% had lived in Scotland for more than 20 years. Overall, education levels were relatively low, with 33.3% having completed only primary school and only 21.9% having attained a university degree or higher. In terms of cancer knowledge, 68.7% of participants reported knowing only “a little bit” about cancer, while 29.1% reported knowing “nothing”. Table 9-2 presents the demographic results of the participants.

Table 9-2 Demographic results of the Phase 5 survey

| **Variables** | **Categories** | **N** | **Percent (%)** |
|---|---|---|---|
| Age | < 30 | 4 | 2.8 |
| | 31-40 | 4 | 2.8 |
| | 41-50 | 24 | 17.0 |
| | 51-60 | 16 | 11.3 |
| | 61-70 | 45 | 31.9 |
| | > 70 | 48 | 34.0 |
| Gender | Female | 119 | 84.4 |
| | Male | 22 | 15.6 |
| Place of Birth | Hong Kong | 84 | 59.6 |
| | Mainland China | 44 | 31.2 |
| | Malaysia | 5 | 3.6 |
| | Macao | 4 | 2.8 |
| | Brunei | 2 | 1.4 |
| | Indonesia | 1 | 0.7 |
| | Singapore | 1 | 0.7 |
| Years living in Scotland | < 5 years | 23 | 16.3 |
| | 5-10 years | 8 | 5.7 |
| | 10-15 years | 5 | 3.5 |
| | 15-20 years | 13 | 9.2 |
| | > 20 years | 92 | 65.2 |
| Educational Level | Never been educated | 6 | 4.3 |
| | Primary School | 47 | 33.3 |
| | Junior High School | 25 | 17.7 |
| | High School | 32 | 22.7 |
| | Bachelor’s Degree | 15 | 10.6 |
| | Master’s Degree | 14 | 9.9 |
| | Doctoral Degree | 2 | 1.4 |
| Employment Status | Retired | 83 | 58.9 |
| | Unemployed | 26 | 18.4 |
| | Employed Part-Time | 26 | 18.4 |
| | Employed Full-Time | 6 | 4.3 |
| Confidence about cancer knowledge level | I know a little | 97 | 68.8 |
| | I know nothing | 41 | 29.1 |
| | I know a lot | 3 | 2.1 |

### 9.4.3 Knowledge of cancer and cancer services

Nearly half of the participants (49.6%) recognised all six symptoms. However, 10.6% did not recognise any of the six symptoms. In addition, 24.8% recognised one to three of the listed symptoms, while 15.0% recognised four to five symptoms (Figure 9-3).

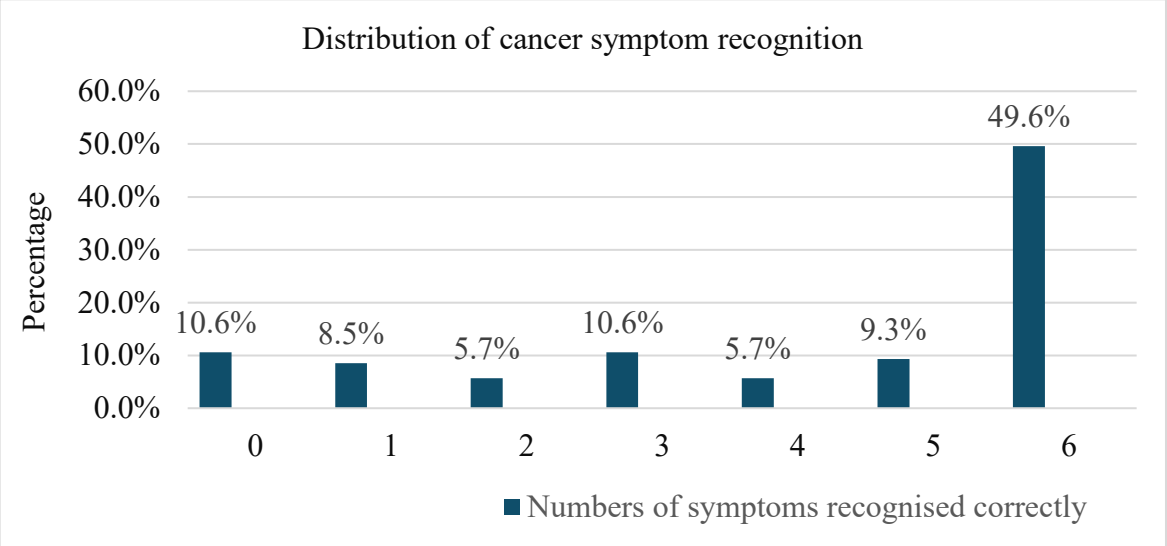



Figure 9-3 Distribution of cancer symptom recognition

Unexplained weight loss was the most recognised sign of cancer (80%), followed by an unexplained lump or swelling (78%). Unexplained bleeding and a change in the appearance of a mole were recognised by 70% and 67% of participants, respectively. The least recognised symptoms were persistent cough or hoarseness (60%) and persistent difficulty swallowing (64%) (Figure 9-4).

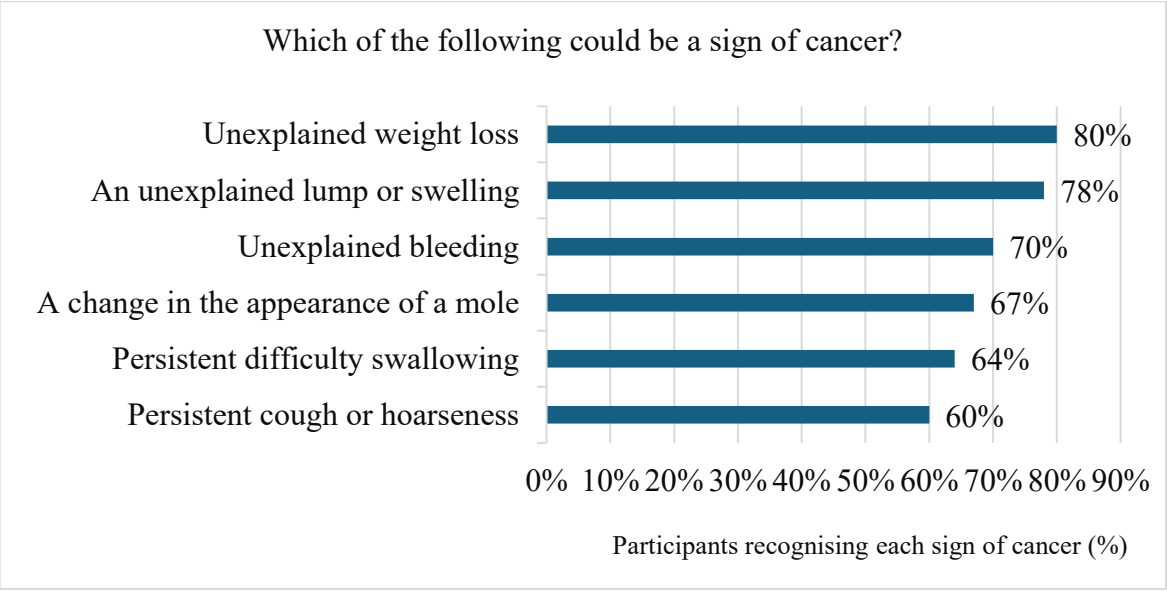



Figure 9-4 Results of cancer symptom awareness

Only 26% of participants (n = 37) had heard of local cancer organisations, charities, or campaigns, and only 16 of them were able to name one, with Cancer Research UK being the most frequently mentioned. Among these 37 participants, nearly half (48%) reported obtaining this information through local communities, followed by social media (22%), the internet (11%), and people they knew, such as family members or friends (19%).

### 9.4.4 Prevalent beliefs about cancer

Fifty-eight per cent of participants agreed that "*Cancer is like a death sentence*", followed by 37% who agreed that cancer cannot be treated even with advanced medical technology. Nearly one-third (34%) agreed that recovery after cancer is difficult, while 29% seemed to believe in fate and as such that getting cancer cannot be prevented. Only a small proportion of respondents (between 5% and 16%) agreed with statements that indicated discriminatory attitudes towards people with cancer. The detailed survey results on cancer beliefs are presented in Table 9-3.

Table 9-3 Prevalence of unhelpful cancer beliefs among ethnic Chinese immigrants

| **Unhelpful beliefs about cancer** | **Responses to statement: n (%)** | |
|---|---|---|
| | Agree/Strongly Agree | Disagree/ Strongly Disagree |
| Cancer is like a death sentence. | 81 (58%) | 60 (42%) |
| It is impossible to treat cancer regardless of highly developed medical science. | 52 (37%) | 89 (63%) |
| It is very difficult to be healthy again once a person is diagnosed with cancer. | 49 (34%) | 92 (66%) |
| If people's fate is to get cancer, they will get cancer and there is nothing they can do to change fate. | 41 (29%) | 100 (71%) |
| Thinking of cancer will cause it to happen. | 28 (20%) | 113 (80%) |
| People with cancer are easily recognised through their looks. | 23 (16%) | 118 (84%) |
| I feel uncomfortable when I am with someone who has cancer. | 16 (12%) | 125 (88%) |
| People with cancer would not be able to make contributions to society. | 10 (7%) | 131 (93%) |
| I would avoid interacting with people who have cancer. | 6 (5%) | 135 (95%) |

### 9.4.5 Behaviours of cancer prevention

A total of 65%, 61%, and 46% of participants were aware of the Scottish cancer screening programmes for breast, cervical, and bowel cancer, respectively. Nearly half (46%) of participants reported receiving cancer-related information from ethnic Chinese communities, and 63% indicated they would be more willing to follow cancer screening recommendations from their general practitioner (GP). Details for these results are presented in Table 9-4.

Table 9-4 Awareness, preference and channels to receive cancer prevention information

| **Awareness, preference and channels to receive cancer prevention information** | | **N (%)** |
|---|---|---|
| Knowledge about cancer screening programmes in Scotland | Breast Cancer | 92 (65) |
| | Cervical Cancer | 86 (61) |
| | Bowel Cancer | 65 (46) |
| | I do not know | 35 (25) |
| | Liver Cancer | 22 (16) |
| | Prostate Cancer | 22 (16) |
| | Lung Cancer | 20 (14) |
| If someone informed me about cancer screening, I would be more willing to undergo it. | My GP | 89 (63) |
| | My family | 33 (23) |
| | Ethnic Chinese community | 29 (21) |
| | My friend | 18 (13) |
| Channels for obtaining information about cancer and cancer prevention | Local community | 65 (46) |
| | Internet | 62 (44) |
| | Friends/ Family | 49 (35) |
| | News on the TV/ Newspaper | 49 (35) |
| | Fundraising initiatives by cancer charities | 30 (21) |
| | Advertisement about cancer prevention | 27 (19) |

Regarding intentions to engagement of cancer prevention behaviours, 78% of participants disagreed that cancer screening is unnecessary if a person feels well. However, only 63% recognised early detection as an important strategy for reducing cancer risk, whereas 87% believed that eating healthy food was important. Fear of screening results (32%) was the most reported subjective pressure when deciding to engage in cancer screening. Self-perceived difficulty in booking a doctor's appointment (62%) and lack of confidence in speaking with doctor (55%) were commonly reasons for them decided to delayed help seeking. Details of the intention to engage with cancer prevention behaviours are presented in Table 9-5.

Table 9-5 Intention to engage with cancer prevention behaviours

| **Theory of planned behaviour dimensions** | **Item** | **Response option** | **N (%)** |
|---|---|---|---|
| Attitude | If I feel well, I do not need to get cancer screening | Disagree/Strongly disagree | 110 (78) |
| | | Agree/Strongly agree | 31 (22) |
| | Strategies to reduce the risk of cancer | Eating healthy food | 123 (87) |
| | | Engage in regular exercise | 96 (68) |
| | | Getting tested to find cancer early | 89 (63) |
| | | Not smoking | 86 (61) |
| | | Not being exposed to someone's smoke | 76 (54) |
| | | Limited alcohol consumption | 75 (53) |
| | | Maintaining a healthy weight | 75 (53) |
| | | I cannot do anything to prevent cancer | 3 (2) |
| Subjective norms | The reasons to prevent you attending cancer screening programs | I would be worried what the doctor might find | 45 (32) |
| | | None can stop me | 37 (26) |
| | | I do not have symptoms, so why get tested for cancer? | 27 (19) |
| | | Tests might be painful | 26 (18) |
| | | I do not understand what the tests do | 26 (18) |
| | | Getting tested takes a lot of time | 24 (17) |
| | | I do not know if the tests are safe | 23 (16) |
| | | Getting tested is expensive | 21 (15) |
| | | What my friends or family think about these tests | 11 (8) |
| | | My religious faith | 3 (2) |
| Perceived behavioural control | Reasons that might cause you to delay seeing a doctor | It would be difficult to make an appointment with my doctor | 87(62) |
| | | I would not feel confident talking about my symptoms with the doctor | 78(55) |
| | | I have too many other things to worry about | 55 (39) |
| | | I would be scared | 39 (28) |
| | | I would be worried about wasting the doctor's time | 27 (19) |
| | | It would be difficult for me to arrange transport to go to the doctor | 25 (18) |

### 9.4.6 Correlation between age, years of immigration, and employment status

There was a statistically significant correlation between age groups and years since immigration ($p< 0.001$), indicating a strong relationship (Cramér's $V=0.57$, $p< 0.001$). The Liner-by-liner association showed a significant ordinal trend (Person $\chi^2= 42.54$, $p< 0.001$), suggesting that older individuals were more likely to have lived in Scotland for a longer period. Similarly, there is a statistically significant correlation between age group and employment status ($p< 0.001$), indicating a strong relationship (Cramér's $V=0.54$, $p< 0.001$). The Line-by-liner association showed a significant ordinal trend (Person $\chi^2=73.80$, $p< 0.001$), suggesting that older participants were more likely to be retired. After the Cramér's V test, the employment status and years of immigration was excluded for the further inferential analysis. Table 9-6 presents the details of this correlation.

Table 9-6 Correlation between age and years of immigration

| **Variable** | | **< 50 years, (n)** | **50-70 years, (n)** | **> 70 years, (n)** | **Pearson $\chi^2$ ; P value** | **Linear-by linear** | **Cramer's V; P value** |
|---|---|---|---|---|---|---|---|
| Years of immigration | < 20 years | 26 | 19 | 4 | 45.64; 0.00 | 42.54; 0.00 | 0.57; 0.00 |
| | > 20 years | 6 | 42 | 44 | | | |
| Employment status | Retired | 0 | 38 | 45 | 83.61; 0.00 | 73.80; 0.00 | 0.54; 0.00 |
| | Un-employed | 6 | 12 | 3 | | | |
| | Employed | 26 | 11 | 0 | | | |

### 9.4.7 Association between age and cancer beliefs

Participants aged over 70 years were significantly more likely to agree that diagnosis of cancer is related to fate and cannot be prevented ($p=0.002$). Participants aged 50-70 years were more likely to believe that "*Cancer is like a death sentence*" (65.6%), followed by those over 70 years old (56.3%). There was also a statistically significant association between age and the discriminatory belief that a cancer diagnosis could lead to social discrimination ($p=0.001$). However, the number of participants who agreed with this statement was very small ($n=10$), and none of those aged under 50 years endorsed it. As a result, this finding has limited interpretive value. Table 9-7 presents the detailed cross-tabulation between age and beliefs of cancer.

Table 9-7 Association between age and cancer beliefs

| **Statements** | **Respondents agreeing or strongly agreeing to the statement by age group (n, %)** | | | **Test statistic; P value** |
|---|---|---|---|---|
| | **< 50** | **50-70** | **>70** | |
| 1. It is impossible to treat cancer regardless of highly developed medical science. | 6, 18.8 | 26, 42.6 | 20, 41.7 | 5.86; 0.054 |
| 2. Cancer is like a death sentence | 14, 43.8 | 40, 65.6 | 27, 56.3 | 4.13; 0.127 |
| 3. If people's fate is to get cancer, they will get cancer and there is nothing they can do to change fate. | 2, 6.3 | 20, 32.8 | 19, 39.6 | **0.002** |
| 4. Thinking of cancer will cause it to happen. | 6, 18.8 | 15, 24.6 | 7, 14.6 | 1.72; 0.423 |
| 5. It is very difficult to be healthy again once a person is diagnosed with cancer. | 9, 28.1 | 19, 31.1 | 21, 43.8 | 2.68; 0.261 |
| 6. People with cancer are easily recognised through their looks | 6, 18.8 | 7, 11.5 | 10, 20.8 | 1.93; 0.386 |
| 7. People with cancer would not be able to make contributions to society. | 0, 0.0 | 1, 1.6 | 9, 18.8 | **0.001** |
| 8. I feel uncomfortable when I am with someone who has cancer. | 1, 3.1 | 8, 13.1 | 7, 14.6 | 0.235 |
| 9. I would avoid interacting with people who have cancer. | 2, 6.3 | 3, 4.9 | 1, 2.1 | 0.660 |

### 9.4.8 Association between gender and cancer beliefs

Female participants were more likely than males to believe that cancer was a death sentence ($p = 0.029$), with 61.3% of females agreeing or strongly agreeing compared with 36.4% of males. Females were more likely than males to believe that cancer could not be treated ($p=0.016$), with 41.2% of females agreeing compared with 13.6% of males. Detailed cross-tabulations between gender and cancer beliefs are presented in Table 9-8.

Table 9-8 Association between gender and cancer beliefs

| **Statement** | **Respondents agreeing or strongly agreeing to the statement by gender group (n, %)** | | **Test statistic; P-value** |
|---|---|---|---|
| | **Female** | **Male** | |
| 1. It is impossible to treat cancer regardless of highly developed medical science. | 49, 41.2 | 3, 13.6 | **0.016** |
| 2. Cancer is like a death sentence. | 73, 61.3 | 8, 36.4 | 4.740; **0.029** |
| 3. If people's fate is to get cancer, they will get cancer and there is nothing they can do to change fate. | 36, 30.3 | 5, 22.7 | 0.510; 0.475 |
| 4. Thinking of cancer will cause it to happen. | 24, 20.2 | 4, 18.2 | 1.000 |
| 5. It is very difficult to be healthy again once a person is diagnosed with cancer. | 45, 37.8 | 4, 18.2 | 0.091 |
| 6. People with cancer are easily recognised through their looks. | 19, 16.0 | 4, 18.2 | 0.759 |
| 7. People with cancer would not be able to make contributions to society. | 10, 8.4 | 0, 0.0 | 0.362 |
| 8. I feel uncomfortable when I am with someone who has cancer. | 15, 12.6 | 1, 4.5 | 0.467 |
| 9. I would avoid interacting with people who have cancer. | 5, 4.2 | 1, 4.5 | 1.000 |

### 9.4.9 Association between education level and cancer beliefs

Education level has association with the belief to viewing cancer as a death sentence (p=0.048) and getting cancer related to "fate" (p=0.026). These two beliefs about cancer were more prevalent among participants with below-bachelor's degree education than among those with a bachelor's degree or higher (61.8% vs 41.9% and 33.6% vs 12.9%, respectively). Detailed cross-tabulations between education level and cancer beliefs are presented in Table 9-9.

Table 9-9 Association between education level and cancer beliefs

| **Statements** | **Respondents agreeing or strongly agreeing to the statement by education level (n, %)** | | **Test statistic; P-value** |
|---|---|---|---|
| | **Below bachelor's degree** | **Bachelor's or above degree** | |
| 1. It is impossible to treat cancer regardless of highly developed medical science. | 45, 40.9 | 7, 22.6 | 3.490; 0.062 |
| 2. Cancer is like a death sentence | 68, 61.8 | 13, 41.9 | 3.911; **0.048** |
| 3. If people's fate is to get cancer, they will get cancer and there is nothing they can do to change fate. | 37, 33.6 | 4, 12.9 | **0.026** |
| 4. Thinking of cancer will cause it to happen. | 21, 19.1 | 7, 22.6 | 0.185; 0.667 |
| 5. It is very difficult to be healthy again once a person is diagnosed with cancer. | 39, 35.5 | 10, 32.3 | 0.109; 0.741 |
| 6. People with cancer are easily recognised through their looks. | 16, 14.5 | 7, 22.6 | 1.144; 0.285 |
| 7. People with cancer would not be able to make contributions to society. | 9, 8.2 | 1, 3.2 | 0.691 |
| 8. I feel uncomfortable when I am with someone who has cancer. | 15, 13.6 | 1, 3.2 | 0.195 |
| 9. I would avoid interacting with people who have cancer. | 4, 3.6 | 2, 6.5 | 0.613 |

### 9.4.10 Prediction models for cancer beliefs

Predictors were identified in Model 1 for the belief that cancer is untreatable, and in Model 3 for the belief that a cancer is not preventable. In Model 1, gender emerged as a predictor (Wald=4.612, Sig=0.032), with males being less likely than females to believe that cancer is an incurable disease (OR=0.234, Sig=0.032, 95% CI 0.062, 0.881). In Model 3, age was a predictor (Wald=6.388, Sig=0.041), with under 50 years less likely than those over 70 years to believe that diagnosis with cancer related to their fate and cancer cannot be preventable (OR=0.127, Sig=0.012, 95% CI 0.026, 0.630). Although the 50–70 age group showed a statistically significant result in Model 7 (OR=0.070, p=0.012, 95% CI 0.008, 0.580), the number of respondents who agreed with this discriminatory belief about cancer was very small (n=10), compared with those who disagreed (n=131). This imbalance resulted in sparse data and reduced the power of this model and limited the interpretability of the finding. Full details of the regression models are presented in Table 9-10.

Table 9-10 Prediction models for cancer beliefs

Model 1:

| **It is impossible to treat cancer regardless of highly developed medical science** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B[1] | S.E. [2] | Wald[3] | df[4] | Sig[5] | EXP (B) [6] | 95% CI[7] for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | 1.413 | .890 | 2.522 | 1 | .112 | 4.108 | | |
| Age (Ref > 70) | | | 4.004 | 2 | .135 | | | |
| < 50 | -1.077 | .591 | 3.316 | 1 | .069 | .341 | .107 | 1.086 |
| 50-70 | .041 | .400 | .010 | 1 | .919 | 1.042 | .475 | 2.283 |
| Gender | -1.450 | .675 | 4.612 | 1 | **.032** | .234 | .062 | .881 |
| Education level | -.112 | .554 | .041 | 1 | .839 | .894 | .301 | 2.649 |
| Note: Mode Chi-square = 3.280, df=5, P= .657 | | | | | | | | |

Model 2:

| **Cancer is like a death sentence** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | Sig | EXP (B) | 95% CI for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | 1.688 | .741 | 5.192 | 1 | .023 | 5.408 | | |
| Age (Ref > 70) | | | 2.402 | 2 | .301 | | | |
| < 50 | -.331 | .511 | .421 | 1 | .516 | .718 | .264 | 1.953 |
| 50-70 | .405 | .404 | 1.007 | 1 | .316 | 1.499 | .680 | 3.308 |
| Gender | -.910 | .509 | 3.193 | 1 | .074 | .402 | .148 | 1.092 |
| Education level | -.349 | .486 | .516 | 1 | .473 | .705 | .272 | 1.829 |
| Note: Mode Chi-square = 6.035, df= 5, P= .303 | | | | | | | | |

Model 3:

| **If people's fate is to get cancer, they will get cancer and there is nothing they can do to change fate** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | Sig | EXP (B) | 95% CI for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | .416 | .886 | .220 | 1 | .639 | 1.516 | | |
| Age (Ref > 70) | | | 6.388 | 2 | .041 | | | |
| < 50 | -2.064 | .817 | 6.378 | 1 | **.012** | .127 | .026 | .630 |
| 50-70 | -.304 | .404 | .566 | 1 | .452 | .738 | .334 | 1.629 |
| Gender | -.178 | .596 | .089 | 1 | .766 | .837 | .260 | 2.693 |
| Education level | -.570 | .646 | .778 | 1 | .378 | .566 | .159 | 2.006 |
| Note: Mode Chi-square = 4.254 , df= 5, P= .513 | | | | | | | | |

[1] B= Regression coefficient
[2] S.E.= Standard Error of B
[3] Wald= Chi-square test of whether a coefficient differs from zero
[4] df= Degrees of freedom
[5] Sig. = P value
[6] EXP (B)= Odds Ratio
[7] CI= Confidence Interval

Model 4:

| Thinking of cancer will cause it to happen | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | Sig | EXP (B) | 95% CI for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | -1.936 | .915 | 4.481 | 1 | .034 | .144 | | |
| Age (Ref > 70) | | | 1.923 | 2 | .382 | | | |
| < 50 | .127 | .667 | .036 | 1 | .849 | 1.135 | .307 | 4.198 |
| 50-70 | .656 | .507 | 1.675 | 1 | .196 | 1.927 | .714 | 5.202 |
| Gender | -2.65 | .639 | .172 | 1 | .678 | .767 | .219 | 2.681 |
| Education level | .413 | .592 | .486 | 1 | .486 | 1.511 | .473 | 4.822 |
| Note: Mode Chi-square = 2.704, df= 5, P= .746 | | | | | | | | |

Model 5:

| It is very difficult to be healthy again once a person is diagnosed with cancer | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | Sig | EXP (B) | 95% CI for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | .630 | .820 | .590 | 1 | .442 | 1.877 | | |
| Age (Ref > 70) | | | 2.888 | 2 | .236 | | | |
| < 50 | -.808 | .548 | 2.175 | 1 | .140 | .446 | .152 | 1.305 |
| 50-70 | -.547 | .407 | 1.813 | 1 | .178 | .578 | .261 | 1.283 |
| Gender | -1.105 | .614 | 3.243 | 1 | .072 | .331 | .099 | 1.103 |
| Education level | .328 | .523 | .394 | 1 | .530 | 1.389 | .498 | 3.872 |
| Note: Mode Chi-square = 6.011 , df= 5, P= .305 | | | | | | | | |

Model 6:

| People with cancer are easily recognised through their looks | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | Sig | EXP (B) | 95% CI for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | -1.945 | .926 | 4.416 | 1 | .036 | .143 | | |
| Age (Ref > 70) | | | 1.735 | 2 | .420 | | | |
| < 50 | -.388 | .646 | .360 | 1 | .548 | .679 | .191 | 2.406 |
| 50-70 | -.705 | .538 | 1.719 | 1 | .190 | .494 | .172 | 1.418 |
| Gender | -.023 | .644 | .001 | 1 | .972 | .978 | .277 | 3.452 |
| Education level | .557 | .606 | .843 | 1 | .359 | 1.745 | .532 | 5.728 |
| Note: Mode Chi-square = 2.867, df= 4, P= .580 | | | | | | | | |

Model 7:

| People with cancer would not be able to make contributions to society | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | Sig | EXP (B) | 95% CI for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | 17.305 | 7683.413 | .000 | 1 | .998 | 32779776.791 | | |
| Age (Ref > 70) | | | 6.076 | 2 | **.048** | | | |
| < 50 | -19.698 | 6869.133 | .000 | 1 | .998 | .000 | .000 | |
| 50-70 | -2.660 | 1.079 | 6.076 | 1 | **.014** | .070 | .008 | .580 |
| Gender | -18.677 | 7683.413 | .000 | 1 | .998 | .000 | .000 | |
| Education level | .094 | 1.194 | .006 | 1 | .938 | 1.098 | .106 | 11.392 |
| Note: Mode Chi-square = .069, df= 5, P= 1.000 | | | | | | | | |

Model 8:

| I feel uncomfortable when I am with someone who has cancer | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | Sig | EXP (B) | 95% CI for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | .169 | 1.561 | .012 | 1 | .914 | 1.184 | | |
| Age (Ref > 70) | | | 1.366 | 2 | .505 | | | |
| < 50 | -1.332 | 1.141 | 1.364 | 1 | .243 | .264 | .028 | 2.469 |
| 50-70 | -.141 | .562 | .063 | 1 | .802 | .869 | .289 | 2.614 |
| Gender | -.850 | 1.089 | .609 | 1 | .435 | .427 | .051 | 3.614 |
| Education level | -.915 | 1.125 | .661 | 1 | .416 | .401 | .044 | 3.634 |
| Note: Mode Chi-square = 2.492, df= 4, P= .646 | | | | | | | | |

Model 9:

| I would avoid interacting with people who have cancer | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | Sig | EXP (B) | 95% CI for EXP (B) | |
| | | | | | | | Lower | Upper |
| Constant | -4.269 | 1.838 | 5.393 | 1 | .020 | .014 | | |
| Age (Ref > 70) | | | .652 | 2 | .722 | | | |
| < 50 | .925 | 1.346 | .427 | 1 | .492 | 2.521 | .180 | 35.236 |
| 50-70 | .897 | 1.172 | .585 | 1 | .444 | 2.452 | .246 | 24.394 |
| Gender | -.123 | 1.195 | .011 | 1 | .918 | .884 | .085 | 9.200 |
| Education level | .486 | 1.089 | .199 | 1 | .656 | 1.625 | .192 | 13.748 |
| Note: Mode Chi-square = 5.903, df= 5, P= .316 | | | | | | | | |

## 9.5 Discussion

### 9.5.1 Summary of main findings

This is the first known study to access knowledge and beliefs about cancer and intentions to engage in cancer prevention among ethnic Chinese immigrants in Scotland.

The main findings related to knowledge of cancer and cancer services included:

- Only a small proportion of the ethnic Chinese public were aware of supportive cancer care services in Scotland.
- Recognition of cancer signs appeared to be reasonable, with half of sample able to identify all six listed signs.
- "Persistent cough or hoarseness" was the least recognised cancer-related symptom.

The main findings related to beliefs and about cancer included:

- The most prevalent fatalistic belief about cancer is "cancer is like a death sentence".
- Age, gender and education level had an association with fatalistic beliefs about cancer.

The main findings related to intentions to engage in cancer prevention included:

- Fear of cancer screening results, limited understanding of the importance of early cancer detection, and self-perceived difficulties in accessing services contributed to reluctance to engage in cancer prevention.
- Community organisations play a key role in providing cancer-related information, and individuals are more willing to attend cancer screening when it is recommended by their GP.

### 9.5.2 Explanation of sample characteristics

Most of the respondents were older female and this may be due in part to data being collected from the Chinese women association and elderly centre. However, Conway et al. (2014) also reported gender gaps in participation between male and female members of the Chinese population in England, despite their study not being subject to the same recruitment bias. The influence of masculinity and prevailing social norms have been documented as contributing to men's lower awareness of and engagement with healthcare services (Davis et al., 2012). Apart from the significant gender disparities of this survey, 84

out of 141 participants in this survey were from Hong Kong. This result reflect the historical migration ties between Hong Kong and UK, stemming from the colonial relationship between the two regions, as Hong Kong was a British colony until its return to China in 1997 (Cohen, 2007).

### 9.5.3 Connection with previous phases and literatures

In the previous phases, patients, informal caregivers, and health and social care professionals consistently reported that cancer was often viewed negatively within ethnic Chinese communities and remained a topic of silence. In the Phase 5 survey, this issue was explored within the ethnic Chinese communities, and fatalistic beliefs about cancer were identified. Similar patterns have also been observed among Chinese Americans and other Asian immigrant populations, including Korean communities (Crawford et al., 2016; Guo et al., 2021). However, this result contrasts with a survey of UK adults, which found that a larger proportion of respondents held optimistic attitudes towards cancer (Quaife et al., 2015).

Earlier phases of this project highlighted that diet was perceived as a central component of health among patients. The current survey reported that 87% of ethnic Chinese public considered diet to play a major role in cancer prevention, in comparison with smoking cessation and early cancer screening. Similar results were also found from ethnic Chinese people living in England (Conway et al., 2014). Additionally, in the Phase 5 survey, awareness of supportive cancer care services was limited, as 74% of sample reported that they had never heard of any supportive cancer care organisations. Individuals from minority groups may feel that they are healthy and ageing well and therefore do not need to know about these services (Liu et al., 2021). This finding may help understand the recruitment challenges encountered in the Phase 2 survey (Chapter 6) and Phase 3 in-depth interviews (Chapter 7), when recruitment for patients and informal caregivers was initially reliant on local supportive cancer care organisations.

### 9.5.4 Novel findings of this survey

#### *9.5.4.1 Differences in beliefs about cancer by gender, age, and education level*

The survey identified that fatalistic beliefs about cancer varied across the demographic subgroups, such as gender, age and education differences. Similarly, a UK population study found that lower education level was associated with negative cancer beliefs (Quaife et al., 2015). Individuals with lower education level may have a lower understanding of and exposure to scientific information about improvement of cancer outcomes (Fleary et al.,

2019). The survey reported that females and older age also contribute to the difference in beliefs about cancer, this is similar to the fatalistic beliefs also reported in Korean population (Cho et al. 2013) but contrasts with previous research conducted in the UK and USA, where no association was found between gender or age (Quaife et al. 2015; Sarma et al. 2021). As the survey sample was imbalanced by gender, with 119 female and 22 male participants, the gender-related finding may has limited interpretation power.

#### *9.5.4.2 Knowledge of cancer and intention to engage in cancer prevention among ethnic Chinese immigrants*

Among the sample of ethnic Chinese immigrants, nearly half were able to identify all six listed signs. The early sign of lung cancer "Persistent cough or hoarseness" had the least awareness among all six signs. This finding is consistent with a qualitative study in Australia, which reported low awareness of lung cancer signs among Chinese, Vietnamese, and Arab communities, with the exception of haemoptysis (coughing up blood) (Scott et al., 2014).

In this survey, the self-reported cancer screening uptake among ethnic Chinese immigrants is lower than the Scottish national average: breast cancer screening at 55% (compared to 73%), cervical cancer screening at 48% (compared to 68.7%), and bowel cancer screening at 52% (compared to 67%) (Scottish Government, 2022a). The lower cancer screening participation among ethnic minority groups is not limited to Scotland but is also observed in other very high HDI western countries. For example, Guo et al. (2021) reported that approximately 20% of Chinese American women had never received a Pap smear or mammography screening. And immigrant women residing in Australia had 1% to 16% lower screening rates compared with Australian-born women, with South Asian women showing significantly lower participation (Alam et al., 2021). In this survey, the intention to engage in cancer prevention was interpreted by the theory of planned behaviour, and it appeared to be influenced by fear of cancer screening results (subjective norms), limited awareness of the importance of early detection (attitude), and self-perceived difficulty in accessing services (perceived behavioural control).Previous literature shows that fatalistic beliefs contribute to healthcare avoidance, lower cancer screening uptake, and fear of help seeking (Moser et al., 2014; Jung et al., 2018).

### 9.5.5 Strengths and limitations

The strengths of the Phase 5 survey included community collaboration and the embedding of data collection within the "Cancer Talk" sessions. These approaches created reciprocal benefits for both participants and researchers. In addition, within the overall project, the development purpose of the mixed-methods design informed the development of the data collection instrument. The survey items were explicitly developed to address the objectives of this phase and to contribute to the overall aims of the project.

Several limitations relating to sampling and methodological rigour should be acknowledged. First, two of the participating communities were demographically specific: a women's association and an elderly centre. This contributed to an imbalanced final sample. Secondly, the survey was conducted only in the Greater Glasgow area. This geographic restriction resulted from the limited budget of this project and the reliance on accessible communities through existing networks for data collection. The findings may have some relevance to Edinburgh because its demographic profile is similar to Glasgow. However, the findings may not be generalisable to ethnic Chinese immigrants living in rural areas. Finally, the data collection instrument was a study-specific, literature-informed questionnaire rather than a formally validated psychometric instrument. The absence of pilot testing and formal psychometric validation represents a methodological limitation and may have affected the validity and reliability of the findings. Therefore, the results should be interpreted with appropriate caution.

### 9.5.6 Recommendations

To reduce late cancer diagnosis, Scotland's new 10-year cancer strategy should consider developing initiatives to provide educational sessions for ethnic Chinese communities and raise awareness of the importance of early cancer detection. These initiatives could adopt an approach similar to the "Cancer Talk" sessions delivered as part of the data collection for this survey. Conducting similar research across Scotland, including in rural communities could provide an opportunity to examine whether area of residence contributes to disparities in cancer-related knowledge, beliefs, and intentions to engage in cancer prevention.

Participants in this survey valued the role of community organisations in providing cancer-related information. However, because the survey used a community-based recruitment approach, many participants were already actively engaged with community activities. Therefore, future research should include individuals who are socially isolated or less

engaged with ethnic Chinese community organisations, to explore their views on the role of community support in cancer prevention. By using the theory of planned behaviour to interpret the findings, this survey identified avoidant and reluctant intentions towards early cancer detection among ethnic Chinese immigrants. These intentions may contribute to inequalities in cancer outcomes. Future research should develop and evaluate relevant behaviour change interventions to address such avoidance and reluctance.

Finally, in recognition of the limitations associated with the study-specific, self-designed data collection instrument, formal pilot testing and psychometric evaluation are recommended. Researchers with expertise in scale development could consider developing a validated instrument to assess cancer-related beliefs, knowledge, and intentions to engage in cancer prevention behaviours among populations from Chinese cultural backgrounds. These approaches would help establish the validity and reliability of the instrument for future use.

## 9.6 Chapter summary

The final phase of this project explored the knowledge, beliefs and intention to engage in cancer prevention among ethnic Chinese immigrants in Glasgow. As the interview results (Chapter 7) and focus group results (Chapter 8) highlighted cancer taboo and silence around discussing cancer within ethnic Chinese communities, the Phase 5 survey examined these beliefs among members of the public and found that fatalistic beliefs about cancer were common, particularly the belief that cancer is like a death sentence. Ethnic Chinese immigrants who were female, older adults (aged over 70 years), and those with lower levels of education appeared to be at higher risk of holding such beliefs. The low level of awareness of supportive cancer care organisations further highlighted the value of a community-collaborative approach in conducting cancer-related research among ethnic Chinese group. By interpreting the results with the theory of planned behaviour, reluctance to engage in cancer prevention was evident, reflected in fear of cancer screening results, perceived difficulty in accessing services, and limited recognition of the importance of cancer screening. By Chapter 9, the five interconnected phases of this project have been described in detail. The next chapter brings these findings together to address the overall research aim of the project.

# Chapter 10 : General Discussion

## 10.1 Introduction

The overall aim of this project was to understand the unmet needs, wellbeing, care experience and beliefs towards cancer among ethnic Chinese immigrants in Scotland. This chapter synthesises and integrates the key findings of the whole project in relation to the existing body of literature. It also outlines the recommendations, evidence-based next steps for future research arising from the findings of this project, and the strengths and limitations of the overall project. Finally, the chapter concludes with the overall conclusions of this project and the personal reflections on the PhD journey.

## 10.2 Main findings across the five phases

The main integrated findings from Phases 1 to 5 include three main themes including:

1) Experienced challenges and sources of health inequalities including:

For those affected by cancer:

- Inequality in receiving information related to both content and delivery format.
- Ethnic Chinese immigrants affected by cancer experienced difficulties in accessing and understanding the healthcare system.
- Communication barriers with healthcare professionals extended beyond language difficulties to include limited self-disclosure among ethnic Chinese immigrants.
- Ethnic Chinese informal caregivers required more support .
- Experiences of cancer-related stigma among ethnic Chinese immigrants were influenced by the cancer taboo.

For those without a cancer diagnosis:

- Fatalistic beliefs about cancer were prevalent, especially for older females and those with low education level.
- Ethnic Chinese immigrants had limited knowledge of available supportive cancer services.
- The self-reported cancer screening attendance rate was low.
- Intention to engage in cancer prevention was influenced by not realising the importance of early detection in reducing cancer risk, fear of the results, and perceived difficulties in accessing services.

The health inequality issues identified among ethnic Chinese individuals without a cancer diagnosis were integrated into the following sections alongside the findings for patients and informal caregivers: inequality in receiving information, accessing and understanding the healthcare system, and dealing with cancer-related stigma.

2) The role of community health workers and community-based approaches:

- Community health workers can help engage with ethnic Chinese communities.
- Community based approaches were acceptable way for ethnic Chinese immigrants living with or without cancer to receive information and support.

## 10.4 Challenges and sources of health inequalities

### 10.4.1 Inequality in receiving information

Unmet information needs were consistently identified throughout this project and represented a key aspect of inequality among ethnic Chinese immigrants living with cancer in Scotland (Chapter 5 to 8). In the systematic review (Chapter 5), similar inequalities were reported among Arab immigrants living in other very high HDI countries, such as Australia. Further literature also found that the unmet information needs were reported by Greek patients living in Australia (O'Callaghan et al., 2016). Wu et al. (2022) reported that although Chinese immigrants and native Chinese share the same cultural background, their identified information needs are different, with immigrants reporting a high demand for information to help manage their health condition. In comparison, native Chinese patients tended to prioritise timely access to test results (Wu et al., 2022).

Regarding information content, the importance of dietary information was consistently reported and has also been identified among Chinese Australian cancer survivors (Wang et al., 2021). Ng et al. (2021) reported that ethnic Chinese immigrant patients with cancer in western countries face challenges in making dietary choices as they navigate between western medical advice and traditional Chinese understandings of the role of food in health and illness. This issue was also raised during the Phase 4 focus group with health and social care professionals (Chapter 8). Tang et al. (2023a) reported that variations in energy and nutrient requirements across ethnic groups and living environments contribute to differences in dietary practices and nutritional needs between Eastern and Western cultural contexts. In this project, the perceived importance of diet was also evident in Phase 5 survey (Chapter 9), with higher proportion of ethnic Chinese public without cancer diagnosis believed that eating healthily could prevent cancer, rather than viewing

participation in cancer screening as an important preventive strategy. Diet holds strong cultural values among ethnic Chinese communities and it was strongly shaped by traditional Chinese medicine, which emphasises the balance of ‘yin’ and ‘yang’ in food to maintain health and prevent diseases (Zou et al., 2022).

Beyond dietary information needs, this project also identified inequalities in the way information was provided (Chapter 5 to 8). Lack of bilingual information reinforced inequalities in access to the information (Chapter 7 and 8). The inequalities in access to information can contribute to disparities in health literacy (Sørensen et al., 2015; Fry et al., 2023). Even native speakers often struggle to fully understand the health information provided to them (Lui et al., 2022). Comprehending health information in a second language not only increases the risk of misunderstanding but also amplifies patients’ experiences of vulnerability during cancer care (Holden et al., 2021). Patients from ethnic minority groups who have limited English proficiency to understand information are more likely to report poor quality of life than native-born patients (Lui et al., 2022). Individuals in vulnerable situations, like a diagnosis of cancer, tend to revert to their mother tongue as a familiar and emotionally safe space (Birkelund et al., 2025). Additionally, this project was reported that information in written format is more desirable than verbal (Chapter 7 and 8). Patients are more likely to forget spoken information, especially when the amount of information is large and complex (Sakai et al.2017).

Throughout this project, healthcare professionals were consistently reported as the preferred channel for receiving medical information (Chapter 5 to 9). In the in-depth interviews (Chapter 7), patients and informal caregivers expressed a preference for receiving information from hospitals, while ethnic Chinese members of the public in the Phase 5 survey (Chapter 9) reported that GPs were their preferred source of cancer screening recommendations. This preference was the same with Chinese Americans and Chinese Australians (Jung et al., 2018), but was not observed in other ethnic minority groups such as those from Islamic countries (Veeravagu et al., 2025). Such a pattern may be explained by Chinese cultural factors, where doctors are regarded as authoritative figures, and individuals tend to follow their medical advice and decisions (Wang et al., 2013b). However, this project was found that sometimes healthcare professionals did not provide sufficient information to ethnic Chinese (Chapter 7 and 8). Healthcare professionals may assume that patients are able to understand information in their second language, but they may not fully recognise the extent of patients’ understanding or the amount of information they require (Kim et al., 2024).

### 10.4.2 Accessing and understanding the healthcare system

Evidence from the UK shows that immigrant groups face significant challenges in accessing high-quality cancer care, partly due to unfamiliarity with the healthcare system (Delon et al., 2022). In this project, navigating the healthcare system was identified as the second major unmet need contributing to health inequalities among ethnic Chinese patients and informal caregivers (Chapters 5 to 8). Furthermore, many ethnic Chinese members of the public reported limited awareness of current supportive cancer care services and low self-reported cancer screening uptake (Chapter 9). This finding from Chapter 9 highlights an important issue in access to healthcare services, as people cannot benefit from services that they do not know exist or are unwilling to engage with.

Similar to information needs, the broader literature indicates that unfamiliarity with healthcare system is also experienced by Latina immigrant cancer survivors in the USA and Southern European immigrants navigating the Norwegian healthcare system (Li et al., 2021; Birkelund et al., 2024). Evidence from the systematic review (Chapter 5) also identified this unfamiliarity among Arab immigrant patients. Therefore, this is not a unique issue for the ethnic Chinese minority group or for Scotland as a host country. Rather, it represents a broader challenge faced by many immigrant communities across various host nations. Immigrants' navigation of a new healthcare system is often influenced by their experiences with healthcare services prior to migration (Herrero-Arias and Diaz, 2021). Scotland has a well-established primary care system with GPs providing referrals to secondary care. However, in many countries, such as China, GPs and primary care services are not routinely involved, and patients commonly seek care directly from hospital (Hougaard et al., 2011; Akhtar et al., 2022).

### 10.4.3 Communication

Communication challenges were the third identified area of inequality in receiving better cancer care among ethnic Chinese (Chapter 5 to 8). Achieving positive health outcomes depends largely on the extent to which a shared understanding is established through effective communication (Kwame and Petrucka, 2021). Communication with healthcare professionals without a shared language has been shown to contribute to miscommunication and reduced patient involvement in decision-making (Birkelund et al., 2024). Chinese speaking patients reported significantly greater communication difficulties and less confidence in speaking English than Greek or Arab patients (Hyatt et al., 2017). Evidence from the systematic review (Chapter 5) indicated that Arab immigrants primarily

reported language barriers as the main factor affecting communication. However, among ethnic Chinese immigrants, the factors affecting communication extended beyond language barriers and also included limited self-disclosure (Chapter 7 and 8). Chinese cultural values, particularly those rooted in Confucian traditions, that prioritise social harmony and respect for authority, may make patients less open to expressing their needs (Badanta et al., 2022).

Although interpreter services are available in Scotland to facilitate communication, findings from this project suggest that both the availability and quality of these services remain limited (Chapter 7 and 8). Vange et al. (2023) reported that healthcare providers' attitudes play a significant role in influencing the utilisation of interpreter services. Informal caregivers in Phase 3 (Chapter 7) described situations in which healthcare providers assumed that interpreter support was unnecessary, thereby limiting informal caregivers' access to these services. Similarly availability issue also be reported in European countries (Vange et al., 2023). In terms of the quality of interpreter services, health and social care professionals found that dialect mismatches and literal translation were reported as key issues when ethnic Chinese immigrants used these services (Chapter 8). Similar concerns were also identified from systematic review chapter among Arab immigrants living in Australia (Chapter 5). This highlights the importance of assessing dialect preferences prior to assigning interpreters.

### 10.4.4 Caring for the informal caregiver

The fourth inequality issue reported in this project is related to the lack of equitable support for informal caregivers (Chapter 6 to 8). Carers Scotland (2023a) reported that informal caregivers experience severe psychological distress. Evidence from a survey conducted in the USA shows that immigrant informal caregivers are more likely to experience severe psychological distress than USA.-born informal caregivers (Yuen et al., 2018). The cancer diagnosis affects the entire family system, and there is now a growing recognition that the needs of caregivers should be acknowledged across the survivorship continuum (Miller et al., 2022).

This project indicated that informal caregivers had lower levels of emotional, social/family, and functional wellbeing than patients (Chapter 6). For social/family and emotional wellbeing, ethnic Chinese informal caregivers reported limited access to social and family support (Chapter 6 and 7). Ryan and Sacha (2025) reported that 51% of carers from ethnic minority groups had never heard of the any supportive services for them. Inequalities in

access to supportive services for informal caregivers are also experienced by Black and other Asian minority ethnic groups (Minority Ethnic Carers of People Project, 2025). Hu et al. (2018) reported that Chinese caregivers tend to prioritise concerns about patients' conditions over their own health and wellbeing. In the Chinese language, there is no direct translation for the term 'carer'. Individuals perceive themselves primarily as family members, rather than as occupying a caregiving role (Greenwood, 2018). As a result, caring for a family member may be seen as a personal or familial responsibility, which may reduce the likelihood of accessing formal carer support services (Greenwood, 2018).

For functional wellbeing, the lack of shared caregiving role, such as the ability to rotate caregiving responsibilities among family members, limited informal caregivers' time for work and leisure activities (Chapter 6 and 7). This may be partly explained by immigration patterns in the UK, with this being predominantly driven by employment and education, with comparatively lower rates of family reunification (Lazard et al., 2021). Ethnic Chinese informal caregivers reported that the absence of extended family support created significant difficulties, particularly in balancing work responsibilities, which in turn contributed to financial strain within the family (Chapter 6 and 7). Similarly, Minority Ethnic Carers of People Project (2025) reported that informal carers from ethnic minority groups are substantially more likely to be in poverty, with 67% of them suffering financial difficulties, primarily due to their inability to work as a result of caregiving responsibilities. Moreover, a systematic review reported that income loss due to reduced working hours was the most commonly reported contributor to financial toxicity following a cancer diagnosis for a family in publicly funded healthcare systems (Longo et al., 2020).

Notably, sample bias for this project may exaggerate the inequality issues among ethnic Chinese informal caregivers. In this project, most of the informal caregivers were caring for their spouse (Chapter 6 and 7), and evidence shows that caring for a spouse or partner is more likely than caring for other relationships where an individual is suffering with psychological distress (Zhou et al., 2024). With the exception of a mother caring for her child for more than 5 years, the remaining informal caregivers in the Phase 3 in-depth interviews were relatively new caregivers (Chapter 7). Mosher et al. (2013) point out that significant challenges are experienced by newcomer caregivers as they often have limited experience of this role, leading to distress and anxiety. Moreover, in the in-depth interviews with informal caregivers (Chapter 7), four of the five informal caregivers were male. Within the Chinese cultural context, gender norms may have a detrimental impact on male caregivers' emotional experiences (Gao et al., 2024). Traditional expectations rooted in

patriarchal and masculine ideals often position men primarily as financial providers rather than caregivers for the family (Gao et al., 2024). As a result, male caregivers may be less familiar with domestic and caregiving roles, which can create emotional strain and challenges in adapting to caregiving responsibilities (Gao et al., 2024).

### 10.4.5 Dealing with cancer-related stigma

In this project, cancer-related stigma was reported by ethnic Chinese patients (Chapter 5 to 8) and informal caregivers (Chapter 6 to 8). Despite Arab immigrant patients in the systematic review (Chapter 5) not reporting stigma, cancer-related stigma is not exclusive to ethnic Chinese populations. Similar experiences have also been reported among African patients with cancer (Mwobobia et al., 2025). Findings from the Phase 5 survey (Chapter 9) suggest that fatalistic beliefs about cancer within the ethnic Chinese individuals without cancer diagnosis may be an important factor contributing to cancer-related stigma for patients and informal caregivers. The definition of cancer fatalism is associated with fear, hopelessness, and the belief in the inevitability of death (Powe and Finnie, 2003). Individuals who hold fatalistic beliefs about cancer avoid discussing cancer (Crawford et al., 2016), which was also highlighted by health and social care professionals in the focus group (Chapter 8).

Cancer related stigma contributed to patients concealing their cancer diagnosis to their friends, colleagues, and even to their family (Chapter 7). Shim et al. (2021) reported that concealment of a cancer diagnosis from colleagues was often considered a self-protective strategy, as 20.7% of patients with cancer experienced workplace discrimination and faced a twofold higher risk of job loss compared with patients who did not report workplace discrimination. In some cultural contexts, cancer may be perceived as contagious or as a form of punishment resulting from an individual's or their ancestors' immoral behaviour (Miller et al., 2022). Consequently, individuals affected by cancer experience self-blame and stigmatisation, and even their family may be discriminated against and socially rejected (Jin et al., 2021). There are an increasing number of patients with cancer who have shifted their cancer care from the hospital to the community; however fatalistic beliefs about cancer within the communities can often reinforce stigma and social exclusion for patients (Leung et al., 2017; Warmoth et al., 2020).

The absence of peer support groups and Scottish Chinese supportive cancer care organisations may have limited opportunities for ethnic Chinese cancer survivors to overcome cancer-related stigma (Chapter 7 and 8). Gaining new information/knowledge

from peers was also a preference among ethnic Chinese patients and informal caregivers (Chapter 7). Peer support is a reciprocal process of giving and receiving (Ramchand et al., 2017). Peer support operates within a non-hierarchical relationship, with interactions between individuals with the same illness, which can foster a sense of normalcy through shared experiences and mutual comparison (Gidugu et al., 2015). For example, group-based psychosocial interventions have been shown to effectively reduce internalised stigma by incorporating education sessions, peer support, and sharing personal experiences among individuals with serious mental illness (Kim et al., 2024). A pilot study using a psychoeducation programme among Chinese American breast cancer survivors reported that peer monitoring could improve wellbeing and reduce self-stigma (Lu et al., 2014).

## 10.5 The role of community health workers

This project found that ethnic Chinese communities played a crucial role in reaching out to the ethnic Chinese population (Chapter 5 to 9). The systematic review (Chapter 5) showed that more than half of the included studies (17 of 31) recruited participants through community-based approaches, either alone or in combination with clinical recruitment. From the experience of this project, community collaborative showed an effective way to connect and collecting data from ethnic Chinese immigrants. These findings demonstrate that building and sustaining ongoing community partnerships is an effective strategy for increasing the engagement and enrolment of underrepresented populations.

Community health workers may be well placed to address the healthcare inequalities related to difficulties in navigating the healthcare system (Section 10.4.2). Existing literature shows that Asian immigrants often rely on community-based support to navigate healthcare services (Son et al., 2018). Non-hospital and community-based settings were favoured for accessibility and comfort (Grant et al., 2025). Community health workers primarily serve as a bridge between vulnerable groups and health services, playing a key role in connecting communities with the healthcare system (Wells et al., 2011). Additionally, a systematic review by Kim et al. (2022) indicated that community-based health worker interventions are a valuable resource for improving cancer screening rates in ethnic minority groups. In this project, ethnic Chinese members of the public reported that local Chinese communities were their common source of receiving cancer related information (Chapter 9). Fung et al. (2018) conducted a randomised control trial and found that community-based cancer education seminars improved gaps in cancer knowledge and screening intent. Furthermore, a quasi-experimental study reported that a cancer prevention

programme delivered by community health workers significantly improved health literacy and screening uptake among the intervention group of Chinese immigrants in Korea (Kim et al., 2022).

## 10.6 Recommendations from the whole project

The recommendations for each phase have been presented in the relevant chapters, while this section provides recommendations arising from the whole project.

### 10.6.1 Person-centred care framework

The current person-centred care framework (Chapter 3, Figure 3-1) does not explicitly incorporate cultural values. The findings of this project propose that cultural considerations should be the first step when providing cancer care for ethnic minority group patients. This point is particularly important in settings and countries with culturally diverse populations. In addition, this project provided a detailed explanation of how to apply the dimensions of "*respect for patients' values, preferences and expressed needs*", "*information, communication and education*", and "*involvement of family and friends*". Figure 10-1 presents the adapted person-centred care framework for culturally diverse people affected by cancer. The emboldened boxes in Figure 10-1 indicate the new additions to the original framework based on the findings of this project.

- **Respect for patients' values, preferences and expressed needs:** Attention should be given to patients' help-seeking behaviours. Needs for patients from diverse backgrounds are dynamic.
- **Information, communication and education:** Information should be delivered in plain and easy-to-understand language. Where important information may be difficult to understand, providing written notes for patients to take home may represent good practice. Patients from Eastern cultural backgrounds may have limited familiarity with the concept of patient autonomy. Healthcare professionals should proactively communicate with patients to ensure they are satisfied with their care. Additionally, assessing patients' informational needs and their ability to understand medical information prior to consultations may be a useful practice for individuals for whom English is a second language.
- **Involvement of family and friends:** When delivering person-centred care, healthcare professionals should also consider the wellbeing of informal caregivers.

In addition, friends may be unaware of the patient's cancer diagnosis, as some patients may not wish to disclose this information.

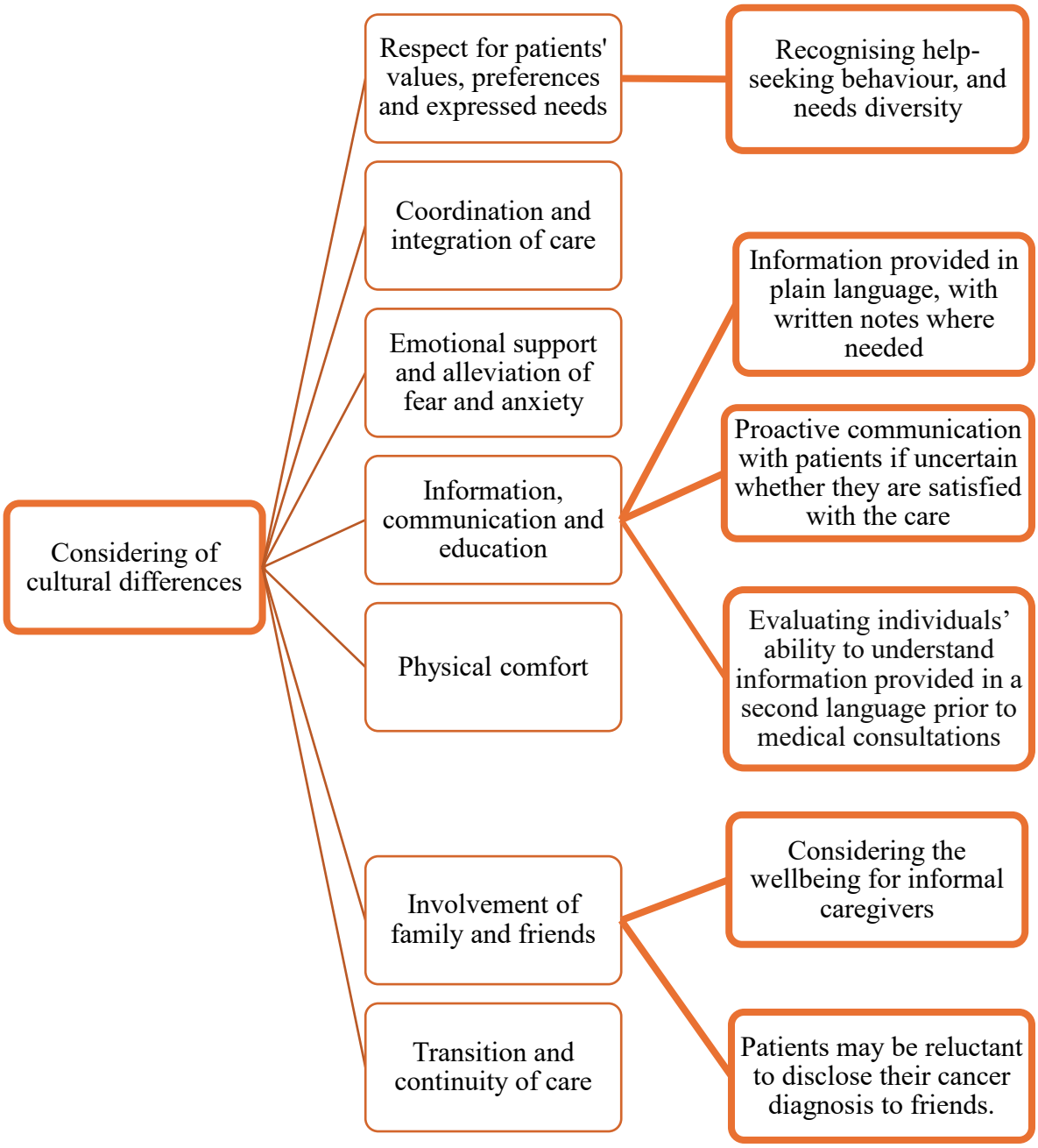



Figure 10-1 Adapted person-centred care framework for culturally diverse people affected by cancer

### 10.6.2 New 10-year cancer strategy

To achieve the aim of the new 10 years cancer strategy to provide equitable cancer care, this project provided several recommendations for the new 10 years cancer strategy.

Firstly, NHS Scotland could consider developing multilingual video resources that provide step-by-step guidance on navigating the Scottish healthcare system, from diagnosis through to supportive cancer care. Secondly, when allocating interpreters, it is necessary to assess patients' dialect preferences. Although it may not be feasible to accommodate all dialects, consideration should at least be given to the two most widely spoken dialects among ethnic Chinese populations, Mandarin and Cantonese, to enhance communication effectiveness.

### 10.6.3 Supportive cancer care organisations

This project identified several reasons why ethnic Chinese immigrants may be reluctant to access supportive cancer care services, including difficulties expressing emotional concerns in a second language and limited awareness of the services available. At present, supportive cancer care organisations may not fully recognise the importance of community networks in the daily lives of ethnic Chinese immigrants. Therefore, this project recommends that supportive cancer care organisations collaborate with local ethnic minority communities to promote their available services and, where possible, involve bilingual staff in supporting patients and informal caregivers from ethnic minority groups.

### 10.6.4 Policy

This project recommends the development of relevant policies to protect informal caregivers' employment and promote greater flexibility in the workplace. Where an informal caregiver is the only person available to care for a family member with cancer while also being the main income earner, appropriate policies should be in place to safeguard their employment. For example, employers could be encouraged to avoid dismissing caregivers during the initial months of assuming a caregiving role and, where feasible, to offer flexible working arrangements, such as hybrid working.

## 10.7 Next Steps

In 2025, a researcher from the Scottish Government's Health and Social Care Analysis Division, who was conducting a rapid review of ethnic and racialised inequalities in cancer care, expressed interest the findings of the overall project. This demonstrates the potential policy relevance of this project and highlights growing attention to the cancer care experiences and support needs of individuals from ethnic minority groups. This section outlines future research opportunities arising from the overall project. Three main areas are identified and expanded upon as follows.

### 10.7.1 Developing an information package to address unmet information needs

Findings from this project clearly indicated that providing bilingual information by healthcare professionals and incorporating dietary and nutritional guidance into routine care could help address prevalent unmet information needs. The first step for future research would be to co-design an information package with patients and informal caregivers to understand how they believe the information package should be structured and delivered. The second step could involve conducting focus groups with health and social care professionals to explore the acceptability and feasibility of implementing the information package in clinical practice. The revised package could then be presented again to patients and informal caregivers for further feedback. This iterative process may require several rounds of consultation until consensus is reached among the relevant stakeholder groups. Once consensus has been achieved, the next step could be to conduct a feasibility study to assess the practicality and acceptability of implementing the information package in routine care.

### 10.7.2 Feasibility study to evaluate the role of community health workers within ethnic Chinese communities

Findings from this project indicated that community health workers who speak Chinese and understand Chinese culture could act as trusted liaisons, helping to bridge linguistic and cultural gaps and make cancer care more inclusive and accessible. The first step for future research could be to replicate and validate the findings of this project in larger ethnic Chinese communities across Scotland. A proposed feasibility study to evaluate the role of community health workers could include two main components. The first would have an educational purpose, with community health workers delivering relevant cancer-related information to the community. This could build on the approach used in the Phase 5 (Chapter 9) “Cancer Talk” sessions. Following the educational sessions, outcomes could include changes in cancer-related knowledge among ethnic Chinese community members, changes in individuals’ intentions to engage in cancer prevention behaviours, and reductions in cancer-related stigma among patients and informal caregivers.

The second component would have a supportive and counselling purpose, primarily assisting patients and informal caregivers when they require help with issues such as navigating the healthcare system, accessing psychological support, and interpretation. Both components could be evaluated at baseline and at one- and three-month follow-up to

explore whether this role is feasible, acceptable, and potentially effective in improving cancer-related knowledge and wellbeing.

### 10.7.3 Establishing healthcare professional-led peer support groups

This project found that patients and informal caregivers expressed a need to interact with others who had similar experiences and to receive practical information. Future projects could consider establishing a Scottish branch of the Chinese Association for Cancer Care or supporting existing supportive cancer care organisations to develop dedicated support groups for individuals from Chinese backgrounds. Concerns have been raised in the literature that information shared by peers may sometimes be inaccurate, highlight the need for appropriate professional oversight (Lazard et al., 2021). In addition, as discussed earlier in Section 10.4.1, given the trusted role of healthcare professionals, this group may be particularly effective and acceptable if guided by healthcare professionals or individuals with healthcare background such as retired nurses.

## 10.8 Strengths and limitations

The strengths and limitations of each phase have been acknowledged in the relevant chapters, while this section presents the strengths and limitations of the whole project.

The key strengths for the whole project included:

- **Exploratory work:** As outlined in the Phase 1 systematic review (Chapter 5), there is no empirical research in Scotland or more broadly in the United Kingdom. This project is a first step and contributes new evidence to this underexplored area of research, learning how well this population lives with cancer in Scotland, what survivorship issues exist, and what aspects these people feel are priorities to enhance their wellbeing.
- **The value of the data:** Ethnic Chinese immigrants are recognised as a underrepresented population, and the data collection process in this project demonstrated the challenges of engaging them in cancer-related research. Therefore, the data generated are especially valuable and may serve as pioneering evidence in improving the inclusivity and diversity of research on underrepresented populations.
- **Pragmatic research paradigm:** Pragmatism offers the flexibility and responsiveness needed to adapt research design and methods in response to real-world complexities, while maintaining a clear focus on addressing the research aim.

By embracing this philosophical stance, this project allowed for methodological flexibility, enabling modifications and expansion where necessary to better achieve its objectives.

- **Hybrid multistage mixed-methods approach:** This project adopted a novel mixed-methods design that incorporated both exploratory and explanatory sequential approaches. The triangulation purpose of the project enhanced the trustworthiness and reliability of the findings. Its complementary purpose enabled a more comprehensive explanation of the results. Its developmental purpose ensured that each study remained aligned with the overall research aim and that the different phases were relevant and interconnected.
- **Multiple theory driven:** This project applied the core principles of the person-centred care framework. Additional theories and frameworks included the implementation of a person-centred care framework, the social determinants of health framework, and the theory of planned behaviour. These supplementary theories or frameworks strengthened the methodological decisions and enhanced the rigour of the study's design and discussion.
- **Inclusive PPIE activities:** The inclusion of PPIE activities ensured that the evidence generated from this project reflected the relevant stakeholder's preferences and priorities. In this project, PPIE representatives provided valuable insights, such as the need to offer questionnaires in different language versions. This consideration of language preferences helped align the project with person-centred care principles and made participation more accessible and comfortable for participants. Additionally, collaboration with PPIE representatives enabled the development of strong connections with ethnic Chinese communities and supported the successful conduct of the research.
- **Shared cultural background:** The shared cultural background between the PhD researcher and the community helped establish trust and create direct connections. This is particularly important when engaging ethnic Chinese populations. And the prior experience as a clinical nurse helped establish trust with participants and enabled the PhD researcher to demonstrate greater empathy during interviews.

The key limitations of the whole project included:

- **Language bias of the researcher:** The PhD researcher's Mandarin-speaking background may have inadvertently limited the inclusion of ethnic Chinese who are Cantonese speaking. This is particularly relevant as many ethnic Chinese immigrants in Scotland originate from Hong Kong, where Cantonese is the primary spoken dialect. This language mismatch may have constrained the researcher's ability to build trust and communicate effectively with some community members.
- **Researcher's position:** The position of the PhD researcher is a native Chinese speaker with clinical oncology healthcare experience in China and is currently pursing doctoral degree study in the Scotland. This background inevitably shaped the qualitative parts of this project, including the interview processes, thematic analysis and interpreting the data, which carried the risk of introducing preconceptions. To alleviate this, the data analysis process and themes were discussed and reviewed with two supervisors who have expertise in qualitative research and do not share the same cultural background.
- **Geographical limitations:** As the PPIE activities used to promote this project were mainly conducted in major cities, including Glasgow, Edinburgh, and Dundee, for Phases 2 and 3 (Chapters 6 and 7), and only in Glasgow for Phase 5 (Chapter 9), the generalisability of the findings from the overall project may be limited to ethnic Chinese immigrants living in urban areas.

## 10.9 Conclusion

This project represents the first empirical investigation in Scotland, and more broadly within the UK, to explore the unmet needs, wellbeing, care experiences, and beliefs towards cancer among ethnic Chinese immigrant. Through a hybrid multistage mixed-methods design framed by a pragmatic research paradigm, and strengthened by meaningful PPIE activities, this project offers a comprehensive and culturally grounded understanding of the multidimensional challenges faced by this underserved population. As Scotland moves toward its 2023-2033 new 10-year cancer strategy, the insights from this project offer timely evidence to inform policy and practice changes that can better meet the needs of immigrant and minority populations. Community-based research is an important first step to gaining access to minority groups, with the support of community leaders. Providing information in plain language, improving navigation of the healthcare system, strengthening the availability and quality of interpreter services, and developing peer support programmes will be essential in addressing inequalities and enhancing the wellbeing of ethnic Chinese immigrants affected by cancer in Scotland. In addition, there is a need to deliver education sessions within ethnic Chinese communities to improve understanding of cancer and promote engagement with cancer prevention, which may help reduce late diagnosis and address cancer taboo within ethnic Chinese communities.

In conclusion, by illuminating the complex interplay between Chinese cultural beliefs, health system structures, communication processes, and social determinants of health, this project provides a strong foundation for advancing person-centred, and culturally responsive cancer care for ethnic Chinese immigrants in Scotland and beyond.

## 10.10 Reflections on my PhD journey

Looking back on my PhD, the journey was very different from what I had imagined when I started in January 2022. At the beginning of my doctoral journey, I often sought reassurance that I was doing things “correctly”. Over time, I learned that independent research rarely involves a single perfect answer. Instead, it requires evaluating alternatives, making and justifying decisions, acknowledging uncertainty, and being prepared to revise those decisions when new evidence or challenges emerge. Through the PhD journey, I developed a deeper understanding of the importance of trust and collaboration in conducting research. My relationship with ethnic Chinese communities also developed considerably throughout this project. At the beginning, it was difficult to establish contact, and some community organisations were hesitant or declined opportunities for me to visit.

Over time, through continued communication, engagement, and trust-building, several organisations became willing to collaborate with me. This change was an important learning experience and strengthened my confidence in community engagement, relationship-building, and communication. These skills, together with the relationships established throughout the project, are outcomes of my PhD journey that extend beyond the completion of the PhD itself.

Working with ethnic Chinese communities in Scotland was one of the most meaningful aspects of my PhD journey. These experiences changed my understanding of what culturally appropriate cancer care means for ethnic Chinese immigrants. Before conducting the empirical phases and engaging directly with patients and informal caregivers, I had not fully appreciated the extent of the challenges they could experience following a cancer diagnosis. I had also not fully recognised how a cancer diagnosis can affect the whole family and bring significant changes to a person's life. Through these in-depth interactions, I developed a greater understanding of the difficulties that immigrants may face when navigating life in a new country while also coping with cancer as a major life-changing condition. Members of the ethnic Chinese communities may not always feel confident in expressing their needs within healthcare or wider society, which may contribute to feelings of being overlooked or marginalised. Listening to these experiences made me realise that my role as a researcher involved more than simply collecting and analysing data. It also involved providing an opportunity for people whose needs may not always be visible or openly expressed to have their voices heard. I was particularly encouraged to hear that some members of the community felt that my research provided an opportunity for them to express their experiences and concerns. Through participants' accounts, I came to understand that many of these challenges were not inevitable and could potentially be reduced if healthcare services were more responsive to the specific needs of this population.

Although the contribution of one PhD project is necessarily limited, I hope that this project can help increase awareness of their needs to the whole society and ensure that their voices are more visible within cancer care research and practice. All of these reflections have reinforced my desire to continue working in cancer and supportive care research. I hope that my future research will continue to involve collaboration with communities to develop and evaluate practical approaches that can make cancer care more accessible, equitable, and culturally responsive for ethnic Chinese immigrants in Scotland and beyond.

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# Appendices:

## Appendix 1: Ethics and amendment approval for the initial project

University of Glasgow

5th April 2023

**MVLS College Ethics Committee**

***Project Title: Evaluating the unmet healthcare needs and quality of life of patients with metastatic breast cancer in China***
***Project No: 200220206***

Dear ***Dr Grigorios Kotronoulas***

The College 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.

- Project end date: End January 2024
- 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: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician
Clinical Lead Scottish Stroke Research Network / NRS Strcke Research Champion
Chair MVLS Research Ethics Committee

Institute of Cardiovascular and Medical Sciences
College of Medical, Veterinary & Life Sciences
University of Glasgow
Room M0.05
Office Block
Queen Elizabeth University Hospital
Glasgow
G51 4TF

jesse.dawson@glasgow.ac.uk

16.05.2023

**RE: Application No. 200220206 – Amendment request**

Project title: Evaluating the unmet healthcare needs and quality of life of patients with metastatic breast cancer in China (PhD project)

Applicants: Dr Grigorios Kotronoulas

Lead Reviewer: Dr Jesse Dawson

Dear Dr Dawson,

We are submitting a request for amendment for the above-mentioned application, which was approved by MVLS Ethics on 5 April 2023.

With this amendment, we request to remove Dalian Medical University Hospital, China due to a rather complicated ethics process that may adversely impact the whole PhD project. Instead, we are proposing to recruit via an online, nation-wide survey in China posted to social media platforms and shared with public patient support organisations, for which we have established that no additional ethics approval from China is required according to Chinese government guidelines.

We have also checked with Dr Debra Stuart to confirm that UofG insurance will still cover the project following this modification. Dr Stuart has advised that, in order for UofG insurance to still apply, we must ensure to clarify in study documents that the project is not clinical in nature and will not intend to change policy or service provision in China. We have therefore slightly amended our study documents to reflect this. We submit revised documents with tracked changes as part of this amendment request.

We are keen to move forward with this project as soon as possible, and as such, we'd be grateful to have the committee's prompt decision on this request.

Yours sincerely,

Dr Grigorios Kotronoulas

Reader in Supportive Cancer Care

School of Medicine, Dentistry & Nursing

College of Medical, Veterinary and Life Sciences, University of Glasgow

Nursing & Health Care, 57-61 Oakfield Avenue, Glasgow, G12 8LL, United Kingdom

E-mail: grigorios.kotronoulas@glasgow.ac.uk

Tel: +44 (0) 141 330 6883

Outlook

**RE: Application No. 200220206 – Amendment request**

From Neil Allan <Neil.Allan@glasgow.ac.uk>
Date Fri 2023-05-19 11:02
To Greg Kotronoulas <grigorios.kotronoulas@glasgow.ac.uk>
Cc Lin Cheng (PGR) < @student.gla.ac.uk>; Deborah Cairns <Deborah.Cairns@glasgow.ac.uk>

Hi all

Jesse has approved this amendment. Please treat this email as confirmation of the committee's approval and I will keep copies of everything in our files for reference.

Regards
Neil

---

*Neil Allan*
*MVLS Ethics Committee Adminstrator*

*School of Infection & Immunity*
*College of Medical, Veterinary & Life Sciences*
*Glasgow Biomedical Research Centre*
*Room 314, Sir Graeme Davies Building*
*University of Glasgow*
*120 University Place*
*Glasgow G12 8TA*
*The University of Glasgow, charity number SC004401*

# Appendix 2: PROSPERO Registration

NIHR | National Institute for Health and Care Research

**PROSPERO**
International prospective register of systematic reviews

## Care experiences and well-being of Asian immigrants with cancer living in western country--A systematic review of international evidence

*Lin Cheng, Grigorios Kotronoulas, Deborah Cairns*

**Citation**
Lin Cheng, Grigorios Kotronoulas, Deborah Cairns. Care experiences and well-being of Asian immigrants with cancer living in western country--A systematic review of international evidence. PROSPERO 2024 Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD42023448605

## REVIEW TITLE AND BASIC DETAILS

**Review title**
Care experiences and well-being of Asian immigrants with cancer living in western country--A systematic review of international evidence

**Review objectives**
1) What is the quality of life of Asian immigrant patients with cancer who live in western countries?
2) What are the healthcare needs of Asian immigrant patients with cancer who live in western countries?
3) What are the care experiences of Asian immigrant patients with cancer who live in western countries?
4) What facilitators or barriers of accessing / using healthcare services in the host country do they identify?

**Keywords**
1 Asian immigrant, 2 Healthcare experience, 3 Healthcare needs, 4 Quality of life, 5 Western country

## SEARCHING AND SCREENING

**Searches**
Database: EMBASE; MEDLINE; CINAHL; PsycINFO
Restrictions: English language only.

Key words related to : 1) Asian immigrant; 2) Healthcare experience; 3) Healthcare needs; 4) Quality of life; 5) Western country
There will be no time limits to this systematic review search.

### Study design
Any relevant primary and secondary study published in English will be considered eligible for inclusion in the review.
Inclusion criteria:
Primary and secondary research of any type of quantitative, mixed methods, and qualitative studies designed to investigate the quality of life, healthcare needs and experience of Asian immigrant patients with cancer living in the western country.
Exclusion criteria:
Case study; Abstract; Study protocols; Commentaries

## ELIGIBILITY CRITERIA

### Condition or domain being studied
This review is concerned with Asian immigrant patients who are affected by cancer. Cancer is when abnormal cells divide in an uncontrolled way. And the lastest cancer data from GLOBOCAN 2020 indicate that cancer continues to be a life-threatening disease worldwide.

### Population
Inclusion criteria:
1) Age > 18 years old
2) Asian immigrant and host in western country
3) Diagnosed with cancer
Exclusion criteria:
1) Age < 18 years old
2) Asian immigrants but not hosting in western country
3) Non-Asian immigrants

### Intervention(s) or exposure(s)
Exposure: Asian immigrant patient diagnosed of cancer receiving care in the host country.

### Comparator(s) or control(s)
The formation of this systematic review was comprised with population, the exposure and the outcomes. The acronyms of these are PEO, which is designed mainly for reviewing qualitative questions. Therefore, this systematic review does not have comparators / control group.

## OUTCOMES TO BE ANALYSED

### Main outcomes
Based on the review questions, the outcomes will be categorised into: 1) overall quality of life for Asian immigrant patients with cancer in western countries. 2) overall unmet needs for Asian immigrant patients with cancer in western countries. 3) healthcare experiences for Asian immigrant patients with cancer in western countries. 4) facilitators and barriers for Asian immigrant patients with cancer to search for healthcare services in the host countries.

### Additional outcomes

Not applicable

## DATA COLLECTION PROCESS

### Data extraction (selection and coding)

The studies retrieved during the searches will be selected for inclusion if they meet the above inclusion criteria.

Procedure to select studies:

Retrieved articles entered into Endnote database

Duplicates removed

Title and abstracts assessed for eligibility

Full papers assessed for eligibility

Discrepancies to be resolved by discussion with second and third reviewers

Procedure to extract data:

1) Study ID; 2) Study Author; 3) Year; 4) Country; 5) Sample size; 6) Sample characteristics; 7) Study Design; 8) Immigrants original country; 9) Current host country; 10) Quality of life questionnaire; 11) Unmet needs questionnaire;12) Overall quality of life; 13) Unmet needs; 14) Experiences of care.

### Risk of bias (quality) assessment

All included studies will be evaluated via the Quality Assessment for Diverse Studies (QuADS) tool. The QuADS tool demonstrates strong reliability and ease of use for application to multi or mixed-methods health services research. The QuADS criteria has 13 items which could comprehensive evaluate all characteristics of studies, from research setting to data analysis. Appraisals will be conducted independently by two reviewers, disagreements will be resolved by a third reviewer.

Studies will not be excluded based on their quality.

Quality scores will be included in any reports produced.

## PLANNED DATA SYNTHESIS

### Strategy for data synthesis

Data synthesis and integration will be conducted following the methods outlined in the Joanna Briggs Institute (JBI) for evidence synthesis. Specially, the 'convergent integrated' approach for mixed-methods systematic review will be used.

The convergent-integrated approach means that the synthesis occurs simultaneously and refers to a process of combing extracted data from quantitative studies and qualitative studies and involves data transformation. This involves extracting data from quantitative studies and translating or converting it into ‘textual descriptions’ to allow integration with qualitative data. The data will be extracted into word documents and imported to NVivo qualitative data analysis software, to facilitate the coding and analysis of this data. A narrative approach to this systematic review will be used, also creating thematic summaries of findings within similar context. Thematic analysis is a method which provides accessible and systematic procedures for generating codes and themes from qualitative data. The aim of thematic analysis is not simply to summarize the data content, but to identify, and interpret, key, but not necessarily all,

features of the data, guided by the research questions. For example, 1) We will group similar facilitators or barriers of accessing healthcare services for Asian immigrants with cancer living in the host country together.2) We will group the similar healthcare needs for Asian immigrants with cancer living in the western country. 3) We will group the more advanced and disadvanced aspect of quality of life of Asian immigrant with cancer living the western country. 4) We will analyse the similar care experience.

### Analysis of subgroups or subsets
Not applicable

## REVIEW AFFILIATION, FUNDING AND PEER REVIEW

### Review team members

- Miss Lin Cheng, University of Glasgow, School of Medicine, Dentistry & Nursing
- Dr Grigorios Kotronoulas, University of Glasgow, School of Medicine, Dentistry & Nursing
- Professor Deborah Cairns, University of Glasgow, School of Health and Wellbeing

### Review affiliation
University of Glasgow, School of Medicine, Dentistry & Nursing

### Funding source
China Scholarship Council; Number: 202108210116

<\/div>

### Named contact
Lin Cheng. University of Glasgow, Nursing & Healthcare School, 57-61 Oakfield Avenue, Room 57/406
@student.gla.ac.uk

## TIMELINE OF THE REVIEW

### Review timeline
Start date: 10 July 2023. End date: 01 May 2024

### Date of first submission to PROSPERO
27 July 2023

### Date of registration in PROSPERO
03 August 2023

## CURRENT REVIEW STAGE

### Publication of review results
The intention is to publish the review once completed.The review will be published in English

### Stage of the review at this submission

| Review stage | Started | Completed |
|---|---|---|
| Pilot work | | |
| Formal searching/study identification | ✓ | |
| Screening search results against inclusion criteria | | |
| Data extraction or receipt of IP | | |
| Risk of bias/quality assessment | | |
| Data synthesis | | |

### Review status
The review is currently planned or ongoing.

## ADDITIONAL INFORMATION

### Additional information
This review will be part of research intended to improve cancer care services in Scotland, becoming more culturally appropriate and person-centred for non-native patients and their families.

### PROSPERO version history

- Version 1.0 published on 03 Aug 2023

### Review conflict of interest
None known

### Country
Scotland

### Medical Subject Headings
Asian; Emigrants and Immigrants; Health Services; Humans; Neoplasms; Quality of Life

### Disclaimer
The content of this record displays the information provided by the review team. PROSPERO does not peer review registration records or endorse their content.

PROSPERO accepts and posts the information provided in good faith; responsibility for record content rests with the review team. The owner of this record has affirmed that the information provided is truthful and that they understand that deliberate provision of inaccurate information may be construed as scientific misconduct.

PROSPERO does not accept any liability for the content provided in this record or for its use. Readers use the information provided in this record at their own risk.

Any enquiries about the record should be referred to the named review contact

## Appendix 3: Systematic Review Search Strategy

Ovid MEDLINE(R) ALL  (1946 to May 01, 2024)

1. exp Neoplasm/
2. exp Carcinoma/
3. exp Hematologic malignancy/
4. (neoplasm* or carcinoma* or tumo?r* or oncolog* or malignan*).tw.
5. (hematooncological or hemato oncological or hemato*).tw.
6. exp "emigrants and immigrants"/
7. exp "transients and migrants"/
8. exp refugees/
9. (immigrant* or immigrate* or emigrant* or emigrate* or refugee*).tw.
10. (migrant* or migrate* or transient* or asylum seek*).tw.
11. exp asian/
12. exp Asian People/
13. exp Asia/
14. exp afghanistan/ or armenia/ or azerbaijan/ or bahrain/ or bangladesh/ or bhutan/ or brunei/ or cambodia/ or china/ or india/ or indonesia/ or iran/ or iraq/ or jordan/ or kazakhstar/ or kuwait/ or kyrgyzstan/ or laos/ or lebanon/ or malaysia/ or mongolia/ or myanmar/ or nepal/ or oman/ or pakistan/ or philippines/ or qatar/ or saudi arabia/ or singapore/ or sri lanka/ or syria/ or taiwan/ or tajikistan/ or thailand/ or timor-leste/ or turkmenistan/ or united arab emirates/ or uzbekistan/ or vietnam/ or yemen/ or japan/ or korea/ or turkey/
15. (afghanistan or afghans or armenia or armenians or azerbaijan or azerbaijani or bahrain or bahraini or bangladesh or bangladeshi or bhutan or bhutanese or brunei or bruneian or cambodia or cambodian or china or chinese or india or indian or iran or iranian or indonesia or indonesian or iraq or iraqi or jordan or jordanian or kazakhstar or kazakhstani or kuwait or kuwaitis or kyrgyzstan or laos or laotian or lebanon or lebanese or malaysia or malaysian or mongolia or mongol or myanmar or burmese or nepal or nepalese or oman or omanis or pakistan or pakistani or philippines or filipino or qatar or qatari or saudi arabia or saudi arabian or singapore or singaporean or sri lanka or sri lankan or syria or syrian or taiwan or taiwanese or tajikistan or thailand or thai or timor-leste or turkmenistan or turkmenistanis or united arab emirates or uzbekistan or vietnam or vietnamese or yemen or yemeni or japan or japanese or korea or korean or turkey or turkish).tw.
16. exp quality of life/
17. exp life quality/
18. “quality of health care”/
19. (“quality of life” or “health related quality of life” or “wellbeing” or “well-being”).tw.

20. ((care or healthcare or “health care”) adj5 (quality or delivery)).tw.
21. ((care or healthcare of “health care”) adj5 (experience* or feeling*)).tw.
22. 1 or 2 or 3 or 4 or 5
23. 6 or 7 or 8 or 9 or 10
24. 11 or 12 or 13 or 14 or 15
25. 23 and 24
26. 16 or 17 or 18 or 19 or 20 or 21
27. 22 and 25 and 26

Total: 123

EMBASE 1947—Present

1. exp neoplasm/
2. exp oncology/
3. exp carcinoma/
4. exp tumor/
5. (neoplasm* or oncolog* or carcinoma* or tumo?r* or malignan*).tw.
6. exp hematologic malignancy/
7. (hematooncological or hemato oncological or hemato*).tw.
8. exp migration/
9. exp immigrant/
10. exp emigrant/
11. exp migrant/
12. exp refugee/
13. (immigrant* or immigrate* or emigrant* or emigrate* or refugee*).tw.
14. (migrant* or migrate* or transient* or asylum seek*).tw.
15. exp asian/
16. exp afghanistan/ or armenia/ or azerbaijan/ or bahrain/ or bangladesh/ or bhutan/ or brunei darussalam/ or cambodia/ or china/ or india/ or indonesia/ or iran/ or iraq/ or jordan/ or kazakhstan/ or kuwait/ or kyrgyzstan/ or laos/ or lebanon/ or malaysia/ or mongolia/ or myanmar/ or nepal/ or oman/ or pakistan/ or philippines/ or qatar/ or saudi arabia/ or singapore/ or sri lanka/ or syrian arab republic/ or taiwan/ or tajikistan/ or thailand/ or timor-leste/ or turkmenistan/ or united arab emirates/ or uzbekistan/ or viet nam/ or yemen/ or japan/ or korea/ or "turkey (republic)"/
17. (afghanistan or afghans or armenia or armenians or azerbaijan or azerbaijani or bahrain or bahraini or bangladesh or bangladeshi or bhutan or bhutanese or brunei or bruneian or cambodia or cambodian or china or chinese or india or indian or iran or iranian or indonesia or indonesian or iraq or iraqi or jordan or jordanian or kazakhstan or kazakhstani or kuwait or kuwaitis or kyrgyzstan or laos or laotian or lebanon or lebanese or malaysia or malaysian or mongolia or mongol or myanmar or burmese or nepal or nepalese or oman or omanis or pakistan or pakistani or philippines or filipino or qatar or qatari or saudi arabia or saudi arabian or singapore or singaporean or sri lanka or sri lankan or syria or syrian or taiwan or taiwanese or tajikistan or thailand or thai or timor-leste or turkmenistan or turkmenistanis or united arab emirates or uzbekistan or vietnam or vietnamese or yemen or yemeni or japan or japanese or korea or korean or turkey or turkish).tw.
18. exp quality of life/
19. exp wellbeing/
20. exp life quality/
21. “healthcare quality”/

22. ("quality of life*" or "health related quality of life*" or wellbeing* or "well-being*").tw.
23. ((care or healthcare or “health care”) adj5 (quality or delivery)).tw.
24. ((care or healthcare or “health care”) adj5 (experience* or feeling*)).tw.
25. 1 or 2 or 3 or 4 or 5 or 6 or 7
26. 8 or 9 or 10 or 11 or 12 or 13 or 14
27. 15 or 16 or 17
28. 26 and 27
29. 18 or 19 or 20 or 21 or 22 or 23 or 24
30. 25 and 28 and 29

Total: 261

CINAHL

S1 MH neoplasms+

S2 MH oncology+

S3 MH carcinoma+

S4 TI ((cancer* or carcinoma* or neoplas* or tumo#r* or malignan*)) OR AB ((cancer* or carcinoma* or neoplas* or tumo#r* or malignan*))

S5 S1 OR S2 OR S3 OR S4

S6 MH immigrants+

S7 MH refugees+

S8 TI ((immigrant* or immigrate* or emigrant* or emigrate* or refugee* or migrant* or migrate* or transient* or “asylum seeker*”)) OR AB ((immigrant* or immigrate* or emigrant* or emigrate* or refugee* or migrant* or migrate* or transient* or “asylum seeker*))

S9 S6 OR S7 OR S8

S10 MH asians+

S11 (MH "Asia+") OR (MH "Kazakhstan") OR (MH "Kyrgyzstan") OR (MH "Tajikistan") OR (MH "Turkmenistan") OR (MH "Uzbekistan") OR (MH "Borneo") OR (MH "Brunei") OR (MH "Cambodia") OR (MH "East Timor") OR (MH "Indonesia") OR (MH "Laos") OR (MH "Malaysia") OR (MH "Myanmar") OR (MH "Philippines") OR (MH "Singapore") OR (MH "Thailand") OR (MH "Timor") OR (MH "Vietnam") OR (MH "Afghanistan") OR (MH "Bangladesh") OR (MH "Bhutan") OR (MH "India") OR (MH "Nepal") OR (MH "Pakistan") OR (MH "Sri Lanka") OR (MH "Bahrain") OR (MH "Iran") OR (MH "Iraq") OR (MH "Israel") OR (MH "Jordan") OR (MH "Kuwait") OR (MH "Lebanon") OR (MH "Oman") OR (MH "Qatar") OR (MH "Saudi Arabia") OR (MH "Syria") OR (MH "Turkey") OR (MH "United Arab Emirates") OR (MH "Yemen") OR (MH "China+") OR (MH "Hong Kong") OR (MH "Japan") OR (MH "Macao") OR (MH "Mongolia") OR (MH "North Korea") OR (MH "South Korea") OR (MH "Taiwan")

S12 TI ( (afghanistan or afghans or armenia or armenians or azerbaijan or azerbaijani or bahrain or bahraini or bangladesh or bangladeshi or bhutan or bhutanese or brunei or bruneian or cambodia or cambodian or china or chinese or india or indian or iran or iranian or indonesia or indonesian or iraq or iraqi or jordan or jordanian or kazakhstar or kazakhstan or kazakhstani or kuwait or kuwaitis or kyrgyzstan or laos or laotian or lebanon or lebanese or malaysia or malaysian or mongolia or mongol or myanmar or burmese or nepal or nepalese or oman or omanis or pakistan or pakistani or philippines or filipino or qatar or qatari or "saudi arabia" or "saudi arabian" or singapore or singaporean or "sri lanka" or "sri lankan" or syria or syrian or taiwan or taiwanese or tajikistan or thailand or thai or "timor-leste" or turkmenistan or turkmenistanis or "united arab emirates" or uzbekistan or vietnam or vietnamese or yemen or yemeni or japan or japanese or korea or korean or turkey or turkish) ) OR AB ( (afghanistan or afghans or armenia or armenians or azerbaijan or azerbaijani or bahrain or bahraini or bangladesh or bangladeshi or bhutan or bhutanese or brunei or bruneian or cambodia or cambodian or china or chinese or india or indian or iran or iranian or indonesia or indonesian or iraq or iraqi or jordan or jordanian or kazakhstar or kazakhstan or kazakhstani or kuwait or kuwaitis or kyrgyzstan or laos or laotian or lebanon or lebanese or malaysia or malaysian or mongolia or mongol or

myanmar or burmese or nepal or nepalese or oman or omanis or pakistan or pakistani or philippines or filipino or qatar or qatari or "saudi arabia" or "saudi arabian" or singapore or singaporean or "sri lanka" or "sri lankan" or syria or syrian or taiwan or taiwanese or tajikistan or thailand or thai or "timor-leste" or turkmenistan or turkmenistanis or "united arab emirates" or uzbekistan or vietnam or vietnamese or yemen or yemeni or japan or japanese or korea or korean or turkey or turkish) )

S13 S10 OR S11 OR S12

S14 MH quality of life

S15 MH wellness

S16 MH life experiences

S17 MH happiness

S18 TI ( ("quality of life*" or "health related quality of life*" or wellbeing* or "well-being*") ) OR AB ( ("quality of life*" or "health related quality of life*" or wellbeing* or "well-being*") )

S19 ( (care or healthcare or "health care") N4 (experience* or feeling*) ) OR AB ( (care or healthcare or "health care") N4 (experience* or feeling*) )

S20 TI ((care or healthcare or “health care”) N4 (quality or delivery) OR AB ((care or healthcare or “health care”) N4 (quality or delivery))

S21 S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20

S22 S9 AND S13

S23 S5 AND S21 AND S22

Total: 96

# Appendix 4: Consensus-Based Checklist for Reporting of Survey studies (CROSS)

Phase 2 : Survey for ethnic Chinese living with cancer

**Checklist for Reporting Of Survey Studies (CROSS)**

| Section/topic | Item | Item description | Reported on page |
|---|---|---|---|
| **Title and abstract** | | | |
| Title and abstract | 1a | State the word "survey" along with a commonly used term in title or abstract to introduce the study's design. | **74** |
| | 1b | Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussion, and conclusions. | **N/A** |
| **Introduction** | | | |
| Background | 2 | Provide a background about the rationale of study, what has been previously done, and why this survey is needed. | **74** |
| Purpose/aim | 3 | Identify specific purposes, aims, goals, or objectives of the study. | **74** |
| **Methods** | | | |
| Study design | 4 | Specify the study design in the methods section with a commonly used term (e.g., cross-sectional or longitudinal). | **74** |
| | 5a | Describe the questionnaire (e.g., number of sections, number of questions, number and names of instruments used). | **79-83** |
| Data collection methods | 5b | Describe all questionnaire instruments that were used in the survey to measure particular concepts. Report target population, reported validity and reliability information, scoring/classification procedure, and reference links (if any). | **79-83** |
| | 5c | Provide information on pretesting of the questionnaire, if performed (in the article or in an online supplement). Report the method of pretesting, number of times questionnaire was pre-tested, number and demographics of participants used for pretesting, and the level of similarity of demographics between pre-testing participants and sample population. | **N/A** |
| | 5d | Questionnaire if possible, should be fully provided (in the article, or as appendices or as an online supplement). | **257-267** |
| Sample characteristics | 6a | Describe the study population (i.e., background, locations, eligibility criteria for participant inclusion in survey, exclusion criteria). | **74-76** |
| | 6b | Describe the sampling techniques used (e.g., single stage or multistage sampling, simple random sampling, stratified sampling, cluster sampling, convenience sampling). Specify the locations of sample participants whenever clustered sampling was applied. | **74-75** |
| | 6c | Provide information on sample size, along with details of sample size calculation. | **76** |
| | 6d | Describe how representative the sample is of the study population (or target population if possible), particularly for population-based surveys. | **76** |

| | | | |
|---|---|---|---|
| Survey administration | 7a | Provide information on modes of questionnaire administration, including the type and number of contacts, the location where the survey was conducted (e.g., outpatient room or by use of online tools, such as SurveyMonkey). | **78** |
| | 7b | Provide information of survey's time frame, such as periods of recruitment, exposure, and follow-up days. | **86** |
| | 7c | Provide information on the entry process:<br>–>For non-web-based surveys, provide approaches to minimize human error in data entry.<br>–>For web-based surveys, provide approaches to prevent "multiple participation" of participants. | **86** |
| Study preparation | 8 | Describe any preparation process before conducting the survey (e.g., interviewers' training process, advertising the survey). | **76-78** |
| Ethical considerations | 9a | Provide information on ethical approval for the survey if obtained, including informed consent, institutional review board [IRB] approval, Helsinki declaration, and good clinical practice [GCP] declaration (as appropriate). | **85** |
| | 9b | Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorized access. | **85-86** |
| Statistical analysis | 10a | Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis. | **84** |
| | 10b | Report any modification of variables used in the analysis, along with reference (if available). | **N/A** |
| | 10c | Report details about how missing data were handled. Include rate of missing items, missing data mechanism (i.e., missing completely at random [MCAR], missing at random [MAR] or missing not at random [MNAR]) and methods used to deal with missing data (e.g., multiple imputation). | **89-90** |
| | 10d | State how non-response error was addressed. | **89-90** |
| | 10e | For longitudinal surveys, state how loss to follow-up was addressed. | **N/A** |
| | 10f | Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample. | **N/A** |
| | 10g | Describe any sensitivity analysis conducted. | **N/A** |
| **Results** | | | |
| Respondent characteristics | 11a | Report numbers of individuals at each stage of the study. Consider using a flow diagram, if possible. | **87** |
| | 11b | Provide reasons for non-participation at each stage, if possible. | **87** |
| | 11c | Report response rate, present the definition of response rate or the formula used to calculate response rate. | **89** |
| | 11d | Provide information to define how unique visitors are determined. Report number of unique visitors along with relevant proportions (e.g., view proportion, participation proportion, completion proportion). | **N/A** |
| Descriptive results | 12 | Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes. | **88-89** |

| | | | |
|---|---|---|---|
| Main findings | 13a | Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and p-values. | **N/A** |
| | 13b | For multivariable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate). | **N/A** |
| | 13c | Provide details about any sensitivity analysis performed. If there are considerable amount of missing data, report sensitivity analyses comparing the results of complete cases with that of the imputed dataset (if possible). | **N/A** |
| **Discussion** | | | |
| Limitations | 14 | Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders. | **Key considerations in Chapter 6 and the final discussion (Chapter 10)** |
| Interpretations | 15 | Give a cautious overall interpretation of results, based on potential biases and imprecisions and suggest areas for future research. | **Key considerations in Chapter 6 and the final discussion (Chapter 10)** |
| Generalizability | 16 | Discuss the external validity of the results. | **Key considerations in Chapter 6 and the final discussion (Chapter 10)** |
| **Other sections** | | | |
| Role of funding source | 17 | State whether any funding organization has had any roles in the survey's design, implementation, and analysis. | **N/A** |
| Conflict of interest | 18 | Declare any potential conflict of interest. | **N/A** |
| Acknowledgements | 19 | Provide names of organizations/persons that are acknowledged along with their contribution to the research. | **xvi** |

# Checklist for Reporting Of Survey Studies (CROSS)

Phase 5: Survey for ethnic Chinese immigrants without cancer diagnosis

| Section/topic | Item | Item description | Reported on page |
|---|---|---|---|
| **Title and abstract** | | | |
| Title and abstract | 1a | State the word "survey" along with a commonly used term in title or abstract to introduce the study's design. | **150** |
| | 1b | Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussion, and conclusions. | **N/A** |
| **Introduction** | | | |
| Background | 2 | Provide a background about the rationale of study, what has been previously done, and why this survey is needed. | **150** |
| Purpose/aim | 3 | Identify specific purposes, aims, goals, or objectives of the study. | **150** |
| **Methods** | | | |
| Study design | 4 | Specify the study design in the methods section with a commonly used term (e.g., cross-sectional or longitudinal). | **150** |
| | 5a | Describe the questionnaire (e.g., number of sections, number of questions, number and names of instruments used). | **155-156** |
| Data collection methods | 5b | Describe all questionnaire instruments that were used in the survey to measure particular concepts. Report target population, reported validity and reliability information, scoring/classification procedure, and reference links (if any). | **155-156** |
| | 5c | Provide information on pretesting of the questionnaire, if performed (in the article or in an online supplement). Report the method of pretesting, number of times questionnaire was pre-tested, number and demographics of participants used for pretesting, and the level of similarity of demographics between pre-testing participants and sample population. | **N/A** |
| | 5d | Questionnaire if possible, should be fully provided (in the article, or as appendices or as an online supplement). | **268-271** |
| Sample characteristics | 6a | Describe the study population (i.e., background, locations, eligibility criteria for participant inclusion in survey, exclusion criteria). | **151** |
| | 6b | Describe the sampling techniques used (e.g., single stage or multistage sampling, simple random sampling, stratified sampling, cluster sampling, convenience sampling). Specify the locations of sample participants whenever clustered sampling was applied. | **151** |
| | 6c | Provide information on sample size, along with details of sample size calculation. | **151** |
| | 6d | Describe how representative the sample is of the study population (or target population if possible), particularly for population-based surveys. | **151** |
| Survey administration | 7a | Provide information on modes of questionnaire administration, including the type and number of contacts, the location where the survey was conducted (e.g., outpatient room or by use of online tools, such as SurveyMonkey). | **151-154** |

| | | | |
|---|---|---|---|
| | 7b | Provide information of survey's time frame, such as periods of recruitment, exposure, and follow-up days. | **159** |
| | 7c | Provide information on the entry process:<br>–>For non-web-based surveys, provide approaches to minimize human error in data entry.<br>–>For web-based surveys, provide approaches to prevent "multiple participation" of participants. | **156** |
| Study preparation | 8 | Describe any preparation process before conducting the survey (e.g., interviewers' training process, advertising the survey). | **151-154** |
| Ethical considerations | 9a | Provide information on ethical approval for the survey if obtained, including informed consent, institutional review board [IRB] approval, Helsinki declaration, and good clinical practice [GCP] declaration (as appropriate). | **158** |
| | 9b | Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorized access. | **N/A** |
| Statistical analysis | 10a | Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis. | **156-158** |
| | 10b | Report any modification of variables used in the analysis, along with reference (if available). | **N/A** |
| | 10c | Report details about how missing data were handled. Include rate of missing items, missing data mechanism (i.e., missing completely at random [MCAR], missing at random [MAR] or missing not at random [MNAR]) and methods used to deal with missing data (e.g., multiple imputation). | **N/A** |
| | 10d | State how non-response error was addressed. | **N/A** |
| | 10e | For longitudinal surveys, state how loss to follow-up was addressed. | **N/A** |
| | 10f | Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample. | **N/A** |
| | 10g | Describe any sensitivity analysis conducted. | **N/A** |
| **Results** | | | |
| Respondent characteristics | 11a | Report numbers of individuals at each stage of the study. Consider using a flow diagram, if possible. | **159** |
| | 11b | Provide reasons for non-participation at each stage, if possible. | **N/A** |
| | 11c | Report response rate, present the definition of response rate or the formula used to calculate response rate. | **159** |
| | 11d | Provide information to define how unique visitors are determined. Report number of unique visitors along with relevant proportions (e.g., view proportion, participation proportion, completion proportion). | **N/A** |
| Descriptive results | 12 | Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes. | **159-160** |
| Main findings | 13a | Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and p-values. | **158,165-171** |

| | | | |
|---|---|---|---|
| | 13b | For multivariable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate). | **165,168-171** |
| | 13c | Provide details about any sensitivity analysis performed. If there are considerable amount of missing data, report sensitivity analyses comparing the results of complete cases with that of the imputed dataset (if possible). | **N/A** |
| **Discussion** | | | |
| Limitations | 14 | Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders. | **Key considerations for Chapter 9 and the final discussion (Chapter 10)** |
| Interpretations | 15 | Give a cautious overall interpretation of results, based on potential biases and imprecisions and suggest areas for future research. | **Key considerations for Chapter 9 and the final discussion (Chapter 10)** |
| Generalizability | 16 | Discuss the external validity of the results. | **Key considerations for Chapter 9 and the final discussion (Chapter 10)** |
| **Other sections** | | | |
| Role of funding source | 17 | State whether any funding organization has had any roles in the survey's design, implementation, and analysis. | **N/A** |
| Conflict of interest | 18 | Declare any potential conflict of interest. | **N/A** |
| Acknowledgements | 19 | Provide names of organizations/persons that are acknowledged along with their contribution to the research. | **xvi** |

# Appendix 5: Consolidated criteria for reporting qualitative studies (COREQ)

Phase 3: In-depth interview for ethnic Chinese immigrants living with cancer

| Item No | Guide Questions/Description | Reported on Page # |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| **Personal Characteristics** | | |
| 1. Interviewer/ facilitator | Which author/s conducted the interview or focus group? | **PhD student** |
| 2. Credentials | What were the researcher's credentials? E.g., PhD, MD | **PhD student** |
| 3. Occupation | What was their occupation at the time of the study? | **PhD student** |
| 4. Gender | Was the researcher male or female? | **Female** |
| 5. Experience and training | What experience or training did the researcher have? | **Research development courses in qualitative research organised by the MVLS Graduate School at the University of Glasgow** |
| **Relationship with participants** | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | **N/A** |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research? | **Yes, they were informed at the beginning of the interview** |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | **192, researcher's position** |
| **Domain 2: study design** | | |
| **Theoretical framework** | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | **Descriptive qualitative research** |
| **Participant selection** | | |
| 10. Sampling | How were participants selected? e.g., purposive, convenience, consecutive, snowball | **Purpose & convenience & Snowball (74-75).** |
| 11. Method of approach | How were participants approached? e.g., face-to-face, telephone, mail, email | **Email** |
| 12. Sample size | How many participants were in the study? | **Six patients and five informal caregivers** |
| 13. Non-participation Setting | How many people refused to participate or dropped out? Reasons? | **Ten patients and three informal caregivers dropped (Page 109)** |

| Item No | Guide Questions/Description | Reported on Page # |
|---|---|---|
| 14. Setting of data collection | Where was the data collected? e.g., home, clinic, workplace | **Online / Phone** |
| 15. Presence of nonparticipants | Was anyone else present besides the participants and researchers? | **No** |
| 16. Description of sample | What are the important characteristics of the sample? e.g. demographic data, date | **111-112** |
| **Data collection** | | |
| 17. Interview guide | Were questions, prompts, and guides provided by the authors? Was it pilot tested? | **Yes (105-106 )** |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | **No** |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | **Audio** |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | **During and after** |
| 21. Duration | What was the duration of the interviews or focus group? | **Around 1 hour** |
| 22. Data saturation | Was data saturation discussed? | **Yes (14)** |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | **No** |
| **Domain 3: analysis and findings** | | |
| **Data analysis** | | |
| 24. Number of data coders | How many data coders coded the data? | **One (the PhD researcher) with reviewed by two supervisors** |
| 25. Description of the coding tree | Did the authors provide a description of the coding tree? | **N/A** |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | **Derived from the data** |
| 27. Software | What software, if applicable, was used to manage the data? | **NVivo** |
| 28. Participant checking | Did participants provide feedback on the findings? | **No** |
| **Reporting** | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number | **Yes** |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | **Yes** |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | **Yes** |
| 32. Clarity of minor themes | Is there a description of diverse cases or a discussion of minor themes? | **Yes** |

Phase 4: Focus group with health and social care professionals with experience to provide cancer care for ethnic Chinese immigrants

| Item No | Guide Questions/Description | Reported on Page # |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| **Personal Characteristics** | | |
| 1. Interviewer/ facilitator | Which author/s conducted the interview or focus group? | **PhD student** |
| 2. Credentials | What were the researcher's credentials? E.g., PhD, MD | **PhD student** |
| 3. Occupation | What was their occupation at the time of the study? | **PhD student** |
| 4. Gender | Was the researcher male or female? | **Female** |
| 5. Experience and training | What experience or training did the researcher have? | **Research development courses in qualitative research organised by the MVLS Graduate School at the University of Glasgow** |
| **Relationship with participants** | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | **Some extent.** |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research? | **Yes, they were informed at the beginning of the interview** |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | **193, researcher's position** |
| **Domain 2: study design** | | |
| **Theoretical framework** | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | **Descriptive qualitative research** |
| **Participant selection** | | |
| 10. Sampling | How were participants selected? e.g., purposive, convenience, consecutive, snowball | **Purpose & convenience & Snowball (134).** |
| 11. Method of approach | How were participants approached? e.g., face-to-face, telephone, mail, email | **Email** |
| 12. Sample size | How many participants were in the study? | **Four health or social care professionals** |
| 13. Non-participation Setting | How many people refused to participate or dropped out? Reasons? | **One (137-138)** |
| 14. Setting of data collection | Where was the data collected? e.g., home, clinic, workplace | **Online** |
| 15. Presence of nonparticipants | Was anyone else present besides the participants and researchers? | **No** |
| 16. Description of sample | What are the important characteristics of the sample? e.g. demographic data, date | **138** |

| Item No | Guide Questions/Description | Reported on Page # |
|---|---|---|
| **Data collection** | | |
| 17. Interview guide | Were questions, prompts, and guides provided by the authors? Was it pilot tested? | **Yes (136)** |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | **No** |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | **Audio** |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | **During and after** |
| 21. Duration | What was the duration of the interviews or focus group? | **Around 1.5 hour** |
| 22. Data saturation | Was data saturation discussed? | **Yes (135)** |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | **No** |
| **Domain 3: analysis and findings** | | |
| **Data analysis** | | |
| 24. Number of data coders | How many data coders coded the data? | **One (the PhD researcher) with reviewed by two supervisors** |
| 25. Description of the coding tree | Did the authors provide a description of the coding tree? | **N/A** |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | **Derived from the data** |
| 27. Software | What software, if applicable, was used to manage the data? | **NVivo** |
| 28. Participant checking | Did participants provide feedback on the findings? | **No** |
| **Reporting** | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number | **Yes** |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | **Yes** |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | **Yes** |
| 32. Clarity of minor themes | Is there a description of diverse cases or a discussion of minor themes? | **Yes** |

# Appendix 6: Flyers for empirical phases

Flyer for Phase 2 and Phase 3 data collection

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University of Glasgow | College of Medical, Veterinary & Life Sciences

## Are you an ethnic Chinese living in Scotland? Are you affected by cancer? We need your help.

Living with cancer can be challenging. We would like to know about your healthcare needs, quality of life and experiences of care.

By taking part in our study, you can help to improve care services for ethnic Chinese immigrants with cancer in Scotland.

### Please consider taking part if:

| You are a patient | You are a family member |
|---|---|
| You are 18 years old or older. | You are 18 years old or older. |
| You are diagnosed with cancer (any type of cancer). | You are a family member of a patient with cancer (any type), who originally comes from mainland China or Hong Kong or Macao or Taiwan, but now lives in Scotland. |
| You are an ethnic Chinese who was born in mainland China or Hong Kong or Macao or Taiwan or Malaysia or Singapore. | You may be an ethnic Chinese who was born in mainland China or Hong Kong or Macao or Taiwan or Malaysia or Singapore. |
| You now live in Scotland. | You may live in Scotland. |

Scan the QR code to find out more

The study involves an online survey and an optional interview.

Or click here

***For more information, please contact Miss Lin Cheng (palliative care Nurse):***

✉ @student.gla.ac.uk OR ☎ 0141 330 6813/3754

This PhD project has received ethical approval from the **MVLS Ethics Committee, *University of Glasgow.***

Flyer for Phase 2 and 3 public involvement and engagement event

格拉斯哥大學及英國華人關懷癌症協會合辦

University of Glasgow

CHINESE ASSOCIATION FOR CANCER CARE 英國華人關懷癌症協會



Flyer for Phase 4 focus group data collection



Flyer for Phase 5 “Cancer Talk” sessions and data collection




我们的讲座不仅限于知识的传递，我们更希望通过互动和讨论，帮助家长们更深入地了解如何更好地支持家人的健康。因此，我们将一起完成一份关于癌症知识与信念的调查问卷。

* 80% 的肝癌由乙型肝炎所引致，故我们会在现场提供乙型肝炎检测，帮助大家防患于未然（请带备你的 CHI 号码）

扫描二维码来预订座位
上午场 10:30-11:30
下午场 13:30-14:30

Waverley care

University of Glasgow

# Appendix 7: Quantitative data collection instruments

Phase 2 : Survey for ethnic Chinese living with cancer

**Demographic Questionnaire**

Who are you?

A: I am the patient B: I am the family member

**For patients:**

1) **How did you get to know about this survey?**

A: From supportive cancer care organisations B: Online C: Word of mouth

2) **How old are you?**

A: <30 B: 30-40 C: 41-50 D: 51-60 E: 61-70 F: >70

3) What is your sex?

A: Female B: Male C: Prefer not to say

4) **As an ethnic Chinese, where were you born?**

A: Mainland China B: Hong Kong C: Macao D: Taiwan E: Malaysia F: Singapore

5) **How long have you lived in Scotland for?**

A: < 5 years B: 5-10 years C: > 10 years

6) **What is your highest education level?**

A: Never been educated B: Primary school C: Junior high school D: High school

E: Bachelor's degree F: Master's degree G: Doctoral degree

7) **What is your employment status?**

A: Retired B: Unemployed C: Employed full-time D: Employed part-time

E: On sick leave F: Other (Please indicate): _____

8) **How would you describe the area in which you live?**

A: I live in a city B: I live in a suburb or town near a city

C: I live in a rural area, e.g. a remote town or village

9) **What is your marital status?**

A: Single B: Partner C: Married D: Divorced E: Widowed

10) **What is your religion?**

A: Buddhism B: Christianity C: Catholic D: Islam E: None

F: Other _____

**11) What is your average monthly household income?**

A: < £2000 B: £2000--£3000 C: £3000--£4000 D: >£4000

**12) How many children do you have?**

A: 0 B: 1 C: >1

**13) Do you have any dependants in your household? (this means people who 'depend' on your financial support for their survival, e.g. retired parents, children below 18 years old, or people with mental or physical disability)**

A: Yes (please indicate number of dependants: ___) B: No

**14) What type of cancer do you have?**

A: Lung cancer B: Breast cancer C: Liver cancer D: Colon cancer E: Stomach cancer

F: Other solid tumour _____ G: Non-solid tumour _____

**15) How long has it been since you were diagnosed with cancer?**

A: <6 months B: 6-12 months C: 1-2 years D: 2-5 years E: > 5 year

**16) What stage is your cancer?**

A: Stage 1 (the cancer is localised to a small area)

B: Stage 2 (the cancer has grown, but it hasn't spread)

C: Stage 3 (the cancer has grown larger and has possibly spread to lymph nodes)

D: Stage 4 (the cancer has spread to other organs or areas of your body)

E: I do not know

**17) What type of treatment or care are you receiving right now? (Please tick all that apply)**

A: Chemotherapy B: Targeted therapy C: Radiotherapy D: Immunotherapy

E: Hormone therapy F: Alternative therapy (e.g. Chinese Medicine)

G: Palliative care / symptom management only H: I do not know

**18) Are you interested in an interview with the researcher to discuss your experiences of care?**

A: Yes, I am interested (Please leave your email address so that we can contact you _____)

B: No, I am not interested

**For caregiver:**

1) **How did you get to know about this survey?**

A: From supportive cancer care organisations B: Online C: Word of mouth

2) **How old are you?**

A: < 30 B: 30-40 C: 41-50 D: 51-60 E: 61-70 F: >70

3) **What is your sex?**

A: Female B: Male C: Prefer not to say

4) **If you are an ethnic Chinese, where were you born?**

A: Mainland China B: Hong Kong C: Macao D: Taiwan E: Malaysia F: Singapore

G: I was born in another country (Please indicate which country): _____

5) **How long have you lived in Scotland?**

A: < 5 years B: 5-10 years C: > 10 years

D: I do not live in Scotland (Please indicate where you live): _____

6) **What is your relationship with the advanced cancer patients in your care?**

A: Parent B: Husband/Wife C: Son/Daughter D: Partner

E: Other family relationship (Please indicate): ___

7) **What is your highest education level?**

A: Never been educated B: Primary school C: Junior high school D: High school

E: Bachelor's degree F: Master's degree G: Doctoral degree

8) **What is your employment status?**

A: Retired B: Unemployed C: Employed full-time D: Employed part-time

E: Other (Please indicate): _____

9) **How would you describe the area in which you live?**

A: I live in a city B: I live in a suburb or town near a city

C: I live in a rural area, e.g. remote town or village

10) **What is your religion?**

A: Buddhism B: Christianity C: Catholic D: Islam E: None F: Other _____

11) **What is your average monthly household income?**

A: < £2000 B: £2000--£3000 C: £3000--£4000 D: > £4000

12) **How many children do you have?**

A: 0 B: 1 C: >1

13) **Do you have any dependants in your household? (this means people who 'depend' on your financial support for their survival, e.g. retired parents, children below 18 years old, or people with mental or physical disability)**

A: Yes (please indicate number of dependants: ___) B: No

14) **What type of cancer does someone in your care have?**

A: Lung cancer B: Breast cancer C: Liver cancer D: Colon cancer E: Stomach cancer

F: Other solid tumour_____ G: Non-solid tumour _____ H: I do not know

15) **How long have you been caring for a family member with cancer?**

A: < 6 months B: 6-12 months C: 1-2 years D: 2-5 years E: > 5 years

16) **Do you know the stage of cancer of your family member?**

A: Stage 1 (the cancer is localised to a small area)

B: Stage 2 (the cancer has grown, but it hasn't spread)

C: Stage 3 (the cancer has grown larger and has possibly spread to lymph nodes)

D: Stage 4 (the cancer has spread to other organs or areas of the body)

E: I do not know

17) **Are you interested in in an interview with the researcher to discuss your experiences of care?**

A: Yes, I am interested (Please leave your email address so that we can contact you_____)

B: No, I am not interested

Phase 2: FACT-G

## FACT-G (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

| | PHYSICAL WELL-BEING | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|---|---|---|---|---|---|
| GP1 | I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| GP2 | I have nausea | 0 | 1 | 2 | 3 | 4 |
| GP3 | Because of my physical condition, I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| GP4 | I have pain | 0 | 1 | 2 | 3 | 4 |
| GP5 | I am bothered by side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| GP6 | I feel ill | 0 | 1 | 2 | 3 | 4 |
| GP7 | I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |

| | SOCIAL/FAMILY WELL-BEING | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|---|---|---|---|---|---|
| GS1 | I feel close to my friends | 0 | 1 | 2 | 3 | 4 |
| GS2 | I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |
| GS3 | I get support from my friends | 0 | 1 | 2 | 3 | 4 |
| GS4 | My family has accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GS5 | I am satisfied with family communication about my illness | 0 | 1 | 2 | 3 | 4 |
| GS6 | I feel close to my partner (or the person who is my main support) | 0 | 1 | 2 | 3 | 4 |
| Q1 | *Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box and go to the next section.* | ☐ | | | | |
| GS7 | I am satisfied with my sex life | 0 | 1 | 2 | 3 | 4 |

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## FACT-G (Version 4)

**Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

| | EMOTIONAL WELL-BEING | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|---|---|---|---|---|---|
| GE1 | I feel sad | 0 | 1 | 2 | 3 | 4 |
| GE2 | I am satisfied with how I am coping with my illness | 0 | 1 | 2 | 3 | 4 |
| GE3 | I am losing hope in the fight against my illness | 0 | 1 | 2 | 3 | 4 |
| GE4 | I feel nervous | 0 | 1 | 2 | 3 | 4 |
| GE5 | I worry about dying | 0 | 1 | 2 | 3 | 4 |
| GE6 | I worry that my condition will get worse | 0 | 1 | 2 | 3 | 4 |

| | FUNCTIONAL WELL-BEING | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|---|---|---|---|---|---|
| GF1 | I am able to work (include work at home) | 0 | 1 | 2 | 3 | 4 |
| GF2 | My work (include work at home) is fulfilling | 0 | 1 | 2 | 3 | 4 |
| GF3 | I am able to enjoy life | 0 | 1 | 2 | 3 | 4 |
| GF4 | I have accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GF5 | I am sleeping well | 0 | 1 | 2 | 3 | 4 |
| GF6 | I am enjoying the things I usually do for fun | 0 | 1 | 2 | 3 | 4 |
| GF7 | I am content with the quality of my life right now | 0 | 1 | 2 | 3 | 4 |

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Phase 2: FACT-G Caregiver

**FACT-G Caregiver (Version 4)**

Below is a list of statements that other people facing an illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

| | **PHYSICAL WELL-BEING** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| GP1 | I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| GP2 | I have nausea | 0 | 1 | 2 | 3 | 4 |
| GP3 | Because of my physical condition, I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| GP4 | I have pain | 0 | 1 | 2 | 3 | 4 |
| GP FC5 | Are you currently taking any medication or receiving other medical treatments? ☐ No ☐ Yes If yes, I am bothered by side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| GP6 | I feel ill | 0 | 1 | 2 | 3 | 4 |
| GP7 | I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |

| | **SOCIAL/FAMILY WELL-BEING** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| GS1 | I feel close to my friends | 0 | 1 | 2 | 3 | 4 |
| GS2 | I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |
| GS3 | I get support from my friends | 0 | 1 | 2 | 3 | 4 |
| GS FC4 | My family has accepted the illness | 0 | 1 | 2 | 3 | 4 |
| GS5 | I am satisfied with family communication about my illness | 0 | 1 | 2 | 3 | 4 |
| GS6 | I feel close to my partner (or the person who is my main support) | 0 | 1 | 2 | 3 | 4 |
| Q1 | *Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.* | | | | | |
| GS7 | I am satisfied with my sex life | 0 | 1 | 2 | 3 | 4 |

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## FACT-G Caregiver (Version 4)

**Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

| | EMOTIONAL WELL-BEING | Not at all | A little bit | Some-what | Quite a bit | Very much |
|---|---|---|---|---|---|---|
| GE1 | I feel sad | 0 | 1 | 2 | 3 | 4 |
| GE FC2 | I am satisfied with how I am coping with my family member's illness | 0 | 1 | 2 | 3 | 4 |
| GE FC3 | I am losing hope in the fight against my family member's illness | 0 | 1 | 2 | 3 | 4 |
| GE4 | I feel nervous | 0 | 1 | 2 | 3 | 4 |
| GE FC5 | I worry about my family member dying | 0 | 1 | 2 | 3 | 4 |
| GE FC6 | I worry that my family member's condition will get worse | 0 | 1 | 2 | 3 | 4 |

| | FUNCTIONAL WELL-BEING | Not at all | A little bit | Some-what | Quite a bit | Very much |
|---|---|---|---|---|---|---|
| GF1 | I am able to work (include work at home) | 0 | 1 | 2 | 3 | 4 |
| GF2 | My work (include work at home) is fulfilling | 0 | 1 | 2 | 3 | 4 |
| GF3 | I am able to enjoy life | 0 | 1 | 2 | 3 | 4 |
| GF FC4 | I have accepted my family member's illness | 0 | 1 | 2 | 3 | 4 |
| GF5 | I am sleeping well | 0 | 1 | 2 | 3 | 4 |
| GF6 | I am enjoying the things I usually do for fun | 0 | 1 | 2 | 3 | 4 |
| GF7 | I am content with the quality of my life right now | 0 | 1 | 2 | 3 | 4 |


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Phase 2: SCNS-SF 34

**SUPPORTIVE CARE NEEDS SURVEY**
**SHORT FORM 34**
**(SCNS-SF34)**

The Cancer Council New South Wales
Centre for Health Research & Psycho-oncology (CHeRP)

**INSTRUCTIONS**

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Put a circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

| | | |
|---|---|---|
| **NO NEED** | **1** | **Not applicable** – This was not a problem for me as a result of having cancer. |
| | **2** | **Satisfied** - I did need help with this, but my need for help was satisfied at the time. |
| **SOME NEED** | **3** | **Low need** - This item caused me concern or discomfort. I had little need for additional help. |
| | **4** | **Moderate need** – This item caused me concern or discomfort. I had some need for additional help. |
| | **5** | **High need** - This item caused me concern or discomfort. I had a strong need for additional help. |

**For example**

| **In the last month, what was your level of need for help with:** | | **No need** | | **Some need** | | |
|---|---|---|---|---|---|---|
| | | **Not applicable** | **Satisfied** | **Low need** | **Moderate need** | **High need** |
| **1.** | Being informed about things you can do to help yourself to get well | 1 | 2 | 3 | (4) | 5 |

*If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.*

**Now please complete the survey on the next 2 pages.**

| In the last month, what was your level of need for help with: | | No need | | Some need | | |
|---|---|---|---|---|---|---|
| | | Not applicable | Satisfied | Low need | Moderate need | High need |
| 1. | Pain | 1 | 2 | 3 | 4 | 5 |
| 2. | Lack of energy/tiredness | 1 | 2 | 3 | 4 | 5 |
| 3. | Feeling unwell a lot of the time | 1 | 2 | 3 | 4 | 5 |
| 4. | Work around the home | 1 | 2 | 3 | 4 | 5 |
| 5. | Not being able to do the things you used to do | 1 | 2 | 3 | 4 | 5 |
| 6. | Anxiety | 1 | 2 | 3 | 4 | 5 |
| 7. | Feeling down or depressed | 1 | 2 | 3 | 4 | 5 |
| 8. | Feelings of sadness | 1 | 2 | 3 | 4 | 5 |
| 9. | Fears about the cancer spreading | 1 | 2 | 3 | 4 | 5 |
| 10. | Worry that the results of treatment are beyond your control | 1 | 2 | 3 | 4 | 5 |
| 11. | Uncertainty about the future | 1 | 2 | 3 | 4 | 5 |
| 12. | Learning to feel in control of your situation | 1 | 2 | 3 | 4 | 5 |
| 13. | Keeping a positive outlook | 1 | 2 | 3 | 4 | 5 |
| 14. | Feelings about death and dying | 1 | 2 | 3 | 4 | 5 |
| 15. | Changes in sexual feelings | 1 | 2 | 3 | 4 | 5 |
| 16. | Changes in your sexual relationships | 1 | 2 | 3 | 4 | 5 |
| 17. | Concerns about the worries of those close to you | 1 | 2 | 3 | 4 | 5 |
| 18. | More choice about which cancer specialists you see | 1 | 2 | 3 | 4 | 5 |
| 19. | More choice about which hospital you attend | 1 | 2 | 3 | 4 | 5 |
| 20. | Reassurance by medical staff that the way you feel is normal | 1 | 2 | 3 | 4 | 5 |
| 21. | Hospital staff attending promptly to your physical needs | 1 | 2 | 3 | 4 | 5 |
| 22. | Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs | 1 | 2 | 3 | 4 | 5 |

| In the last month, what was your level of need for help with: | | No need | | Some need | | |
|---|---|---|---|---|---|---|
| | | Not applicable | Satisfied | Low need | Moderate need | High need |
| **23.** | Being given written information about the important aspects of your care | 1 | 2 | 3 | 4 | 5 |
| **24.** | Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home | 1 | 2 | 3 | 4 | 5 |
| **25.** | Being given explanations of those tests for which you would like explanations | 1 | 2 | 3 | 4 | 5 |
| **26.** | Being adequately informed about the benefits and side-effects of treatments before you choose to have them | 1 | 2 | 3 | 4 | 5 |
| **27.** | Being informed about your test results as soon as feasible | 1 | 2 | 3 | 4 | 5 |
| **28.** | Being informed about cancer which is under control or diminishing (that is, remission) | 1 | 2 | 3 | 4 | 5 |
| **29.** | Being informed about things you can do to help yourself to get well | 1 | 2 | 3 | 4 | 5 |
| **30.** | Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it | 1 | 2 | 3 | 4 | 5 |
| **31.** | Being given information about sexual relationships | 1 | 2 | 3 | 4 | 5 |
| **32.** | Being treated like a person not just another case | 1 | 2 | 3 | 4 | 5 |
| **33.** | Being treated in a hospital or clinic that is as physically pleasant as possible | 1 | 2 | 3 | 4 | 5 |
| **34.** | Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up | 1 | 2 | 3 | 4 | 5 |

**Thank you for completing this survey**

*Centre for Health Research & Psycho-oncology (2003) Supportive Care Needs Survey – Short Form 34.*
*The Supportive Care Needs Survey – Short Form 34 may not be copied or used without permission.*
*To request permission, please email: CHeRP@newcastle.edu.au*

The Cancer Council New South Wales
Centre for Health Research & Psycho-oncology (CHeRP)

Phase 5: Survey for ethnic Chinese immigrants without cancer diagnosis

# Survey Questionnaire

**Thank you for taking the time to fill out this questionnaire. Once you have completed this questionnaire, please return it to the researcher. Please ask us if you have any questions.**

**Please confirm that you have read and understand the Participant Information Sheet version 1.0 dated 22 05 2024** ☐

**Please confirm that you agree to take part in this study** ☐

**Part 1: Information about you:**

1. How old are you?
   A. <30 B: 30-40 C: 41-50 D: 51-60 E: 61-70 F:>70

2. What is your sex?
   A: Female B: Male

3. As an ethnic Chinese, where were you born?
   A: Mainland China B: Hong Kong C: Macao D: Taiwan E: Malaysia
   F: Singapore G: Other____

4. How long have you lived in Scotland for?
   A:< 5 years B: 5-10 years C: 10-15 years D: 15-20 years E: > 20years

5. What is your highest education level?
   A: Never been educated B: Primary school C: Junior high school
   D: High school E: Bachelor's degree F: Master's degree G: Doctoral degree

6. What is your employment status?
   A: Retired B: Unemployed C: Employed full-time D: Employed part-time
   E: Student F: Other (Please indicate): _____

7. How much do you know about cancer?
   A: I know a lot about it
   B: I know a little
   C: I know nothing

**Part 2: Knowledge and beliefs about cancer:**

8. Which of the following could be a sign of cancer? (circle Yes or No)

| | | |
|---|---|---|
| a. An unexplained lump or swelling | Yes | No |
| b. Unexplained bleeding | Yes | No |
| c. Persistent cough or hoarseness | Yes | No |
| d. Persistent difficulty swallowing | Yes | No |
| e. A change in the appearance of a mole | Yes | No |
| f. Unexplained weight loss | Yes | No |

9. Read each of the following statements and think if you agree or disagree (circle your response):

| | | | | |
|---|---|---|---|---|
| a. It is impossible to treat cancer regardless of highly developed medical science | Strongly agree | Agree | Disagree | Strongly disagree |
| b. Cancer is like a death sentence | Strongly agree | Agree | Disagree | Strongly disagree |
| c. If people's fate is to get cancer, they will get cancer and there is nothing they can do to change fate. | Strongly agree | Agree | Disagree | Strongly disagree |
| d. Thinking of cancer will cause it to happen. | Strongly agree | Agree | Disagree | Strongly disagree |
| f. It is very difficult to be healthy again once a person is diagnosed with cancer. | Strongly agree | Agree | Disagree | Strongly disagree |
| g. People with cancer are easily recognised through their looks. | Strongly agree | Agree | Disagree | Strongly disagree |
| h. People with cancer would not be able to make contributions to society. | Strongly agree | Agree | Disagree | Strongly disagree |
| i. I feel uncomfortable when I am with someone who has cancer | Strongly agree | Agree | Disagree | Strongly disagree |
| j. I would avoid interacting with people who have cancer. | Strongly agree | Agree | Disagree | Strongly disagree |

**Part 3: Cancer prevention**

10. Cancer screening is checking for cancer in people who don't have symptoms. Which cancers do you think are screened for in Scotland? (Circle all that apply)
    A: Breast cancer (women) B: Cervical cancer (women)

C: Prostate cancer (men) D: Lung cancer E: Liver cancer
F: Bowel cancer G: I don't know

11. I would be more likely to get screened for cancer if I was asked by:
A: My family B: A friend C: My GP D: Chinese community group
E: Other_____

12. If I feel well, I don't need to get cancer screening.
A: Strongly agree B: Agree C: Disagree D: Strongly disagree

13. Which of the following might stop you from screened for cancer? (circle all that apply)
A: I don't understand what the tests do
B: I don't know if the tests are safe
C: My religious faith
D: What my friends or family think about these tests
E: Getting tested takes a lot of time
F: Getting tested is expensive
G: Tests might be painful
H: I'd be worried what the doctor might find
I: I don't have symptoms, so why get tested for cancer?
J: None of them can stop me
14. Which of the following tests have you had in the past?
A: Mammogram (for women aged 50-71)
B: Pap test (for women aged 25-64)
C: Bowel test/ poo sample (for men and women aged 50-74)
D: PSA-test (for men over 50)
E: None but I will get tested for _____ (indicate from A to D) when I am eligible.
F: None and I have no plans to get tested.
15. Which of the following do you use to learn about cancer and how it can be prevented? (circle all that apply)
A: Friends/ Family B: News on the TV/ Newspaper C: Internet
D: Advertisements about cancer E: Fundraising initiatives by cancer charities
F: Local community G: Other, describe_____

16. I believe the following can help lower my risk for cancer (circle all that apply).
A: Eating healthy food
B: Getting tested to find cancer early
C: Not smoking
D: Staying physically active
E: Not being exposed to someone's smoke
F: Limiting alcohol consumption

G: Maintaining a healthy weight
H: Other_____
I: I cannot do anything to prevent cancer

17. Sometimes people put-off going to see the doctor, even when they have a symptom that they think might be serious. Which of the following might put you off going to the doctor?

| | | |
|---|---|---|
| a. I would be too scared | Yes | No |
| b. I would not feel confident talking about my symptom with the doctor | Yes | No |
| c. It would be difficult to make an appointment with my doctor | Yes | No |
| d. I have too many other things to worry about | Yes | No |
| e. I would be worried about wasting the doctor's time | Yes | No |
| f. It would be difficult for me to arrange transport to go to the doctor | Yes | No |

**Part 4: Cancer services in Scotland**

18. Have you ever heard of any cancer organisations, charities or campaigns in Scotland?
    A: Yes, please indicate the name if you remember: _____
    B: No, never
19. If you answered yes to the last question, how did you get to know about these organisations? (circle all that apply)
    A: Internet
    B: From a friend
    C: From a family member
    D: Advertisements in the media
    E: Local community
    F: Other_____

# Appendix 8: Permission for use of data collection instruments in Phase 2

Permission to use for FACT-G series instruments

FACIT.org FACIT trans

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Name ("Licensee"): Lin Cheng; Dr.Grigorios Kotronoulas; Prof. Deborah Cairns; U of Glasgow

Measurement: FACT-G, FACT-G-Caregiver

Language(s): English, Simplified Chinese.FACT-G only

Study Title ("Study"): Evaluating the quality of life and unmet needs for Chinese immigrants and their families who are affected by advanced cancer in Scotland

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**Signature:** Li Cheng Jul 27, 2... 16:12 GMT+1)

**Email:** )student.gla.ac.uk

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Name ("Licensee"): Lin Cheng; Dr. Grigorios Kotronoulas; Prof. Deborah Cairns

Measurement: FACT-G

Language(s): Chinese (Traditional)

Study Title ("Study"): Evaluating the quality of life and unmet needs for ethnic Chinese immigrants and their families who are affected by cancer in Scotland

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**Signature:** Lin Cheng (Sep 19, 2023 14:17 GMT+1)

**Email:** @student.gla.ac.uk

Permission to use SCNS-SF 34 instrument

**From:** Allison Boyes <allison.boyes@newcastle.edu.au>
**Sent:** 18 September 2023 2:36
**To:** Lin Cheng (PGR) < _____@student.gla.ac.uk>
**Cc:** Greg Kotronoulas <grigorios.kotronoulas@glasgow.ac.uk>; Deborah Cairns <Deborah.Cairns@glasgow.ac.uk>
**Subject:** RE: Interested about SCNS-SF34 Questionnaire

Dear Crystal,

Thank you for your email.

You are welcome to use the SCNS-SF34 in your research. Please find attached a copy of the survey, the User Manual, and some key papers which may be useful to you. I've also attached a paper about using the survey in an electronic/digital format given your intention to use it in an online survey.

I confirm that there is a Mandarin version of the survey and have attached that version to this email along with the publication describing its cultural and linguistic translation and validation.

Please don't hesitate to contact me if I can be of any assistance, or if there is an opportunity to collaborate with you and your colleagues on this research.

Regards,

Allison

**Dr Allison Boyes**

Senior Research Academic | College of Health, Medicine & Wellbeing
Program Leader | HMRI Equity in Health and Wellbeing Research Program
T: +(
E: allison.boyes@newcastle.edu.au
W: https://www.newcastle.edu.au/profile/allison-boyes orcid.org/0000-0003-1721-0533
The University of Newcastle
University Drive, Callaghan NSW 2308 Australia

**From:** Wendy Wing Tak Lam <wwtlam@hku.hk>
**Sent:** 27 September 2023 9:32
**To:** Lin Cheng (PGR) · @student.gla.ac.uk>
**Subject:** Re: Interested about SCNS-SF 34 Questionnaire

Daer Crystal,
Here is the Chinese prison of the SCNS-34 questionnaire.

Best,
Wendy

Wendy WT Lam, RN, PhD, FFPH
Associate Professor
Head, Division of Behavioural Sciences, School of Public Health
Academic program director, Master of Public Health
Director, Jockey Club Institute of Cancer Care
Li Ka Shing Faculty of Medicine
The University of Hong Kong
Tel:
President, International Psycho-oncology Society

HKU Med LKS Faculty of Medicine
School of Public Health
香港大學公共衛生學院

On 25 Sep 2023, at 8:49 PM, Lin Cheng (PGR) < @student.gla.ac.uk> wrote:

Hello Dr. Wendy Lam

Hope you are well!

I am a PhD student in University of Glasgow, Scotland, UK. My research interest is about supportive cancer care. I am quite interested about the SCNS-SF 34 questionnaire, which





is more suitable for my survey. As most our potential participants may come from HongKong, and they may prefer to read the traditional Chinese version of SCNS-SF 34. I have liaised with Allision, and she said that maybe you have already tested the validity and reliability of SCNS-SF 34 in traditional Chinese. May I ask you help? Could you please send me the traditional Chinese version? Appreciate for your help.

Looking forward for your reply and happy to discuss more.

Best wish
Crystal

# Appendix 9: Ethic Approvals

University of Glasgow

16th October 2023

**MVLS College Ethics Committee**

***Project Title: Understanding the healthcare needs and experiences of care of Chinese immigrants affected by cancer in Scotland***
***Project No: 200220455***

Dear Dr Grigorios Kotronoulas,

The College 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.

- Project end date: As stated in 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
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.
- For projects requiring the use of an online questionnaire, the University has an Online Surveys account for research. To request access, see the University's application procedure at https://www.gla.ac.uk/research/strategy/ourpolicies/useofonlinesurveystoolforresearch/.

Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician
Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion
Chair MVLS Research Ethics Committee

Institute of Cardiovascular and Medical Sciences
College of Medical, Veterinary & Life Sciences
University of Glasgow
Room M0.05
Office Block
Queen Elizabeth University Hospital
Glasgow
G51 4TF

jesse.dawson@glasgow.ac.uk

# Amendment approval email for Phase 4 focus group

Hi Crystal

Good news below from MVLS ethics. I will send you the files that have been approved.

Best wishes
Greg

Sent from my Galaxy

-------- Original message --------
From: MVLS Ethics Admin <mvls-ethics-admin@glasgow.ac.uk>
Date: 03/01/2024 17:53 (GMT+02:00)
To: Greg Kotronoulas <grigorios.kotronoulas@glasgow.ac.uk>, MVLS Ethics Admin <mvls-ethics-admin@glasgow.ac.uk>
Subject: RE: Application No. 200220455

Hi Greg

The Chair says this is fine to do. I'll keep everything on file for reference.

Regards
Neil

---

*Neil Allan*
*MVLS Ethics Committee Adminstrator*

*School of Infection & Immunity*
*College of Medical, Veterinary & Life Sciences*
*Glasgow Biomedical Research Centre*
*Room 314, Sir Graeme Davies Building*
*University of Glasgow*
*120 University Place*
*Glasgow G12 8TA*
*The University of Glasgow, charity number SC004401*

# Amendment approval email for Phase 5 survey

**RE: Request about privacy notice for an anonymous survey**

NeilAllan
To: Lin Cheng (PGR); MVLS Ethics Admin
Cc: Greg Kotronoulas

Flagged

You replied on Fri 2024-05-31 13:00

Hi Crystal

Sorry for the delay. The committee says the amendment is fine to approve.

Regards
Neil

---

*Neil Allan*
*MVLS Ethics Committee Administrator*

*School of Infection & Immunity*
*College of Medical, Veterinary & Life Sciences*
*Glasgow Biomedical Research Centre*
*Room 314, Sir Graeme Davies Building*
*University of Glasgow*
*120 University Place*
*Glasgow G12 8TA*
*The University of Glasgow, charity number SC004401*

---

**From:** Lin Cheng (PGR) <[redacted]student.gla.ac.uk>
**Sent:** Thursday, May 23, 2024 2:36 PM
**To:** MVLS Ethics Admin <mvls-ethics-admin@glasgow.ac.uk>
**Cc:** Greg Kotronoulas <grigorios.kotronoulas@glasgow.ac.uk>
**Subject:** Re: Request about privacy notice for an anonymous survey

Hello again Neil

Sorry, we do a slightly change for the PIS, if you do not mind, can we update it in here and please the ethic committee review this final version?

The project number is : 200220435, and the title is " Understanding the healthcare needs and experiences of care of Chinese immigrants affected by cancer in Scotland".

I am really sorry if this makes any inconvenience. Thanks for your help!

Best wish
Crystal

# Appendix 10: Participant Information Sheets, Privacy Notices and Consent forms

Phase 2 : Survey for ethnic Chinese living with cancer

University of Glasgow | College of Medical, Veterinary & Life Sciences

**PARTICIPANT INFORMATION SHEET**
**ONLINE SURVEY**
**Version 1, 25.07.2023**

**1. Study title**

Evaluating the quality of life and unmet needs of Chinese immigrants and their families who are affected by cancer in Scotland

**2. Invitation paragraph**

My name is Lin Cheng, a Chinese nurse and a PhD student in Nursing at the University of Glasgow, Scotland, UK. You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**3. What is the purpose of the study?**

Immigrants living in a foreign country might face challenges in daily life, such as cultural and language barriers. The challenge might be greater for patients and families who are affected by cancer. The overall aim of this study is to understand how cancer services in Scotland can be improved to meet the needs of Chinese immigrants who are affected by cancer.

The study involves an online survey and online / telephone interviews. Here, we invite you to consider taking part in the survey only. The survey will help us to better understand your healthcare needs and quality of life. Whether you are a Chinese immigrant patient or a family member affected by cancer, your experiences will help us see how we can better support people like you in the future.

**4. Why have I been invited to participate?**

You have been invited to take part because you:

- Are 18 years old or older.
- Chinese immigrant patient with any type of cancer who lives in Scotland.
  OR
- Family member of a Chinese immigrant patient with cancer who lives in Scotland.

We plan to recruit up to 164 patients and 164 family members.

**5. Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given the information sheet and privacy notice. You will then be asked to sign a consent form. If you sign the consent form and then decide not to take part, you are still free to withdraw at any time and without giving a reason.

**6. What will happen to me if I take part?**

The survey will be conducted online. Taking part in the survey will not require or pose any restrictions to your lifestyle. You will be expected to take the survey at a time that suits you best. You will not have anything to prepare, and there are no right or wrong answers.

**7. What do I have to do?**

For patients, the survey has three sections:

- In section 1, we will ask some background information about you and your health.
- In section 2, we will ask you about any problems you might be experiencing or needs you might have.
- In section 3, we will ask you about your current quality of life.

For family members, the survey has two sections:

- In session 1, we will ask some background information about you.
- In session 2, we will ask about your current quality of life.

We expect the survey will take you 15-20 minutes to complete. The survey will be available in English or Chinese for patients. The survey will be available in English only for family members.

**8. What are the possible disadvantages and risks of taking part?**

This study does not pose any direct disadvantage or risk, and does not affect your health, treatment or circumstances. However, we understand that thinking about your condition and health needs as part of the survey might upset you. If you do feel that some questions are upsetting you, you can pause and continue a bit later or leave the survey by closing your internet browser and completely withdraw from the study without any penalty.

**9. What are the possible benefits of taking part?**

You will receive no direct benefit from taking part in this study. The information that is collected during this study will give us a better understanding of the unmet needs, quality of life for Chinese immigrant patients and families who are affected by cancer in Scotland. We will use this information to generate basic mind map of how to empower you and your families to live more better in the future.

**10. Will my taking part in this study be kept confidential?**

Yes. All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and no one outside of this research team will be able to find out your information which could identify you. We will use the University of Glasgow proved platform “Qualtrics” to collect your data, and it could ensure your data security, privacy and confidentiality. After we finish the data collection period, your data will be deleted from “Qualtrics”. All data in electronic format will be securely stored and back up with password protected on secure online servers at the University of Glasgow.

**11. What will happen to my data?**

The university is responsible for looking after your information and using it properly. Your anonymised research data (i.e. demographic information and information you provide at the online survey) will be stored in archiving facilities in line with the University of Glasgow retention policy of at least 10 years. Your data will form part of the study result that will be

published in Lin Cheng's PhD thesis, expert journals, conferences, and presentations. Your name will not appear in any publication.

Your rights to access, change or move the information we store may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. Researchers from the University of Glasgow collect, store and process all personal information in accordance with General Data Protection Regulation (2018). You can find out more about how we use your information by reading the Privacy Notice that comes with this information sheet and from the PhD student, Lin Cheng (please see 'Contact for Further Information' below).

**12. What will happen to the results of the research study?**

The overall results of this study will be written up as a part of Lin Cheng's thesis for the requirements for the degree of Doctor of Philosophy (PhD) in Nursing at the University of Glasgow. It is expected that the study will be published in high quality international peer reviewed journals and conferences between 2024 to 2025. Anything else that you fill in the questionnaires will not be identified. We will also prepare a plain Chinese summary of the study's findings and make it available to you should you with to have a copy.

**13. Who is organising and funding the research?**

The University of Glasgow is organising this study as part of a programme of doctoral studies. The funding comes from China Scholarship Council in the form of the PhD scholarship.

**14. Who has reviewed the study?**

The study has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee, University of Glasgow.

**15. Contact for Further Information:**

**Lin Cheng (PhD Student)**
PhD Student in Nursing & Healthcare
School of Medicine, Dentistry & Nursing
University of Glasgow, Scotland, UK
Tel:
Email: _____@student.gla.ac.uk (UK) _____ (China)

**Dr. Grigorios Kotronoulas (First Supervisor)**
Reader in Supportive Cancer Care
School of Medicine, Dentistry & Nursing
University of Glasgow, Scotland, UK
Tel : +44 (0)
Email : grigorios.kotronoulas@glasgow.ac.uk

**Prof Deborah Cairns (Second Supervisor)**
Professor of Health and Neurodevelopmental Conditions
School of Health and Wellbeing
University of Glasgow, Scotland, UK
Tel: +44 (0)

Email: Deborah.Cairns@glasgow.ac.uk

**Thank you for taking the time to read this Participant Information Sheet.**
**Please do not hesitate to contact us if you require any further information.**

## Privacy Notice for Project "Evaluating the quality of life and unmet needs for Chinese immigrants and their families who are affected by cancer in Scotland"

### Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data processed in relation to which you fill into the survey. This privacy notice will explain how the University of Glasgow will process your personal data.

### Why we need it

We will ask a question about whether you are interested in attending the in-depth interview, and if you are interested about it, then we will collect you identifiable personal data (email address) to contact with you for the in-depth interview process.

We are also gathering some personal data, e.g. your age but not date of birth, time since diagnosis, stage of disease, treatment protocol. We will treat this kind of personal data as research data.

### Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is "public task/official authority" for personal data. . "Public task/official authority" covers activities undertaken as part of the core functions of the University. For your health data, we need to collect them on the basis that it is necessary for archiving purposes, scientific or historical research purposes or statistical purposes.

### What we do with it and who we share it with

Your research data and personal data used as research data you provide will be processed only by the PhD student and her PhD supervisors at the University of Glasgow in the Scotland, United Kingdom. The self-designed demographic questionnaire will collect personal data, e.g. on your age but not date of birth, time since diagnosis, stage of disease, treatment protocol. If you are interested to attend the in-depth interview which is an another part of this PhD project, then we will ask you write down your email. We will use the University of Glasgow approved platform Qualtrics® to collect your data. After we finish the data collection period, your data will be deleted from the Qualtrics® server and stored on secure University of Glasgow servers for the rest of the study. We will create separate folders to store your personal data and research data with password protection. Your data will be treated as strictly confidential and only the PhD student and her PhD supervisors will access it. We will not share any of your data with anyone outside this research group.

### How long we keep it for

According to the University of Glasgow policy, research data and non-identifiable personal data (i.e. gender, age but not date of birth, health data) that we will treat as research data have long-term value, therefore we will safely store them in the University of Glasgow institutional data repository Enlighten for at least 10 years.

Your identifiable personal data (email address) which we collect for potential participants of in-depth interview do not have long term value, therefore we will delete when we finish the data collection of in-depth interview as soon as possible.

### What are your rights?*

You can request access to the information that we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. If you wish to exercise any of these rights, please submit your request via the webform or contact dp@gla.ac.uk.

### Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter.

Privacy Notice, v1, 25.07.2023

Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/.

University of Glasgow | College of Medical, Veterinary & Life Sciences

**Title of Project:** Evaluating the quality of life and unmet needs of ethnic Chinese immigrants and their families who are affected by cancer in Scotland

**Name of Researchers:** Lin Cheng; Dr Grigorios Kotronoulas; Prof Deborah Cairns

## ONLINE CONSENT FORM

**Version 2, 18.09.2023**

I confirm that I have read and understood the Participant Information Sheet version 2, dated 18.09.2023.

I confirm that I have read and understood the Privacy Notice version 2, dated 18.09.2023.

I have had the opportunity to think about the information and ask questions, and I understand the answers I have been given.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I agree to the way my data will be collected and processed and that research data will be stored at least 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.

I understand that all data and information I provide will be kept confidential and will be seen only by the study researchers.

I agree that data described in the information sheet will be kept for the purposes of this research project and they will be used as part of the PhD project and included in a PhD thesis.

I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.

I agree to take part in this study ☐

I do not agree to take part in this study ☐

Phase 3 in-depth interview for ethnic Chinese immigrants living with cancer

University of Glasgow | College of Medical, Veterinary & Life Sciences

# PARTICIPANT INFORMATION SHEET
## In-depth interview
**Version 2, 19.09.2023**

**1. Study title**

How do ethnic Chinese immigrant patients and families who are affected by cancer experience cancer care in Scotland?

**2. Invitation paragraph**

My name is Lin Cheng, a Chinese nurse and a PhD student in Nursing at the University of Glasgow, Scotland, UK. You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**3. What is the purpose of the study?**

Immigrants living in a foreign country might face challenges in daily life, such as cultural and language barriers. The challenge might be greater for patients and families who are affected by cancer. The overall goal of this study is to help us understand in what way cancer services in Scotland can become more culturally aware so that they meet the unique needs of ethnic Chinese immigrants who are affected by cancer.

The study involves an online survey and online / telephone interviews. Here, we invite you to consider taking part in an interview. The interview will help us to better understand your experiences of receiving cancer care as an immigrant in Scotland. Whether you are a ethnic Chinese immigrant patient or a family member affected by cancer, your experiences will help us see how we can better support people like you in the future.

**4. Why have I been invited to participate?**

Patients – You have been invited to take part because:

- You are 18 years old or older.
- You are a patient with cancer (any type).
- You are an ethnic Chinese who originally come from mainland China or Hong Kong or Macao or Taiwan or Malaysia or Singapore.
- You now live in Scotland.

OR

Family members – You have been invited to take part because:

- You are 18 years old or older.
- You are a family member of a patient with cancer, who originally comes from mainland China or Hong Kong or Macao or Taiwan or Malaysia or Singapore, but now lives permanently in Scotland.
- You may be an ethnic Chinese who originally come from mainland China or Hong Kong or Macao or Taiwan or Malaysia or Singapore.

- You may live in Scotland.

**5. Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given the information sheet and privacy notice. You will then be asked to sign a consent form. If you sign the consent form and then decide not to take part, you are still free to withdraw at any time and without giving a reason

**6. What will happen to me if I take part?**

The in-depth interview will be conducted remotely by Teams or telephone. You will be free to choose which option suits you best. We will arrange a suitable time for your interview. The researcher will ask you questions about your experiences of care. We will audio record your interview so that we can analyse the data. Taking part in the interview will not require or pose any restrictions to your lifestyle. You will be expected to take the interview at a time that suits you best.

**7. What do I have to do?**

The interview will take 45-60 minutes of your time. It will be in the form of a conversation with the researcher. You will not have anything to prepare, and there are no right or wrong answers. You will be free to choose whether you want to do your interview in English or Chinese.

**8. What are the possible disadvantages and risks of taking part?**

This study does not pose any direct disadvantage or risk, and does not affect your health, treatment or circumstances. However, we understand that thinking about your condition and health needs as part of the interview might upset you. If you do feel that some questions are upsetting you, you can pause and continue a bit later, or you can completely withdraw from the interview without any penalty.

**9. What are the possible benefits of taking part?**

You will receive no direct benefit from taking part in this study. The information that is collected during this study will give us a better understanding from a cultural perspective about how ethnic Chinese immigrants in Scotland who are affected by cancer perceive and experience healthcare/cancer care services. We will use this information to identify how to potentially improve access to provision of more culturally aware cancer care in Scotland. Your participation can also help us to understand the reasons for any difficulties of ethnic Chinese immigrants with access to healthcare services and how these might be overcome.

**10. Will my taking part in this study be kept confidential?**

Yes. All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and no one outside of this research team will be able to find out your information which could identify you. All data in electronic format will be securely stored and back up with password protected on secure online servers at the University of Glasgow.

**11. What will happen to my data?**

Your identifiable personal data (email address) will only be used to communicate with you. We will take the recording to the analysis process, because we have to listen the interview again and again to do the data analysis. We will transcribe each interview before the analysis begins. If you prefer to take the interview in Chinese, then Lin Cheng will translate the transcription from Chinese into English.

The University of Glasgow is responsible for looking after your information and using it properly. We will securely destroy your identifiable data (email address) one month after the end of the study. Your anonymised research data (i.e. demographic information and information you provide during the interview) will be stored in archiving facilities in line with the University of Glasgow retention policy of at least 10 years. Your data will form part of the study result that will be published in Lin Cheng's PhD thesis, expert journals, conferences, and presentations. Your name will not appear in any publication.

Your rights to access, change or move the information we store may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally- identifiable information possible. Researchers from the University of Glasgow collect, store and process all personal information in accordance with General Data Protection Regulation (2018). You can find out more about how we use your information by reading the Privacy Notice that comes with this information sheet and from the PhD student, Lin Cheng (please see 'Contact for Further Information' below).

**12. What will happen to the results of the research study?**

The overall results of this study will be written up as a part of Lin Cheng's thesis for the requirements for the degree of Doctor of Philosophy (PhD) in Nursing at the University of Glasgow. It is expected that the study will be published in high quality international peer reviewed journals and conferences between 2024 to 2025. Anything else that you give during the interview process will not be identified. We will also prepare a plain Chinese summary of the study's findings and make it available to you should you with to have a copy.

**13. Who is organising and funding the research?**

The University of Glasgow is organising this study as part of a programme of doctoral studies. The funding comes from China Scholarship Council in the form of the PhD scholarship.

**14. Who has reviewed the study?**

The study has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee, University of Glasgow.

**15. Contact for Further Information:**

**Lin Cheng (PhD Student)**
PhD Student in Nursing & Healthcare
School of Medicine, Dentistry & Nursing
University of Glasgow, Scotland, UK
Tel: +44
Email: [redacted]@student.gla.ac.uk

**Dr Grigorios Kotronoulas (First Supervisor)**
Reader in Supportive Cancer Care
School of Medicine, Dentistry & Nursing
University of Glasgow, Scotland, UK
Tel : +
Email : grigorios.kotronoulas@glasgow.ac.uk

**Prof Deborah Cairns (Second Supervisor)**
Professor of Health and Neurodevelopmental Conditions
School of Health and Wellbeing
University of Glasgow, Scotland, UK
Tel: +
Email: Deborah.Cairns@glasgow.ac.uk

**Thank you for taking the time to read this Participant Information Sheet.**
**Please do not hesitate to contact us if you require any further information.**

## Privacy Notice for Project "How do ethnic Chinese immigrant patients and families who are affected by cancer experience cancer care in Scotland?"

### Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data processed in relation to which you give the information during the interview. This privacy notice will explain how the University of Glasgow will process your personal data.

### Why we need it

We need this privacy notice because we are collecting your personal data. Your identifiable personal data (email address) will be used for communication purpose. Your non-identifiable personal data will be treated as research data.

### Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is "public task/official authority" for personal data. . "Public task/official authority" covers activities undertaken as part of the core functions of the University. For the health data for patients group, we need to collect them on the basis that it is necessary for archiving purposes, scientific or historical research purposes or statistical purposes.

### What we do with it and who we share it with

Your research data and personal data used as research data you provide will be processed only by the PhD student and her PhD supervisors at the University of Glasgow in the Scotland, United Kingdom. We will not share any collected to others without our research group. If you prefer to take the interview by Team, then we will start the Team recording. If you prefer to take the interview by telephone, then we will use recorder to record the interview process. The aim of the recording is to help us to do the data analysis. As we have to listen the recording again and again for each interview and find the similar content.

We will create different folders with password protection to store each recording. You data will be treated as strictly confidential and only the PhD student and her PhD supervisors will access it.

### How long we keep it for

According to the University of Glasgow policy, research data and non-identifiable personal data (i.e. gender, age but not date of birth, health data) that we will treat as research data have long-term value, therefore we will safely store them in the University of Glasgow institutional data repository Enlighten for at least 10 years.

Your identifiable personal data (email address) do not have long term value, therefore we will delete when we finish the data collection of in-depth interview as soon as possible.

### What are your rights?*

You can request access to the information that we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. If you wish to exercise any of these rights, please submit your request via the webform or contact dp@gla.ac.uk.

### Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter.

Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/.

University of Glasgow | College of Medical, Veterinary & Life Sciences

**Title of Project:** How do ethnic Chinese immigrant patients and families who are affected by cancer experience cancer care in Scotland?

**Name of Researchers:** Lin Cheng; Dr Grigorios Kotronoulas; Prof Deborah Cairns

## ONLINE CONSENT FORM

**Version 2, 19.09.2023**

I confirm that I have read and understood the Participant Information Sheet version 2, dated 19.09.2023.

I confirm that I have read and understood the Privacy Notice version 2, dated 19.09.2023.

I have had the opportunity to think about the information and ask questions, and I understand the answers I have been given.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I understand that my interview will be recorded.

I agree to the way my data will be collected and processed and that research data will be stored at least 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.

I understand that all data and information I provide will be kept confidential and will be seen only by the study researchers.

I agree that data described in the information sheet will be kept for the purposes of this research project and they will be used as part of the PhD project and included in a PhD thesis.

I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.

I agree to take part in this study ☐

I do not agree to take part in this study ☐

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |

Phase 4 focus group with health and social care professionals with experience to provide cancer care for ethnic Chinese immigrants

University of Glasgow | College of Medical, Veterinary & Life Sciences

**PARTICIPANT INFORMATION SHEET**

**Focus group interview**

**Version 1, 05.12.2023**

**1. Study title**

Experiences of caring for ethnic Chinese people affected by cancer among health and social care staff in Scotland

**2. Invitation paragraph**

My name is Lin Cheng, a Chinese nurse and a PhD student in Nursing at the University of Glasgow, Scotland, UK. You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**3. What is the purpose of the study?**

Immigrants living in a foreign country might face challenges in daily life, such as cultural and language barriers. The challenge might be greater for patients and families who are affected by cancer. The overall goal of this study is to help us understand in what way health and social care services in Scotland can become more culturally aware so that they meet the unique needs of ethnic Chinese who are affected by cancer. We define ethnic Chinese anyone originating from mainland China, Hong Kong, Malaysia, Macao, Singapore or Taiwan.

This study involves a focus group interview. The focus group interview will help us to better understand the experiences of health and social care services staff in Scotland when interacting with ethnic Chinese affected by cancer, what needs ethnic Chinese might voice, and what support should be in place for health and social care staff in Scotland to help them offer more tailored care to ethnic Chinese who are affected by cancer.

**4. Why have I been invited to participate?**

You have been invited to take part because:

- You are 18 years old or older.
- You are member of staff of any health or social care service in Scotland, who has experience of offering care to ethnic Chinese who live in Scotland and are affected by cancer.

**5. Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given the information sheet and privacy notice. You will then be asked to sign a consent form. If you sign the consent form and then decide not to take part, you are still free to withdraw at any time and without giving a reason.

**6. What will happen to me if I take part?**

We will ask you to take part in a focus group interview with other health and social care services staffs. The focus group interview will be conducted online and remotely via Teams. We will audio record the interview so that we can analyse the data. Taking part in the interview will not require or pose any restrictions to your workload, except only for the purposes of the interview.

**7. What do I have to do?**

The focus group interview will take 60-90 minutes of your time. It will be in the form of a conversation with the researcher and other participants. The researcher will ask you questions about your experiences interacting with ethnic Chinese affected by cancer. You can answer questions and discuss with other participants. You will not have anything to prepare, and there are no right or wrong answers.

**8. What are the possible disadvantages and risks of taking part?**

This study does not pose any direct disadvantage or risk. If you do feel that the interview is upsetting you for any reason, you can leave the online call and rejoin, or you can completely withdraw from the interview without any penalty.

**9. What are the possible benefits of taking part?**

Although you will receive no direct benefit from taking part in this study, results from this study will be used to identify ways to provide more culturally aware cancer care in Scotland, which you might find helpful in your daily practice.

**10. Will my taking part in this study be kept confidential?**

Yes. All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number in the interview transcript, and no one outside of this research team will be able to find out your information which could identify you. All data in electronic format will be securely stored and back up with password protected on secure online servers at the University of Glasgow.

**11. What will happen to my data?**

The University of Glasgow is responsible for looking after your information and using it properly. Your identifiable personal data (first and last name, email address) will only be used to communicate with you. We will take the audio recording to the analysis process, because we have to listen the interview again and again to do the data analysis. We will transcribe each interview before the analysis begins.

We will securely destroy your identifiable data one month after the end of the project. Your anonymised research data (i.e. demographic information and information you provide during the interview) will be stored in archiving facilities in line with the University of Glasgow retention policy of 10 years. Your data will form part of the study result that will be published in Lin Cheng's PhD thesis, expert journals, conferences, and presentations. Your name will not appear in any publication.

Your rights to access, change or move the information we store may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. Researchers from the University of Glasgow collect, store and process all personal information in accordance with General Data Protection Regulation

(2018). You can find out more about how we use your information by reading the Privacy Notice that comes with this information sheet and from the PhD student, Lin Cheng (please see 'Contact for Further Information' below).

**12. What will happen to the results of the research study?**

The overall results of this study will be written up as a part of Lin Cheng's thesis for the requirements for the degree of Doctor of Philosophy (PhD) in Nursing at the University of Glasgow. It is expected that the study will be published in high quality international peer reviewed journals and conferences in 2025. No identifiable data will be published. We will also prepare a summary of the study's findings and send a copy to you for your records.

**13. Who is organising and funding the research?**

The University of Glasgow is organising this study as part of a programme of doctoral studies. The funding comes from China Scholarship Council in the form of the PhD scholarship.

**14. Who has reviewed the study?**

The study has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee, University of Glasgow.

**15. Contact for Further Information:**

**Lin Cheng (PhD Student)**
PhD Student in Nursing & Healthcare
School of Medicine, Dentistry & Nursing
University of Glasgow, Scotland, UK
Tel: ·
Email: @student.gla.ac.uk

**Dr Grigorios Kotronoulas (First Supervisor)**
Reader in Supportive Cancer Care
School of Medicine, Dentistry & Nursing
University of Glasgow, Scotland, UK
Tel : ·
Email : grigorios.kotronoulas@glasgow.ac.uk

**Prof Deborah Cairns (Second Supervisor)**
Professor of Health and Neurodevelopmental Conditions
School of Health and Wellbeing
University of Glasgow, Scotland, UK
Tel: ·
Email: Deborah.Cairns@glasgow.ac.uk

**Thank you for taking the time to read this Participant Information Sheet.**
**Please do not hesitate to contact us if you require any further information.**

## Privacy Notice for Project "Experiences of caring for ethnic Chinese people affected by cancer among health and social care staff in Scotland"

### Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data processed in relation to which you give the information during the focus group interview. This privacy notice will explain how the University of Glasgow will process your personal data.

### Why we need it

We need this privacy notice because we are collecting your identifiable personal data, i.e. first & last name and email address. Your personal data will be used for communication purposes. Your non-identifiable personal data (i.e. gender, age but not date of birth) will be treated as research data.

### Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is "public task/official authority" for personal data. "Public task/official authority" covers activities undertaken as part of the core functions of the University.

### What we do with it and who we share it with

Your personal data will be processed only by the PhD student and her PhD supervisors at the University of Glasgow in the Scotland, United Kingdom. We will not share any collected to others without our research group. The focus group interview will be conducted online and remotely via Teams. We will audio record the interview so that we can analyses the data. As we have to listen the recording again and again for the interview and find the similar content.

We will create different folders with password protection to store recording. You data will be treated as strictly confidential and only the PhD student and her PhD supervisors will access it.

### How long we keep it for

According to the University of Glasgow policy, non-identifiable personal data which are treated as research data have long-term value, therefore we will safely store them in the University of Glasgow institutional data repository Enlighten for 10 years.

Identifiable personal data (first & last name, email address) do not have long term value, therefore we will securely delete them soon after the end of the project.

### What are your rights?*

You can request access to the information that we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. If you wish to exercise any of these rights, please submit your request via the webform or contact dp@gla.ac.uk.

### Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter.

Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/.

University of Glasgow | College of Medical, Veterinary & Life Sciences

**Title of Project:** Experiences of caring for ethnic Chinese people affected by cancer among health and social care staff in Scotland

**Name of Researchers:** Lin Cheng; Dr Grigorios Kotronoulas; Prof Deborah Cairns

# ONLINE CONSENT FORM

**Version 1, 11.12.2023**

I confirm that I have read and understood the Participant Information Sheet version 1, dated 05.12.2023.

I confirm that I have read and understood the Privacy Notice version 1, dated 05.12.2023.

I have had the opportunity to think about the information and ask questions, and I understand the answers I have been given.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I understand that this focus group interview will be recorded.

I agree to the way my data will be collected and processed and that research data will be stored for 10 years in university archiving facilities in accordance with relevant Data Protection policies and regulations.

I understand that all data and information I provide will be kept confidential and will be seen only by the study researchers.

I agree that data described in the information sheet will be kept for the purposes of this research project and they will be used as part of the PhD project and included in a PhD thesis.

I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.

I agree to take part in this study ☐

I do not agree to take part in this study ☐

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |

Phase 5: Survey for ethnic Chinese immigrants without cancer diagnosis

University of Glasgow | College of Medical, Veterinary & Life Sciences

**PARTICIPANT INFORMATION SHEET**

**Survey**

**Version 1, 22.05.2024**

**1. Study title**

Perceptions about cancer among ethnic Chinese immigrants in Scotland

**2. Invitation paragraph**

My name is Lin Cheng, a Chinese nurse and a PhD student in Nursing at the University of Glasgow, Scotland, UK. You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**3. What is the purpose of the study?**

We are taking the ethnic Chinese community as an example group of the population in Scotland. We want to understand their views and attitudes towards cancer, so that a more focused approach to cancer education and awareness programs in Scotland can be taken.

It is important to know what views people hold about cancer, because how people think may affect their action to prevent cancer or to respond to cancer symptoms and signs. This knowledge is also important, particularly because people from diverse cultural backgrounds may hold different views about cancer and respond to cancer differently.

**4. Why have I been invited to participate?**

You have been invited to take part because:

- You are 18 years old or older.
- You are an ethnic Chinese who originally come from mainland China or Hong Kong or Macao or Taiwan or Malaysia or Singapore.
- You live in Scotland now.
- You don't have cancer

**5. Do I have to take part?**

No, it is up to you to decide whether to take part. You will be given this participant information sheet and a privacy notice. After you read them, you can decide whether to take part or not.

**6. What will happen to me if I take part?**

You will be asked to take part in a short, anonymous survey. You will not have to prepare anything. Taking part in the survey will not require or pose any restrictions to your lifestyle.

**7. What do I have to do?**

We will ask you to complete a paper-based survey once. The survey will take around 10 minutes of your time. The survey will ask questions about you, what you know about cancer, and how you feel when you think about cancer. Once you have completed the questionnaire, we will ask you to put it in an envelope and give it back to the researcher. Returning the questionnaire will be considered as consent to this study.

**8. What are the possible disadvantages and risks of taking part?**

This study does not pose any direct disadvantage or risk towards your daily life. However, we understand that thinking about the term of cancer might upset you. If you do feel that some questions are upsetting you, you can skip those questions or you can skip the whole questionnaire without any penalty.

**9. What are the possible benefits of taking part?**

You will receive no direct benefit from taking part in this study. By taking part, you can help us understand how much ethnic Chinese immigrants in Scotland know about cancer and what further education we can offer to them based on identified gaps in their knowledge.

**10. Will my taking part in this study be kept confidential?**

Yes. All information which is collected about you, or responses that you provide, during the research will be kept strictly confidential. This is an anonymous survey, and no one outside of this research team will be able to find out your information which could identify you.

**11. What will happen to my data?**

The university is responsible for looking after your information and using it properly. Your anonymised research data (i.e. your responses to the survey) will be stored in archiving facilities in line with the University of Glasgow retention policy of at least 10 years. Your data will form part of the study result that will be published in Lin Cheng's PhD thesis, expert journals, conferences, and presentations. Because this is an anonymous survey, no one will be able to identify you from your responses.

Your rights to access, change or move the information we store may be limited, as we need to manage your information in specific ways for the research to be reliable and accurate. Researchers from the University of Glasgow collect, store and process all personal information in accordance with General Data Protection Regulation (2018). You can find out more about how we use your information by reading the Privacy Notice that comes with this information sheet and from the PhD student, Lin Cheng (see 'Contact for Further Information' below).

**12. What will happen to the results of the research study?**

The overall results of this study will be written up as a part of Lin Cheng's thesis for the requirements for the degree of Doctor of Philosophy (PhD) in Nursing at the University of Glasgow. It is expected that the study will be published in high quality international peer reviewed journals and conferences between 2024 to 2025. We will also prepare a summary of the study's findings and share it with the ethnic Chinese community.

**13. Who is organising and funding the research?**

The University of Glasgow is organising this study as part of a programme of doctoral studies. The funding comes from China Scholarship Council in the form of the PhD scholarship.

**14. Who has reviewed the study?**

The study has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee, University of Glasgow.

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**Lin Cheng (PhD Student)**
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Tel :
Email : grigorios.kotronoulas@glasgow.ac.uk

**Prof Deborah Cairns (Second Supervisor)**
Professor of Health and Neurodevelopmental Conditions
School of Health and Wellbeing
University of Glasgow, Scotland, UK
Tel:
Email: Deborah.Cairns@glasgow.ac.uk

**Thank you for taking the time to read this Participant Information Sheet.**
**Please do not hesitate to contact us if you require any further information.**

# Privacy Notice for Project "Perceptions about cancer among ethnic Chinese immigrants in Scotland"

## Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data processed in relation to which you fill into the survey. This privacy notice will explain how the University of Glasgow will process your personal data.

## Why we need it

We are gathering some personal data, e.g. your age but not date of birth, how long have you lived in Scotland. We will treat this kind of personal data as research data.

## Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is "public task/official authority" for personal data "Public task/official authority" covers activities undertaken as part of the core functions of the University. For your health data, we need to collect them on the basis that it is necessary for archiving purposes, scientific or historical research purposes or statistical purposes.

## What we do with it and who we share it with

Your research data and personal data used as research data you provide will be processed only by the PhD student and her PhD supervisors at the University of Glasgow in the Scotland, United Kingdom. The self-designed questionnaire will collect personal data, e.g. on your age but not date of birth, how long have you lived in Scotland. The survey will be conducted hybrid online or in person. If you decided to take it online, we would use the University of Glasgow approved platform Qualtrics® to collect your data. If you know this survey and decided to take part in after the community's cancer talk, you can fill the questionnaire which on your seat and give it back after the cancer talk finished. After we finish the data collection period, your data will be deleted from the Qualtrics® server and stored on secure University of Glasgow servers for the rest of the study. The paper version of the survey will be stored in a lockable cabinet in the office of Lin Cheng. Your data will be treated as strictly confidential and only the PhD student and her PhD supervisors will access it. We will not share any of your data with anyone outside this research group.

## How long we keep it for

According to the University of Glasgow policy, research data and non-identifiable personal data (i.e. gender, age but not date of birth, health data) that we will treat as research data have long-term value, therefore we will safely store them in the University of Glasgow institutional data repository Enlighten for at least 10 years.

## What are your rights?*

You can request access to the information that we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or erased. If you wish to exercise any of these rights, please submit your request via the webform or contact dp@gla.ac.uk.

## Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter.

Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/.

# Appendix 11: Qualitative interview guides

Phase 3: In-depth interview for ethnic Chinese immigrants living with cancer

**In-depth interview guide—Patient group**

**First step--preparation:**

Express the appreciation and introduction:

1) What the interview is about?
2) What we use the information for?
3) Who will access to the interview?
4) There is no right and wrong answers
5) Ask if it is ok if the interview will be recorded
6) Tell interviewee that they can stop the interviews if they fell like uncomfortable
7) Ask interviewee if they have any questions, comments before the interview begin.

**Second step—Warm up:**

1. Please tell me more about yourself
2. Why do you want to take part in this study?

**Third step—formal interview starting:**

**Healthcare experiences:**

1) Could you please describe your experience of being an immigrant and living with cancer?
2) From your perspective, what is working well in cancer care services in Scotland?
3) Have you been to any supportive cancer care organisations (for example, Macmillan Cancer Support)? If yes, could you please describe your experience? If not, could you please give me the reason.

4) If you decide to participate in a cancer support program in the future. What type of program would you prefer? (e.g. face-to-face, small group meetings, telephone, mailed print materials, online support group)?
5) What are your greatest needs at the moment?
6) From your perspective, what could be improved to better help you meet your needs?

**Formal resources:**

1. What type of health information have you received in relation to your cancer?
    1) Through what channels?
    2) How useful have they been?
2. Have you ever received any culture-specific information or service about supportive cancer care?
    1) If yes, could you please give me some detail about it? Do you have any suggestions?
    2) If no, what kind of culture-specific information or service would you expect to receive?
3. What would you suggest to make the health care system easier to access for ethnic Chinese immigrant patients with cancer?

**In-depth interview guide—Caregiver group**

**First step--preparation:**

Express the appreciation and introduction:

1) What the interview is about?
2) What we use the information for?
3) Who will access to the interview?
4) There is no right and wrong answers
5) Ask if it is ok if the interview will be recorded
6) Tell interviewee that they can stop the interviews if they fell like uncomfortable
7) Ask interviewee if they have any questions, comments before the interview begin.

**Second step—Warm up:**

1. Please tell me more about yourself
2. Why do you want to take part in this study?

**Third step—formal interview starting:**

**Caregiving experience:**

1) What is the impact of caring for a family member with cancer on your daily life?
2) What are some of the challenges you face?
3) Could you please describe the time when you need support to take care your family member?
4) Have you been to any supportive cancer care organisations (for example, Macmillan Cancer Support)? If yes, could you please describe your experience? If not, could you please give me the reason.

5) If you decide to participate in a cancer support program in the future. What type of program would you prefer? (e.g. face-to-face, small group meetings, telephone, mailed print materials, online support group)?
6) What are your greatest needs at the moment?

**Formal resources:**

1) Do you think the healthcare services in Scotland provide the support you need? If not, why? Please give details.

   If yes:

   1) What service are you using now?
   2) How did you find this service?
   3) How often do you use this service?
   4) How could this service be improved for people in the future?

2) What kind of culture-specific services/ information do you expect to receive from the cancer services in Scotland?

Phase 4: Focus group with health and social care professionals with experience to provide cancer care for ethnic Chinese immigrants

## Focus group interview guide

**First step—preparation:**

Express the appreciation and introduction:

1) What is the focus group interview about?

2) What do we use the information for?

3) Who will access to the interview?

4) There are no right and wrong answers.

5) Remind participants that the interview will be recorded.

6) Tell interviewees that they can leave the interview if they felt uncomfortable, and they can come back. Tell participants to keep microphones on mute when they are not speaking. Tell participants to raise hand when they want to speak. Tell participants to avoid talking at the same time with someone else.

7) Ask interviewees if they have any questions, comments before the interview beginning.

**Second step—warm up:**

1. Ask each participants to say their first name when they speak for the first time. And ask each participant to briefly introduce themselves.

**Third step—formal interview starting:**

**Please describe and discuss:**

**Part I:** ***Perceptions and experiences***

1. In your role, in what ways have you interacted with ethnic Chinese affected by cancer?

2. What specific issues have you observed in your interactions with ethnic Chinese affected by cancer?

3. What have they told you about their experiences?

4. In your experience, how do ethnic Chinese immigrant affected by cancer access information on services?

***Part II: Needs and area for improvement***

1. What challenges have you faced interacting with the ethnic Chinese specifically?

2. Do you find that you as a member of staff are prepared to provide culture specific care to ethnic Chinese patients and families? What more support would you personally need?

3. How could health and social care services become more culturally responsive to immigrants affected by cancer, and particularly the ethnic Chinese?

## Appendix 12: Thematic analysis process

Phase 3 – Patient group:

Thematic analysis process for the development of Theme 1 "Personal factors contributing to psychological distress"

| **Quotations** | **Initial codes** | **Category** | **Theme** |
|---|---|---|---|
| *I'm not able to do what I am supposed to do, for my husband and for my children. Sometimes I feel that I was a burden for the whole family, and this led me to have emotional issues, I could not accept that now I am a cancer patient. (Lily: Breast cancer)* | Maternal responsibility, guilty for family | Mother role disruption | Personal factors contributing to psychological distress |
| *I have been diagnosed with cancer twice. The biggest difference is that the mental pressure is much greater, and I feel more anxiety for my second diagnosis. As when I was first diagnosed, I didn't have children, but now I am a mother of two, and my children are still young, so I worry about who will take care of them." (Emma: Breast cancer).* | Maternal responsibility | Mother role disruption | |
| *I do not want my colleagues to know that I was diagnosed with cancer, so I keep it a secret and isolate myself because I do not want to feel a sense of rejection. (Lily: Breast cancer)* | Concealing diagnosis; anticipated rejection; social withdrawal | Personal beliefs about cancer | |
| *During my most depressed moments, I withdrew from all social activities. No-one knows my cancer diagnosis except my husband. And I didn't want to see* | Concealing diagnosis; Social withdrawal; | Personal beliefs about cancer | |

| | | | |
|---|---|---|---|
| *people's vibrant lives while I was dealing with cancer. I felt like life is unfair for me. (Kelly: Breast cancer)* | | | |
| *At the beginning time, I isolated myself, even didn't tell my parents about my cancer diagnosis. My mother found out about my diagnosis from one of my friends. As of now, only my mother knows about my condition. She hasn't told my father or the rest of the family, as my father had serious hypertension. (Kelly: Breast cancer)* | Concealing diagnosis; | Personal beliefs about cancer | |

Thematic analysis process for the development of Theme 2 “Suboptimal interaction with healthcare professionals”

| **Quotations** | **Initial codes** | **Category** | **Theme** |
|---|---|---|---|
| *After I knew that I had cancer. The doctor asked me if I had any questions, I said no, and then the specialist nurse wrote I handled very well! But that was not the case, because I was in a state where I was not in the mood to ask questions. (Mary: Breast cancer)* | Silence misinterpreted by healthcare professionals | Needs not recognised without explicit expression | Suboptimal interaction with health care professionals |
| *My breast nurse gave me her contact details. The main purpose of contacting her was to help me make an appointment with a doctor. In fact, I had very little contact with her. Because she would not proactively tell me anything (Mary: Breast cancer).* | Limited proactive contact; support dependent on patient initiation | Reactive rather than proactive communication | |
| *I have a breast cancer nurse, and I can call her if I feel unwell, but she doesn't proactively check my condition. Maybe it's because they are very busy with many patients. (Emma: Breast cancer)* | Limited proactive contact; support dependent on patient initiation | Reactive rather than proactive communication | |
| *So, as a patient, you must take the initiative to ask questions before they respond. This is quite the opposite of the culture in Asia, where doctors and nurses will actively inquire about your condition. (Emma: Breast cancer)* | Limited proactive contact; different expectations of professional roles | Cultural mismatch in communication expectations | |

| | | | |
|---|---|---|---|
| *Within many Asian cultural, patients may be less inclined to express their needs or challenge healthcare professionals. They are less likely to actively communicate, often passively accepting the care arrangements proposed by doctors or nurses. (Emma: Breast cancer)* | Limited proactive contact; Reluctance to express needs; | Cultural mismatch in communication expectations | |
| *Sometimes I felt anxious, but the nurse didn't know how to respond, it creates a disconnect. It made me feel misunderstood or even feeling of not being treated equally. (Anna: Lymphoma)* | Emotional needs not adequately responded to; feeling misunderstood | Insufficient recognition and response to emotional needs | |
| *My doctor only answered my questions with 'yes or 'no', without giving any detailed explanations. Maybe he thought I wouldn't understand if he explained more, but in reality, I needed more information about my condition. Because of this, I didn't feel I could fully trust him. I even started to doubt whether he had enough knowledge or experience about my disease. (Sarah: Thyroid cancer)* | Emotional needs not adequately responded to; unmet information needs; | Insufficient information and explanation | |

Thematic analysis process for the development of Theme 3 “Limited support from extended networks”

| **Quotations** | **Initial codes** | **Category** | **Theme** |
|---|---|---|---|
| *My mum came from China to support me, even though travelling to Scotland was not easy for her. The love and care from my family made me feel very comforted. (Mary: Breast cancer)* | Emotional comfort from family | Meaning of extended family support despite geographical distance | Limited support from extended networks |
| *My family was in Malaysia. I was studying in Scotland, then working in here, meeting with my husband then we get married. Actually, I did not receive any support from my parents or siblings. Most of my close friends had back to Malaysia after graduation, so I had no one to help expect my husband during that time. This is one of the biggest issues immigrants face: once you fall ill, there is no family to help you. (Emma: Breast cancer)* | Family geographically distant; loss of friendship; husband as primary support | Restricted support network following migration | |
| *I am married to a Scottish person, and my family are still in China, far away from me. After I was diagnosed with cancer, my husband became my main source of emotional and spiritual support. (Sarah: Thyroid cancer)* | Family geographically distant; husband as primary support | Reliance on immediate family/partner | |
| *My parents living in China, in here, only my husband take care of me. Most of my close friends are no longer here because I’ve been living in the UK for many years, and most of them have returned to China. (Kelly: Breast cancer)* | Family geographically distant; loss of friendship; husband as primary support | Restricted support network following migration | |

Thematic analysis process for the development of Theme 4 “Feeling respect and fully informed about the cancer diagnosis”

| **Quotations** | **Initial codes** | **Category** | **Theme** |
|---|---|---|---|
| *My doctor directly told me my diagnosis, and I was fully informed about it and the treatment decision was made by myself. (Lily: Breast cancer)* | Fully informed; autonomy in treatment decision | Being informed and involved in decisions | Feeling respect and fully informed about the cancer diagnosis |
| *I received my diagnosis directly from my doctor, and my husband accompanied me. The doctor directly explained to me about each treatment and gave me time to make the decision. (Kelly: Breast cancer)* | Autonomy in treatment decision | Being informed and involved in decisions | |
| *I had the chance to ask questions and think about the treatment options, instead of just being told what to do. I felt that my opinion mattered. (Emma: Breast cancer)* | Autonomy in treatment decision | Being heard and involved in care | |
| *I was feeling of being respect, and my doctors and nurses do not have discriminate to me. They don’t say “these kind of people”. They treat everyone with equity. (Lily: Breast cancer)* | Feeling respected; | Respectful and equitable care | |
| *The better thing is the humanistic care, and the healthcare professionals are very kind. There is no sense of nerves when talking with doctors. (Sarah: Thyroid cancer)* | Kindness; | Compassionate professional care | |

| | | | |
|---|---|---|---|
| *I was diagnosed with cancer and got treatment when the COVID-19 was start. Scotland was locked down at that time. I was here alone, and my parents in China were unable to apply for a visa, and they couldn't come even if they wanted to. The nurses who take good care for me and come every day to ask whether my parents plan to come. They helped my parents provide proof of faster visas, and this makes me feel very credible. At times when my parents were not around, the care provided by healthcare professionals made me feel that I was still being well cared for. (Anna: Lymphoma)* | Kindness; | Responsive and compassionate support | |
| *The medical team was very responsible and caring. My doctor was great, but he was very busy, so I did not have many chances to meet with him. My care nurses, on the other hand, took very good care of me. I felt that they were very professional. Each time I met my nurse, she explained my condition in detail. (Kelly: Breast cancer)* | Kindness; | Professional and informative care | |

Thematic analysis process for the development of Theme 5 “Patient reported needs and preferences for addressing them”

| Quotations | Initial codes | Category | Sub theme |
|---|---|---|---|
| *There was no guidance in the entire diagnosis and treatment process, to guide me on what I needed to do in every step. I know the procedure at the GP, but I don’t know the procedure at the hospital. (Mary: Breast cancer)* | Lack of guidance; unfamiliar hospital procedures | Need for healthcare navigation and procedural guidance | Ongoing information needs |
| *I struggled with the healthcare process too many times. I often don’t know what steps to take, who to contact, or how long things will take. Without clear guidance, I sometimes feel lost and overwhelmed. (Lily: Breast cancer)* | Unclear care pathway; uncertainty about contacts and waiting; feeling lost | Need for healthcare navigation and procedural guidance | |
| *From the beginning of my diagnosis, I didn’t really know what was going on. I even went back to my GP, but he just told me I’d been referred and that the medical team would contact me. But no one actually explained anything, and I just received a letter at home. I didn’t realise that the letter was actually confirming my surgery appointment. (Sarah: Thyroid cancer)* | Lack of guidance; Unclear referral process | Need for healthcare navigation and procedural guidance | |
| *Because the amount of information is too large, I do receive the brochures from hospital but it is all in English, there is no Chinese translation. If there is a Chinese version of brochures, I would like to read it. (Mary: Breast cancer)* | English-only written information; preference for Chinese materials | Need for linguistically accessible information | |

| | | | |
|---|---|---|---|
| *If it is impossible to communicate with the doctor, at least a translated version of the information leaflet can help patients with language barriers understand some basic information after their treatment. (Anna: Lymphoma)* | Need for translated information; written information supporting language barriers | Need for linguistically accessible information | |
| *In Chinese culture, patients need to pay attention to their diet. But I didn't receive any diet-related information. For example, how much protein should I take every day to help my body recover? (Mary: Breast cancer)* | Lack of dietary guidance; recovery-related dietary information needs | Need for culturally relevant dietary guidance | |
| *Because under the Chinese cultural background, especially for people who have had surgery, there is actually a big taboo on their diet. However, in the UK, the nurses and doctors did not tell me any dietary precautions. Under traditional Chinese culture, after thyroid surgery, I cannot eat foods with particularly high iodine content, but my doctor never told me about it. (Sarah: Thyroid cancer)* | Lack of dietary guidance; | Need for culturally relevant dietary guidance | |
| *I am a mother, so I especially want to know how mothers in other families take care of their families after suffering from cancer. (Mary: Breast cancer)* | Seeking experiences of similar patients; | Need for experiential and peer information | |
| *I am more interested in patients like me who are in survival situations, their prognosis and living conditions. Real life experiences are more helpful than numbers and words to refer. (Anna: Lymphoma)* | Seeking experiences of similar patients; | Need for experiential and peer information | |

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| *I also looked up a lot of information online to learn about other people's experiences, especially those in the early stages of cancer. And I believe that it is very necessary, and I wish the brochures could include some cases of others' experiences. (Kelly: Breast cancer)* | Seeking experiences of similar patients; | Need for experiential and peer information | |
| *My friends and neighbours also give me a lot of care and buy gifts for me, which makes me very touched. But this is not what I need most at the moment. What I need is someone to understand this disease with me. The help from my friends and neighbours give me sometimes becomes a burden. (Sarah: Thyroid cancer)* | Social support not matching needs; feeling burdened by well-intended support; need for understanding | Limitations of non-peer social support | Peer support networks with Chinese cultural background |
| *The most important thing is that friends who haven't experienced cancer can't fully empathise. They sympathise with me, but they don't truly understand. However, communicating with someone who has been through cancer means they can better relate to me. (Kelly: Breast cancer)* | Lack of shared experience; sympathy without full understanding | Value of shared cancer experience | |
| *Interacting with peers means that we can exchange, encourage, and support. Chinese community needs a role model to share their experiences and let others know that having cancer doesn't make us different from anyone else. After treatment, we can live a normal life. (Emma: Breast cancer)* | Mutual encouragement; sharing experiences; cancer survivor as role model | Peer support through shared experience and positive role modelling | |

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| *I know it is difficult to find the peer, but if we can share our thoughts with each other, it means that we can learn from each other. (Lily: Breast cancer)* | Seeking experiences of similar patients; | Mutual learning through shared experience | |
| *I met a Chinese aunt who also suffered from cancer in my living city. We chat a lot after I diagnosed. She was very helpful. To be honest, this was my first time being hospitalised in Scotland and I had no idea what the process was like. This Chinese aunt told me a lot and relieved my anxiety. Therefore, I hope to know which channels have patient groups or peer support. We really need this organisation. (Sarah: Thyroid cancer).* | Practical guidance from peer; reduced anxiety; shared cultural background | Experiential and practical value of peer support | |
| *Communicating in my mother tongue would help me express my feelings more clearly, even though I don't have any issues with English. (Kelly: Breast cancer).* | Preference for mother-tongue communication; easier emotional expression | Need for linguistically appropriate peer support | |
| *Patients of different ages have different needs. For instance, I'm relatively young, and there can be a communication gap between me and older patients. So, it might be helpful to group patients by age. Younger patients, like me, worry about balancing life with work and fertility issues. (Kelly: Breast cancer)* | Age-specific concerns; Seeking experiences of similar patients; | Need for tailored peer matching | |

Phase 3- Informal Caregiver Group

Thematic analysis process for the development of Theme 1 “Life redefined through caregiver” for information caregiver group

| Quotations | Initial codes | Category | Sub theme |
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| *My wife is a patient with cancer, and I need to earn money and care for the whole family. My life has been changed, and I do not have time for myself. There is no way I can go to any parties or take part in social activities. (James: Husband for wife with breast cancer).* | Increased financial responsibility; loss of personal time; reduced social activities | Competing family and caregiving responsibilities | Breadwinner and caregiver role for family |
| *My wife's physical situation could not make money and we have two children, so all the things was on my side. I was almost working like a daddy and mom. (Tom: Husband for wife with breast cancer)* | Increased financial responsibility; increased parenting responsibilities | Competing family and caregiving responsibilities | |
| *I tried to keep working as usual but needed to spend more time for my parents. That meant my schedule was completely filled with family, leaving no time for friends or hobbies. (Daniel: Son for mother with lung cancer)* | Reduced working hours; prioritising family; loss of personal time; reduced social activities | Caregiving responsibilities displacing personal life | |
| *The hospital is far, and I have to drive her there. I try to arrange things so I can go with her to the doctor's appointments, but sometimes they clash with my work.* | Work–care conflict; giving up employment | Employment disrupted by | Work is not fulfilled due to family affairs |

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| *In the end, I had no choice but to give up my job.(James: Husband for wife with breast cancer)* | | caregiving responsibilities | |
| *Right now, she needs me to spend more time at home to take care of her, and that means I need to reduce my working time. (David: Husband for wife with breast cancer)* | Reduced working hours; prioritising caregiving over employment | Employment disrupted by caregiving responsibilities | |
| *Since October last year, I had to take at least six months off from my work. I don't even have time to do part time. (Tom: Husband for wife with breast cancer)* | Inability to maintain employment | Employment disrupted by caregiving responsibilities | |
| *I cannot work, and my husband needs to work and taking this responsibility. We have heavy financial pressure because we need to pay the mortgage and pay the bills. You need to work. But if I go to work, who takes care of my child? (Susan: Mum for daughter with lymphoma)* | Inability to maintain employment | Employment disrupted by caregiving responsibilities | |
| *After I graduated and started to work, actually, I do not have time to spend with my parents. Until my mum got cancer, I know the importance of the family relationship. In a way, I now treasure this time together. (Daniel: Son for mother with lung cancer)* | Recognising importance of family; valuing time together; increased family closeness | Re-evaluation and strengthening of family relationships | Enhanced family cohesion |

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| *I've been able to spend more time with my family, which is something I didn't have before. I used to be focused on work a lot, but now I'm more involved in my kids' lives. I've been able to take on more of my wife's responsibilities, and I can see the benefits of spending more time with the kids. (Tom: Husband for wife with breast cancer)* | Increased family closeness; | Re-evaluation and strengthening of family relationships | |

Thematic analysis process for the development of Theme 2 “Emotional distress” for information caregiver group

| Quotations | Initial codes | Category | Sub theme |
|---|---|---|---|
| *My wife always got emotional crying and this influenced me a lot. But I still need to provide her with mental support. These things really bother me the most. Sometimes I do not know how to comfort her. (James: Husband for wife with breast cancer)* | Affected by patient's distress; | Emotional burden of supporting the patient | Suppressing personal distress to protect family harmony |
| *The first time when I know my mum was diagnosed with lung cancer, I cried in a corner. I should be more confident and positive toward her with her disease. If my mum knew I was upset, then she will worry about me. (Daniel: Son for mother with lung cancer)* | Hiding own distress; maintaining positivity; protecting patient from caregiver's emotions | Suppression of own emotions to protect the patient | |
| *My mum is always overthinking about her current situation. She is so worried that she will die soon and always asked me how long she can still live. This really breaks me down and makes me emotional as well. Although I feel anxious after hearing her say these things, I do not express my own distress. Instead, I continue to encourage her, as I want to keep her happy. (Daniel: Son for mother with lung cancer)* | Affected by patient's distress; Hiding own distress; protecting patient from caregiver's emotions | Suppression of own emotions while providing support | |
| *In the Chinese community, cancer is often seen as something very negative, and people don’t want to talk about it. They don’t want others to know they have* | Cancer perceived as unlucky; cancer associated with shame; | Cancer-related taboo and stigma | Secrecy and silence to talking about cancer |

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| *cancer because it's seen as unlucky or shameful. (Tom: Husband for wife with breast cancer)* | reluctance to discuss cancer; concealment of diagnosis | | |
| *People do not want to tell if someone is sick in their family. They try to avoid the cancer topic as much as possible. If there was someone diagnosed with cancer, they think it is the bad thing in your family. People do not want their neighbour and friend to know this. They just hiding on that. (Susan: Mother for daughter with lymphoma)* | Cancer perceived as unlucky; cancer associated with shame; reluctance to discuss cancer; concealment of diagnosis | Cancer-related taboo and stigma | |
| *I didn't know anything like the sensitivities to chat about cancer in the Chinese community. So I told them that my daughter was diagnosed with cancer and in hospital, and everybody knows this. But nobody coming to visit and even ask 'How are you?' to me. They even avoid contacting me.(Susan: Mother for daughter with lymphoma)* | Cancer perceived as unlucky; Reluctance to discuss cancer; | Social consequences of cancer-related stigma | |

Thematic analysis process for the development of Theme 3 “Practical challenges in providing care” for information caregiver group

| Quotations | Initial codes | Category | Sub theme |
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| *The biggest difficulty is to understand and communicate with the doctor. Sometimes the professional terms make me frustrated and it was hard to understand. (David: Husband for wife with breast cancer)* | Difficulty in understanding medical terminology; | Language barriers to understanding clinical information | Language barriers |
| *Sometimes I lack confidence about my English level, some complicated medical terms I do not understand, so I always ask doctor to repeat or ask write down and Google by myself. (Daniel: Husband for wife with breast cancer)* | Lack of confidence in English; Difficulty in understanding medical terminology; | Language barriers to understanding clinical information | |
| *In the hospital, the language barrier makes it more difficult. You do not know what's going on. When they explain to me, I still do not understand. This makes me feel like I cannot trust them. (Susan: Mother for daughter with lymphoma)* | Difficulty understanding medical terminology; | Language barriers to understanding clinical information | |
| *I know about the cancer support centre, but I haven't been because it's all in English. Expressing deep emotions in English is difficult for me. I can handle everyday conversations, but finding the right words to express my feelings in English is hard. (David: Husband for wife with breast cancer)* | Language barrier to accessing support; difficulty expressing emotions in English | Language barriers to expressing emotional needs | |
| *So far, my mum's situation is worse than before, I do need support from professional staff, but I am not comfortable to speak English when I express my heart feeling.* | Difficulty expressing emotions in English | Language barriers to expressing emotional needs | |

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| *Maybe my English level does not allow me to do this. (Daniel: Son for mother with lung cancer)* | | | |
| *We came to Scotland for work or study and ended up staying, but our families are still back in China. So, we can only ask friends for help, but even friends have their own commitments. Without close family support, making it harder. (Tom: Husband for wife with breast cancer)* | Family geographically distant; Absence of extended family | Restricted support networks following migration | Lack of extended family support |
| *We do not have any other family members in Scotland, we have to do everything by ourselves. The first time, I asked help from my friend to translate for me, as I would like to know what the disease of my child. But everyone is busy, and they have their own things, they cannot go to hospital with me every time. (Susan: Mother for daughter with lymphoma)* | Family geographically distant; Absence of extended family | Restricted and unreliable informal support | |
| *I have two children, dad had to work, so I had to take over our sick child and the whole family. I had no choice, most of the time, I had to bring the younger one with me to the hospital. No one can take care of our second child, I felt very depressed during that time." (Susan: Mother for daughter with lymphoma)* | Absence of extended family; Managing family responsibilities alone; | Consequences of limited extended support | |

Thematic analysis process for the development of Theme 4 “Identified needs and preferences in supportive cancer care” for information caregiver group

| **Quotations** | **Initial codes** | **Category** | **Sub theme** |
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| *I need information in Chinese to help my wife deal with the side effects of her treatment and to guide the care I give her. If the hospital could provide this, it would really help. (James: Husband of wife with breast cancer)* | Need for Chinese information; | Need for bilingual information to support caregiving | Bilingual information provided by hospital |
| *If there were brochures in Chinese, I would definitely read them to ensure that the treatment is correct and to prepare for the next stage of care. I believe the information that I got from the hospital is definitely correct. (David: Husband for wife with breast cancer)* | Need for Chinese written information; trust in hospital information | Need for bilingual information to support caregiving | |
| *Reading English is not easy to every Chinese patient and family members. I have received brochures, but all those are in English, I know they are helpful, but I do not have motivation to read. So most of time I search information on Chinese website, but not 100% sure that was correct.” (Daniel: Son for mother with lung cancer)* | Low engagement with English materials; reliance on Chinese websites; uncertainty about accuracy | Turning to alternative information sources when bilingual information is unavailable | |
| *As the absence of bilingual information from hospital, I think a lot of Chinese patients rely on what they hear from friends or family or what they read on Chinese social media. But that’s not always accurate. It would be better if* | Need for Chinese written information; | Turning to alternative information | |

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| *hospital have bilingual documents for us to read. (Tom: Husband for wife with breast cancer)* | trust in hospital information | sources when bilingual information is unavailable | |
| *If there was more written information available in Chinese, that explains the treatments and what to expect, it might reduce some of the fear. (Tom: Husband for wife with breast cancer)* | Need for Chinese written information; | Need for bilingual information to support caregiving | |
| *After we had just settled everything in Scotland, my wife was diagnosed with cancer. We don't even have a stable income at that time, and we do not know what kind of financial support we could apply for from the government. (David: Husband for wife with breast cancer)* | Lack of information about financial support | Difficulty accessing financial support | Information related to financial support |
| *Our family needed financial support at that time, but I didn't have any information about that. (Susan: Mother of daughter with lymphoma)* | Lack of information about financial support | Difficulty accessing financial support | |
| *I need to talk to someone who truly understands how I feel and can offer advice based on their own experience. Having someone who's been through it makes a big difference. (David: Husband for wife with breast cancer)* | Need to be understood; shared caregiving experience | Value of shared caregiving experience | Peer support |

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| *It can be hard to talk about the stress and challenges you face when you're taking care of someone with cancer. Sometimes, just knowing that someone else understands what you're going through can make a big difference. It's good to have people to talk to who can offer advice and emotional support. (Tom: Husband for wife with breast cancer)* | Need to be understood; shared caregiving experience | Emotional and practical value of peer support | |
| *People around me don't really understand what I'm going through and the pressure I'm under. That's why I need someone to talk to who truly understands how difficult it is to care for my daughter with cancer. (Susan: Mother for daughter with lymphoma)* | Need to be understood; shared caregiving experience | Limitations of support from people without caregiving experience | |
| *One day, me and my wife met another couple at the hospital who shared a similar cultural background and also had breast cancer. We had a nice chat. It was comforting to talk with someone who understood. (David: Husband for wife with breast cancer)* | Need to be understood; shared caregiving experience | Value of experiential and cultural similarity | |
| *I haven't experienced discrimination, but the language barrier is definitely an issue. Having better translation services would help a lot. When we first met the doctor, we asked for a translator. Sometimes the doctor arranged one, but sometimes not. Maybe the doctor assumed my wife's English was good enough, but my English is not, and I still need to fully understand the treatment and everything.(David: Husband for wife with breast cancer)* | Inconsistent interpreter provision; caregiver's language needs overlooked; | Need for consistent and individualised interpreter support | Interpreter services |

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| *I think having more language support would be a start. Maybe more translators who are trained in medical terminology. (Tom: Husband for patient with breast cancer)* | Need for more interpreters; | Need for appropriately trained interpreters | |
| *I think the government could consider transportation services to help patients get to the hospital. And this can help alleviate the burden for family member, as we have to earn money and take care for family member at the same time. For immigrants like us, we have to rely on ourselves for everything. (David: Husband for patient with breast cancer)* | Need for transport assistance; balancing employment and caregiving; | Need for practical support to manage competing responsibilities | Transport services |
| *Sometimes transportation is an issue. For example, my wife had an appointment in Glasgow, but I had to pick up my kids at the same time. So, having someone to help with transport or transport service would be really helpful. It's hard to be in two places at once, I need to care for my wife but my children are also waiting for me. (Tom: Husband for patient with breast cancer)* | Need for transport assistance; balancing childcare and caregiving responsibility; | Need for practical support to manage competing responsibilities | |

Phase 4: Focus Group

Thematic analysis process for the development of Theme 1 “Experiences of interacting with ethnic Chinese immigrants affected by cancer”

| **Quotations** | **Initial codes** | **Category** | **Sub theme** |
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| *Chinese people don’t feel comfortable to seek formal help. Even if they know about the service, they prefer to deal with things themselves. No matter how good the service is, they would rather rely on family members or close friends for support. (Jane, Oncology Nurse)* | Reluctance to seek formal support; | Preference for informal over formal support | Limited self-disclosure and reluctance to seek formal support |
| *I’ve found that they rely on their own knowledge or things they’ve heard from family or friends to help them. If their networks can’t provide the information, they might look things up online using Google. But even with limited sources, they’re still not willing to reach out for external support. (Linda, Social care worker)* | Reluctance to seek formal support; | Preference for informal over formal support | |
| *Chinese patients are less disclosive themselves, they do not ask their questions and just wait. And this makes the treatment team feel like they are satisfied with everything. However, the truth is that they bring their questions back to home. (Emily, Social care worker)* | Limited disclosure; unexpressed needs; | Unexpressed needs within healthcare interactions | |
| *In Western style the relationship between the patient and healthcare provider is totally different, from the Chinese expectation. In Western healthcare, the relationship between doctors and patients is more distant. It’s a professional relationship, and there’s a clear boundary. But in Chinese culture, patients want a* | Different expectations of patient and healthcare | Mismatch in expectations of healthcare relationships | |

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| *closer, warmer relationship with their healthcare providers. They want to feel cared for, not just as patient. (Helen, Social care worker)* | professional relationships; | | |
| *There are a lot of dietary myths in Chinese culture, especially around what patients can and cannot eat. One of my patients, who was diagnosed with breast cancer, told me she couldn't eat chicken because it contains hormones. (Jane: Oncology Nurse)* | Culturally influenced dietary belief; | Traditional dietary beliefs influencing food choices | Chinese culture beliefs of diet role |
| *Many patients adjust their diets based on traditional Chinese beliefs, particularly those from the older generation. They are very careful about what they eat after treatment, but some of these dietary beliefs are not based on any evidence and are simply followed because others do the same or have told them to. (Linda: Social care worker)* | Culturally influenced dietary belief; | Traditional dietary beliefs influencing food choices | |
| *People don't know the science behind those myths. They follow cultural beliefs about what they should and shouldn't eat, but they might not have accurate information about what's healthy. (Helen: Social care worker)* | Culturally influenced dietary belief; | Traditional dietary beliefs influencing food choices; | |
| *I think professionals should be aware of some Chinese cultural habits. For instance, Chinese people always drink hot water instead of cold water, which is completely different from the Western style. Not just water, but also food. In Western culture, they eat salads, but Chinese people don't like to eat cold food. They believe cold food is bad for their health. (Helen: Social care worker)* | Culturally influenced dietary belief; | Need for recognition of culturally embedded dietary practices | |

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| *I also came across a case where a Chinese patient believed certain foods are good for specific organs. However, when they talk to doctors or nurses, they're told not to follow those traditional ideas because there's no research to support them. So, they're confused. Should they trust the doctors, or should they follow what their culture tells them? In Chinese culture, everyone says certain foods are healthy, but in here, the doctors say no, so they don't know what to do. (Helen: Social care worker)* | Culturally influenced dietary belief; Conflicting dietary advice; tension between traditional and biomedical knowledge | Tension between cultural and biomedical dietary knowledge | |
| *Normally, the Chinese because age-wise, whoever has cancer tends to be from the older generation. And I think it's a taboo in the Chinese community; they don't talk about it. (Helen: Social care worker)* | Reluctance to discuss cancer; | Cancer-related taboo | Cancer is a taboo subject and keeping cancer diagnosis private |
| *I found that my community members don't want to talk about cancer straight away. It seems like a 'big secret' topic, they don't want to tell you anything at all about their cancer diagnosis. They try to withhold, unless you are familiar with them. (Linda: Social care worker)* | Reluctance to discuss cancer; | Cancer-related taboo and concealment | |
| *They won't really let you know their cancer diagnosis until you have a good relationship with them.(Helen Social care worker)* | Reluctance to discuss cancer; trust required before disclosure | Cancer-related concealment and selective disclosure | |

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| *Many people lack understanding of what cancer is. They always associate cancer with death. You got cancer, you are going to die. They have a very negative perspective, and it affects their mental health. Even when they understand that early detection and early treatment can be helpful. But in their mind, they still think that cancer is a penalty for people. They don't see it as something they can fight. (Linda: Social care worker)* | Negative cancer beliefs; | Fatalistic perceptions of cancer | |

Thematic analysis process for the development of Theme 2 “Room for improvement”

| **Quotations** | **Initial codes** | **Category** | **Sub theme** |
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| *At our centre, the elderly sometimes complain that they don't want to go to their appointments because the interpreters aren't good. Sometimes, the interpreter is on the phone, and they can't hear them clearly, so it's difficult for the elderly to understand. (Linda: Social care worker)* | Difficulty using telephone interpreting; | Accessibility limitations of interpreting services | Poor quality of interpreter services |
| *Some patients speak Cantonese or Hakka, but the interpreter is Mandarin speaking, so it does not help. As a result, patients feel that interpreter is not doing it properly. (Linda: Social care worker)* | Interpreter–patient dialect mismatch; | Dialect mismatch in interpreter provision | |
| *Interpreter might just translate words and can't always transfer patient's emotions properly, so patients feel unsupported. (Helen, Social care worker)* | Literal translation; emotional meaning not conveyed; | Loss of emotional meaning through interpretation | |
| *Interpreters often struggle to convey the emotions or personal experiences behind patients' words. But these are exactly sometimes patients want to express and share with their feelings of treatment to doctors. (Jane: Oncology Nurse)* | Literal translation; emotional meaning not conveyed; | Loss of emotional meaning through interpretation | |

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| *Some patients they prefer to go back to Hong Kong because they find it hard to navigate the NHS system when diagnosed with cancer. They don't understand what it means and what help is available. (Helen: Social care worker)* | Difficulty navigating healthcare system; limited awareness of available help; | Difficulty navigating an unfamiliar healthcare system | Access to healthcare |
| *The literacy and understanding are the biggest issue to getting access to healthcare services. Because they do not know what it is, how it is worthy. You need somebody give you some guided direction, what's going on. (Helen: Social Worker)* | Difficulty navigating healthcare system; need for guided direction | Need for healthcare navigation and guidance | |
| *Patients do not know what the services are, where to find help and what resources are available. Therefore, we need experts who know their culture and language to navigate patients to go to the right place to seeking cancer help services. (Jane: Oncology Nurse)* | Difficulty navigating healthcare system; need for culturally and linguistically appropriate navigation | Need for culturally and linguistically tailored navigation | |
| *If NHS have the related position like Chinese speaking community nurse that would be helpful to let patients be familiar with the healthcare system and raise cancer awareness for the public. (Jane: Oncology nurse)* | Need for Chinese-speaking professional; need for guided direction | Culturally and linguistically tailored navigation | |
| *I've been volunteering with a charitable cancer organisation for around four months. I remember when I handing out a Cantonese version of our leaflet to members of my local community, they were so* | Limited awareness of available help; | Limited visibility and reach of existing support resources | |

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| *surprised and eager to take it. They told me they had no idea such material even existed. Their reaction made me realise that the promotion of supportive cancer services may not have been sufficient in the past. (Jane: Oncology nurse)* | insufficient service promotion; | | |
| *I think in Scotland, we need cancer organisations specific for Chinese background patients. England has this kind of organisation, but this is an absence for Scottish cancer care service. (Helen: Social care worker)* | Lack of Chinese-specific cancer organisation; gap in culturally specific cancer support | Limited culturally tailored cancer support | Culturally and linguistically tailored support |
| *Scotland needs to offer peer support groups specifically for Asian people. If there were peer support groups where people could use their first language and share their experiences with others who understand their culture, it would help a lot. (Jane: Oncology nurse)* | Gap in culturally specific cancer support; first-language communication; shared cultural understanding | Need for culturally and linguistically tailored peer support | |
| *If their English isn't good, it's hard for them to find official information. I haven't seen any official publications about cancer in Chinese from NHS website.(Emily: Social care worker)* | Limited official Chinese information; difficulty accessing information | Limited access to authoritative Chinese-language information | |
| *Most official information is in English, but many patients from the Chinese community don't understand it. So, when they experience symptoms, some search for Chinese information online. But they often* | Limited official Chinese information; | Tension between linguistic accessibility | |

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| *cannot distinguish whether this information is reliable then leading to delays in seeking appropriate treatment. (Helen: Social care worker)* | potential delay in help-seeking | and information reliability | |
| *My volunteered charity supportive cancer care organisation has a station in the library with information like leaflets and booklets that they can read. Onsite booklet just shows the English version. But online, we do provide resources in Cantonese. The staff can also email them Cantonese version or even send hard copies by mail to the patients.(Jane: Oncology nurse)* | English-only materials onsite; different formats of information provision | Bilingual resources available but not equally accessible across formats | Considering specific needs for elderly patients |
| *But the reality is how many elderly Chinese people have an email address? Elderly people with cancer don't feel comfortable using technology. I guess that the elderly people are preferring to find the Chinese version booklet onsite at supportive cancer care organisations. (Helen: Social care worker)* | Limited digital literacy; discomfort with technology; preference for onsite printed Chinese materials | Digital barriers to accessing bilingual information | |

# Appendix 13: Publications

Chapter 5 (Systematic Review)

ARTICLE IN PRESS

Seminars in Oncology Nursing 000 (2026) 152246

Contents lists available at ScienceDirect

Seminars in Oncology Nursing

journal homepage: https://www.journals.elsevier.com/seminars-in-oncology-nursing

Review

## Care Experiences and Well-being of Asian Immigrant Cancer Survivors Living in Countries of the Western World Ranked as Very High on the Human Development Index: A Systematic Review of International Evidence

Lin Cheng[a,*], Grigorios Kotronoulas[a], Deborah Cairns[b]

[a] School of Medicine, Dentistry & Nursing, University of Glasgow, Glasgow, Scotland, UK
[b] School of Health and Wellbeing, University of Glasgow, Glasgow, Scotland, UK

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Health inequalities
Equity
Supportive care

ABSTRACT

*Objective:* Cultural diversity is a defining feature of very high Human Development Index countries of the Western world. Asian immigrants represent a growing demographic in these countries and are a vulnerable group at risk of experiencing health disparities, including individuals surviving cancer. We synthesized available research evidence to evaluate the unmet needs, cancer care experience and factors affecting health-related quality of life of Asian immigrant cancer survivors living in countries in the Western world ranked as very high Human Development Index.

*Methods:* This systematic review is reported in accordance with Preferred Reporting Item for Systematic Reviews and Meta-Analyses guidelines. Three electronic databases (MEDLINE, EMBASE, and CINAHL) were systematically searched in September 2023 and again in May 2024 to identify research studies of any design. Predefined inclusion criteria were applied, and findings from the included studies were synthesized narratively.

*Results:* Of 515 records identified, 31 studies met the inclusion criteria: 19 qualitative, 10 quantitative, and two mixed-methods studies. Thirty studies reported on samples of Chinese origin (25 studies with exclusive focus on Chinese immigrants). Six studies reported on samples of Arab origin (one study with exclusive focus on Arab immigrants). Frequently reported unmet needs for both Chinese and Arab immigrants included access to high-quality information, psychological and social support services, and professional interpreter services. Communication with healthcare professionals was often reported as problematic. Psychological burden was commonly reported and negatively affected health-related quality of life in both groups. Cultural beliefs strongly influenced cancer experiences, particularly among Chinese immigrants, who often reported experiencing stigma.

*Conclusion:* While our findings apply predominantly to Chinese and Arab immigrant cancer survivors, it is evident that wealthy living environments and well-developed healthcare systems/services are not panacea. Addressing the unique needs of immigrant cancer survivors, as well as barriers experienced in accessing supportive cancer care in the host country is essential to promoting equitable cancer care. Improving accessibility, navigation, and health literacy are key strategies to optimize outcomes for these populations, together with a need to re-shape supportive care approaches to suit cultural norms and preferences.

*Implications for nursing practice:* To promote equity, nurses are required to demonstrate cultural sensitivity and proactive awareness of how immigrant status might influence how cancer as a personal and family illness can be experienced. Nurses should carefully assess the specific needs of immigrant cancer survivors and enable bespoke navigation within the health care system and in the community to effectively respond to these needs.

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Given his role as EIC, Grigorios Kotronoulas had no involvement in the peer review of this article and had no access to information regarding its peer review. Full responsibility for the editorial process for this article was delegated to another journal editor

* Address correspondence to: Lin Cheng, School of Medicine, Dentistry & Nursing, University of Glasgow, 57-61 Oakfield Avenue (Room 57/406), Glasgow G12 8LL, Scotland, UK.
*E-mail address:* 2391690C@student.gla.ac.uk (L. Cheng).

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**Layperson Summary**

**What we investigated and why**

We looked at existing research about people of Asian backgrounds who live with cancer and as immigrants in Western countries with advanced healthcare systems and a high standard of living. We looked at how these people experience cancer and access to healthcare. This is an important but often overlooked topic, and it is closely linked to people's right to fair access to healthcare.

**How we did our research**

We searched three bibliographic databases. We used specific criteria to decide which studies to include for review. We did a first search in September 2023 and updated it in May 2024. We evaluated how well the research was done, so that we know how strong the findings are. We combined findings from all studies into a narrative.

**What we have found**

We included 31 studies. These studies only involved people of Chinese or Arab backgrounds. The studies showed that Chinese and Arab people often found it difficult to access cancer care in the countries where they live. Many struggled to understand and navigate the healthcare system. Culture had a strong influence on their experiences. Chinese people felt ashamed about their cancer diagnosis. Many Chinese and Arab people needed more information and more social support. Commonly, they did not fully trust interpreter services during medical appointments. Communication problems were not only caused by language barriers, but also by culture-driven breaks in communication with local health professionals.

**What it means**

Current healthcare services do not always meet the needs of Asian immigrants who live with cancer in wealthy Western-world countries. Training the local health professionals, including nurses, to better understand and respond to these people's circumstances, needs and preferences can promote easier access and ensure that fair care is offered.

Recent global immigration patterns reveal that, as of mid-2020, over 40% of the world's international immigrants originated from Asia, with a substantial number residing in very high Human Development Index (HDI) countries of the Western world.[1] According to the World Migration Report by the International Organization for Migration, "Asian immigrants" are defined as individuals whose origins lie in Southeast Asia, South Asia, East Asia, the Middle East, and Central Asia, based on geographical classification.[2] The United Nations Development Programme measures a country's achievements in health, education and income, with a score of 0.800 or above indicating a "very high" level of human development.[3] Western countries are typically defined based on their historical, cultural, political and economic influences originating from Western Europe and expanded through colonialism and globalization.[4] By combining the definition of "very high" HDI countries and Western countries, a focused list of target nations can be established, including but not limited to the United States (USA), Canada, the United Kingdom (UK), Australia, and New Zealand (Table 1).

The concept of identifying people living with and beyond cancer as "cancer survivors" was first introduced by Mullan in the mid-1980s.[5] The National Cancer Institute considers an individual a cancer survivor from the time of diagnosis through the balance of life.[6,7] Today, key issues related to cancer survivorship include access to healthcare and follow up of treatment, management of side effects, risk of secondary cancers, and overall quality of life.[8] Asian immigrants exhibit tremendous heterogeneity in their language, culture and socioeconomic characteristics.[9] Communication with healthcare professionals without a shared language has been shown to contribute to miscommunication and reduced patient involvement in decision making.[10] Moreover, cultural differences influence health beliefs and perceptions of cancer diagnosis, for example, in some Asian cultural, cancer is believed as an "incurable disease," which subsequently influences their treatment adherence.[11,12] Consequently, the delivery of cancer survivorship care becomes even more complex for individuals from culturally and linguistically diverse background living in very high HDI Western countries.

Despite many Asian immigrants residing in very high HDI countries with advanced healthcare systems, inequalities across the cancer care continuum persist.[13] These disparities are evident at multiple stages of cancer care, from early detection to cancer survivorship support.[14-16] Evidence from the UK shows that Asian populations face significant challenges in accessing high-quality cancer care, due in part to unfamiliarity with the healthcare system.[15] They often exhibit a common response of uncertainty and anxiety when they are required to navigate the healthcare system of the host country.[17] Together with the growth of Asian immigrant communities, there is an increasing demand, among cancer survivors from these groups, not only for equitable access to healthcare but also for culturally responsive health services that recognize and accommodate unique values and needs.[18]

There is a pressing need to understand the care experiences, unmet needs, and health-related quality of life (HRQoL) of Asian immigrant cancer survivor. However, to date, no systematic review has yet evaluated evidence focused on this group living in very high HDI Western countries. It is important to focus on these countries as they are the primary target destination for most Asian immigrants today, thus intensifying the need for a foundational framework to develop more culturally sensitive and patient-centered supportive

**Table 1**
List of "Very High" HDI Countries and Western Countries

| | Very high HDI countries | HDI (0–1.0) |
|---|---|---|
| Western Countries | Switzerland | 0.967 |
| | Norway | 0.966 |
| | Iceland | 0.959 |
| | Sweden | 0.952 |
| | Denmark | 0.952 |
| | Germany | 0.950 |
| | Ireland | 0.950 |
| | Australia | 0.946 |
| | Netherlands | 0.946 |
| | Belgium | 0.942 |
| | Finland | 0.942 |
| | United Kingdom | 0.940 |
| | New Zealand | 0.939 |
| | Canada | 0.935 |
| | United States | 0.927 |
| | Luxembourg | 0.927 |
| | Austria | 0.926 |
| | Malta | 0.915 |
| | Spain | 0.911 |
| | France | 0.910 |
| | Cyprus | 0.907 |
| | Italy | 0.906 |
| | Czech Republic | 0.895 |
| | Greece | 0.893 |
| | Poland | 0.881 |
| | Croatia | 0.878 |
| | Portugal | 0.874 |
| | Hungary | 0.851 |

cancer care services. Therefore, this systematic review aimed to identify the unmet needs, care experiences, and factors affecting the HRQoL of Asian immigrant cancer survivors who live in Western countries ranked as very high HDI.

## Methods

This systematic review was registered with PROSPERO (CRD42023448605), and is reported according to the Preferred Reporting Item for Systematic Reviews and Meta-Analyses (PRISMA).[19]

### Search Strategy

Three major electronic databases (MEDLINE, EMBASE and CINAHL) were searched using systematic search strategies. These databases were selected because they are widely recognized as core sources for medical, nursing, and allied health research.[20] A senior librarian at the University of Glasgow was involved in developing the search strategy. The first author (LC) run the actual searches. The detailed strategy of each database is outlined in Supplementary File 1. The reference lists of eligible papers and key relevant articles were also retrieved to identify further eligible studies. Searches were initially run in September 2023. No new eligible articles were found during the second iteration in May 2024.

### Eligibility Criteria

Eligibility criteria were determined based on each component of the Patient, Exposure, and Outcome framework and the objectives of this review. The inclusion criteria were as follows:

- Adult immigrant cancer survivors of Asian ethnicity living in a very high HDI Western country as per Table 1.
- Any form of qualitative or quantitative or mixed methods research that investigated participants' HRQoL and/or unmet needs and/or care experience as primary or secondary outcomes.
- Studies involving ethnically diverse samples were eligible for inclusion if data for participants of Asian ethnicity were analyzed and reported separately.
- Studies published in peer-reviewed journals and written in English.
- No time restrictions were applied to the searches.

Studies were excluded for the following reasons:

- Participants are immigrants not originally from an Asian country, or participants lived in countries not listed in Table 1.
- Participants include second-generation immigrants which means that they were born in the host country.
- Mixed samples of Asian and non-Asian immigrants, where the Asian group was not analyzed separately.
- Investigated outcomes not of relevance to the purpose of this review.
- Case study, abstract, study protocols, and commentaries.

### Study Selection and Data Extraction Procedures

After duplicates were removed, the first author (LC) screened titles and abstracts and completed an initial round of full-text screening. The second and third authors (GK and DC) independently reviewed articles in a second round of full-text screening to reach consensus. Any disagreements or uncertainties were resolved through discussion. Reasons for exclusion at the full-text stage were recorded and documented.

Data from the final sample of eligible articles was extracted. A bespoke data extraction table was developed for this review to aid in the data extraction. One researcher extracted all data, which were then double-checked by the second and third authors (GK and DC). If information in any of the included articles was unclear, the first author (LC) contacted the corresponding author individually to request clarification. Where contact was not feasible, authors discussed the paper at a group meeting to decide whether to include or exclude and how to use its data in the analysis. None of the full-text papers were excluded based on the reason of insufficient information.

### Study Methodological Quality Evaluation

Methodological quality evaluation was conducted via the Quality Assessment for Diverse Studies (QuADS) tool, which is a refined version of the Quality Assessment Tool for Studies with Diverse Designs.[21] The QuADS tool demonstrated moderate inter-rater reliability ($k = 0.66$), face and content validity for application in systematic review with mixed, or multi-methods health services research.[21] The QuADS tool has 13 items, with each item scored from 0 to 3. Total scores can be calculated, although there is no cut-off score for a study to be considered high or low quality. In general, the higher the score, the better the quality. For easier interpretation and in line with previous literature,[22] total QuADS scores were broken down into three groups, whereby a total score between 0 and 13 indicates a low-quality study, a score from 14 to 26 indicates a moderate quality study, and a score from 27 to 39 indicates a high-quality study.

### Synthesis of Study Findings

A narrative approach was used, also creating thematic summaries of findings within similar context.[23] The aim of thematic synthesis is not simply to summarize the data content, but to identify and interpret, key but not necessarily all, features of the data, guided by the research questions. Another benefit of thematic analysis is that outcomes synthesized as a narrative are more contextualized and understandable for readers.[23]

## Results

### Search Results

The initial searches retrieved 480 studies. After removing duplicates ($n = 220$), 260 studies remained for title and abstract screening. Subsequently, full-text versions of 43 potentially relevant studies were assessed for eligibility and 22 studies were retained. Thirty-five additional studies were retrieved through websites and citation searching, as detailed in Fig., with nine of them meeting the inclusion criteria. In total, 31 studies were included in the final sample and reviewed.

### Study Characteristics

The final sample included: 19 qualitative studies:,[24-42] 10 quantitative studies:,[43-52] two mixed-methods studies:.[53,54] Sample sizes ranged from 11 to 44 in qualitative studies, and from 25 to 591 in quantitative studies. Twenty-five of the 31 included studies either reported the mean age or provided sufficient data for the mean age to be calculated.[24,27-30,32,33,35-41,43-51,53,54] Across the included studies, the reported mean age ranged from 37 to 64 years, with a grand mean age of 56 years. Seventeen studies were from the USA,[28-30,32,34-39,41,48,50-54] followed by twelve studies from Australia.[24-27,33,42-46,49] One study was from New Zealand[31] and one from Canada.[47] Twenty five studies focused exclusively on participants of Chinese heritage.[25-32,34-42,45,47,48,50-54] Five studies included multiethnic samples, involving participants of Chinese and Arabic

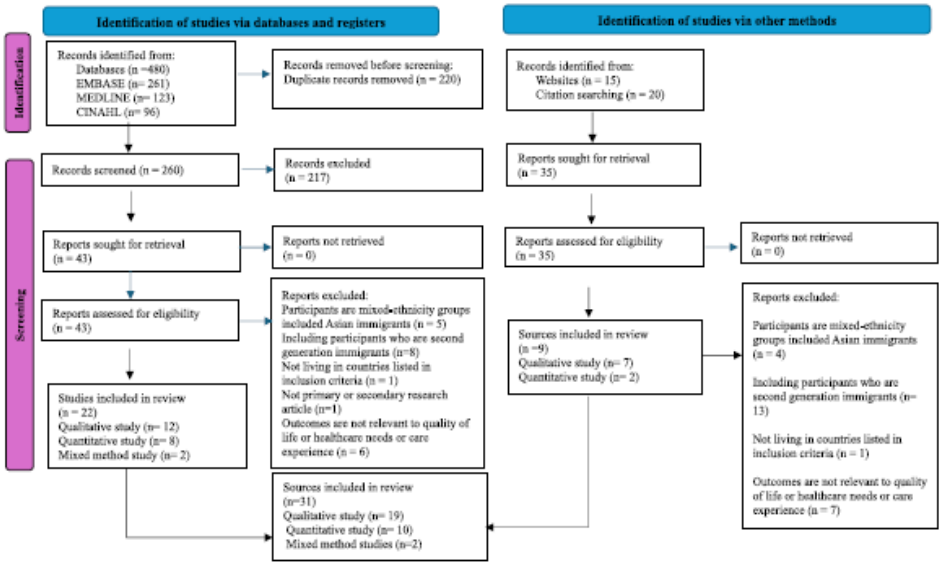



**FIG.** Diagram of the study selection process according to PRISMA. PRISMA, Preferred Reporting Item for Systematic Reviews and Meta-Analyses.

heritage.[33,43,44,46,49] One study focused exclusively on Arab immigrants.[24] Ten studies focused on early stage breast cancer,[28,29,32,37,38,41,48,50,53,54] while two studies exclusively recruited patients with metastatic cancer.[34,35] The included studies recruited participants via three methods: 10 studies recruited via community groups[25-27,30,34,37,38,40,42,50]; 14 studies recruited participants from cancer centers or clinics[28,29,32,33,39,41,43,44,46,47,49,51-53]; and seven studies used both recruitment methods.[24,31,35,36,45,48,54] Full details of included papers characteristics are presented in Tables 2 and 3.

### *Study Methodological Quality*

The methodological quality of the included studies varied, with QuADS scores ranging from 19 to 36 (see details in Supplementary File 2). The overall quality of the reviewed studies was moderate to high. The overall quality score for quantitative studies was generally higher than the qualitative, ranging from 25 to 36 (median = 30) and 19 to 33 (median = 25), respectively. The two mixed methods studies scored 23 and 25 respectively.

### *Unmet Needs*

A range of unmet healthcare needs was reported in 23 out of 31 included papers.[24-27,29,31-33,35-46,52-54] Three unmet needs were the most frequently reported: access to quality information, psychological and social support services, and high-quality interpreter services.

Comprehensive and high-quality information about cancer diagnosis and treatment was the most frequently reported unmet needs among Chinese and Arab immigrant cancer survivors.[25-27,31-33,36,40-42,45,46,52] Insufficient information limited their decision-making process.[25,33,36,37] Cultural differences between Chinese immigrant cancer survivors and local healthcare professionals contributed to conflicting views on the use of traditional Chinese medicine[27,29,36,39,51] and Chinese cancer survivors reported having culturally specific information needs, particularly concerning the compatibility of traditional Chinese medicine with Western standard medical treatment and the role of nutrition in their daily care.[26,27,31,35,36,53]

Apart from the need of information related to their diagnosis, Chinese and Arab immigrant cancer survivors also reported a need for information to help them familiarize with and navigate the healthcare system in the host country.[33,37,39,41,43,45,46] Converging evidence shows that those cancer survivors who did not know how to navigate the healthcare system exhibited higher depression levels,[49] were twice as likely to have higher unmet needs,[46] and experienced delays in treatment.[27,39] Much of the confusion was also because of lack of understanding of the diverse roles and responsibilities of the different members of the multidisciplinary team,[27,33] as well as the existence of support services within the hospital or their local communities.[33] A specific issue for Chinese immigrant cancer survivors living in the USA was lack of understanding of the private health insurance system, which in many cases resulted in putting themselves into financial burden.[37,54]

Both Chinese and Arab immigrant cancer survivors reported the need for appropriate psychological and social support services.[25-27,33,36,37,40,41,43,50,52,54] Many studies consistently found that that peer support services involving individuals with the same ethnic background and health condition represented one of the most prevalent unmet social needs among Chinese immigrants.[26,36,40,52,54]

Finally, five studies found that professional, reliable in-person interpreter service was an unmet need for both Chinese and Arab immigrants.[24,26,33,39,44] The low uptake of interpreter services was partly attributed to the lack of appropriate guidance and advice for them.[26,36] Existing services were frequently criticized for issues related to low accuracy and lack of privacy.[24,26,31,39] Furthermore, the presence of multiple dialects within the same language added complexity to achieving satisfactory interpretation experience.[24,39]

### *HRQoL*

Fifteen of the 31 studies reported on HRQoL,[25,29,30,32,34,39,43,46-51,53,54] identifying three determinants: psychological burden, personal socioeconomic, and social support. The dual pressure of being

**Table 2**
Summary of Methodological Characteristics of 31 Included Studies

| ID | Study | Study design | | | Sample characters Asian immigrants | | | | Data analysis method |
|---|---|---|---|---|---|---|---|---|---|
| | | Methods | Recruitment strategy | Data collection method (relevant to this review aim) | Sample size | Cancer type | Immigrants place of birth | Host Western country | |
| 1 | Alananzeh et al.[24] | Qualitative | Cancer centers; community | In-depth interview | 11 | Any type | Arab heritage | Australia | Thematic analysis |
| 2 | Ming et al.[43] | Quantitative | Cancer centers | 1) Demographic<br>2) FACT-G | 571 for immigration group with 393 for Chinese and Arabic heritage; 274 Anglo-Australian | Any type | Arab<br>Chinese<br>Greek Heritage | Australia | Liner regression; Logistic regression; |
| 3 | Levesque et al.[25] | Qualitative | Community | Focus group and in-depth interview | 24 | Breast cancer | Chinese heritage | Australia | Thematic analysis |
| 4 | Hyatt et al.[44] | Quantitative | Cancer centers | 1) Demographic;<br>2) Self-designed healthcare experience and preferences scale | 848 for immigrants group with 591 for Chinese and Arabic; 593 Australian | 12 common cancer | Arab;<br>Chinese<br>Greek Heritage | Australia | Chi-squared tests |
| 5 | Lim et al.[27] | Qualitative | Community | Focus group | Eight rounds (34 survivors; 28 carers) | Any type | Chinese heritage | Australia | Content comparative analysis |
| 6 | Lim et al.[45] | Quantitative | Cancer centers; community | 1) Demographic;<br>2) HLQ;<br>3) CCCQ | 68 patients; 8 carers | Any type | Chinese heritage | Australia | Liner regression; Canonical correlation analysis |
| 7 | Hsu et al.[28] | Qualitative | Cancer centers | Focus group and in-depth interview | 37 Chinese American; 23 European American | Breast cancer | Chinese heritage | U.S.A. | Content analysis |
| 8 | Butow et al.[46] | Quantitative | Cancer centers | 1) Demographic;<br>2) SCNS;<br>3) CASUN;<br>5) FACT-G | 277 immigrants<br>; 319<br>Anglo-Australian: | Any type | Arab;<br>Chinese<br>Greek Heritage | Australia | Chis-squared and t test; Logistic regression; Nonparametric Spearman's correlation; Baron and Kenney test |
| 9 | Ashing et al.[48] | Quantitative | Cancer centers; community | 1): Demographic;<br>2): FACT-G;<br>3): Social support survey;<br>4) SF-36 | 73 | Breast cancer | Chinese heritage | U.S.A. | Descriptive; T test; Correlation analyses; Linear Regression; R-square |
| 10 | Wang et al.[29] | Qualitative | Cancer centers | Focus group and in-depth interview | 71 (37 immigrants; 7 USA born Chinese; 27 NHW | Breast cancer | Chinese heritage | U.S.A. | Content analysis |
| 11 | Wong-Kim et al.[30] | Qualitative | Community | In-depth interview | 30 | Breast cancer | Chinese heritage | U.S.A. | Narrative analysis using a constant comparative approach |
| 12 | Wang et al.[32] | Mixed methods | Cancer centers | Phase I: Focus group and telephone interview<br>Phase II: Survey | Phase I: four rounds focus group (n = 19); 31 interviews<br>Phase II: 296 (148 NHW; 148 immigrants) | Breast cancer | Chinese heritage | U.S.A. | Phase I: content analysis methods.<br>Phase II: Descriptive; Linear regression |
| 13 | Levesque et al.[26] | Qualitative | Community | Focus group and in-depth interview | 24 | Breast cancer | Chinese heritage | Australia | Thematic analysis |
| 14 | Zhang et al.[31] | Qualitative | Cancer centers; community | In-depth interview | 26 | Breast cancer | Chinese heritage | New Zealand | Thematic content analysis |
| 15 | Lebel et al.[47] | Quantitative | Cancer centers | 1) Demographic;<br>2) Cancer-related stressor checklist;<br>3) Positive & negative affect scale. | 522 (118 immigrants; 404 WBC) | Head and neck cancer | Chinese heritage | Canada | Descriptive; One-way ANOVA; Multiple regression |
| 16 | Wang et al.[32] | Qualitative | Cancer centers | Focus group and in-depth interview | 44 immigrants; 28 NHW | Early stage breast cancer | Chinese heritage | U.S.A. | Content analysis |

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**Table 2** (*Continued*)

| ID | Study | Study design | | | Sample characters Asian immigrants | | | | Data analysis method |
|---|---|---|---|---|---|---|---|---|---|
| | | Methods | Recruitment strategy | Data collection method (relevant to this review aim) | Sample size | Cancer type | Immigrants place of birth | Host Western country | |
| 17 | Shaw et al.[33] | Qualitative | Cancer centers | Focus group and in-depth interview | 18 | Any type | Arab; Chinese Macedonian Heritage | Australia | Thematic analysis |
| 18 | Butow et al.[49] | Quantitative | Cancer centers | 1) Demographic; 2) FACT-G | 596 (277 immigrants; 319 Anglo-Australian) | 12 common cancer | Arab; Chinese Greek Heritage | Australia | Chi-squared and t test; Linear regression; Sobel test |
| 19 | You et al.[50] | Quantitative | Community | 1) Demographic; 2) FACT-B; | 96 | Breast cancer | Chinese heritage | U.S.A. | Descriptive; Regression |
| 20 | Lin et al.[34] | Qualitative | Community | In-depth interview | 12 | Any type of metastatic cancer. | Chinese heritage | U.S.A. | Narrative analysis |
| 21 | Leng et al.[35] | Qualitative | Cancer centers; community | In-depth interview | 12 | Any type stage IV cancer | Chinese heritage | U.S.A. | Inductive analysis |
| 22 | Leng et al.[36] | Qualitative | Cancer centers; community | Focus group | 28 | Any type | Chinese heritage | U.S.A. | Inductive analysis |
| 23 | Chou et al.[51] | Quantitative | Cancer centers | 1) Demographic; 2) SL-ASIAN; 3) MQOLS-CA; 4) SF-36; | 25 | Any type | Chinese heritage | U.S.A. | Descriptive |
| 24 | Warmoth et al.[37] | Qualitative | Community | Expressive writing | 27 | Breast cancer | Chinese heritage | U.S.A. | Content analysis |
| 25 | Choi et al.[38] | Qualitative | Community | Expressive writing | 15 | Breast cancer | Chinese heritage | U.S.A. | Thematic analysis |
| 26 | Sarpel et al.[39] | Qualitative | Cancer centers | Focus group | 29 | Hepatocellular carcinoma | Chinese heritage | U.S.A. | Content analysis |
| 27 | Tsai et al.[54] | Mixed methods | Cancer centers; community | Phase I: Survey; Phase II: In-depth interview | Phase I: 107 Phase II: 16 | Breast cancer | Chinese heritage | U.S.A. | Phase I: One-way ANOVA; Phase II: Thematic analysis |
| 28 | Leng et al.[52] | Quantitative | Cancer centers | Self-designed needs assessment | 59 | Any type | Chinese heritage | U.S.A. | Descriptive ; Chi-squares and correlation; Factor analysis; General linear model |
| 29 | Kwok and White[40] | Qualitative | Community | Focus group | 23 | Breast cancer | Chinese heritage | Australia | Thematic analysis |
| 30 | Tara et al.[41] | Qualitative | Cancer centers | In-depth interview | 11 | Breast cancer | Chinese heritage | U.S.A. | Content analysis |
| 31 | Kwok and White[42] | Qualitative | Community | Focus group | 23 | Breast cancer | Chinese heritage | Australia | Content analysis |

CASUN, Cancer Survivors Unmet Needs Measure; CCCQ, The Cancer Care Coordination Questionnaire; FACT-B, Functional Assessment of Cancer Therapy-Breast; FACT-G, Functional Assessment of Cancer Therapy-General; HLQ, The Health Literacy Questionnaire; MQOLS-CA, Multidimensional Quality of Life Scale-Cancer; NHW, non-Hispanic White; SCNS, Supportive Care Needs Questionnaire; SF-36, Short Form 36 Health Survey; SL-ASIAN, Suinn-Lew Asian Self Identify Acculturation Scale; WBC, Western Born Caucasians.

**Table 3**
Summary of Main Findings of 31 Included Studies

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | Unmet needs | HRQoL | Care experience |
| 1 | Alananzeh et al.[24] | To explore the Arab migrant cancer survivor's experience of use of interpreter services to communicate with health-care providers | High-quality interpreter services. | N/A | Language barrier restrict the communication with healthcare professionals. |
| 2 | Ming et al.[43] | To extend current knowledge to include migrant patients who were in the active treatment phase of the cancer trajectory, which represents the time of highest need for information, support, and practical assistance | 1) Information about navigating the health system.<br>2) Social support to optimize their cancer care. | 1) Migrant had significantly higher levels of anxiety, depression, and lower levels of quality of life.<br>2) Arabic participants had the highest levels of anxiety and depression as well as lowest QoL than other ethnic groups.<br>3) Chinese sample reporting lower anxiety within these three ethnic groups. | Difficulty in navigating the healthcare system and language barriers threat to care experience. |
| 3 | Levesque et al.[25] | To explore the experience of breast cancer for Chinese-Australian women and gain insight into their coping behaviors. | 1) Information about side effect management and psychological support.<br>2) Information about the compatibility of traditional Chinese medicine and Western medicine. | 1) Psychological wellbeing affect HRQoL more than physical well-being.<br>2) Patients frequently experienced a fear of cancer recurrence then lead to anxiety. | Formal support from China-specific organization has great value, as it is a platform of empowerment, encouragement, and information. |
| 4 | Hyatt et al.[44] | To investigate the communication barriers and challenges experienced by Arabic, Greek and Chinese (Mandarin and Cantonese) speaking oncology patients in Australia. | 1) High-quality interpreter services.<br>2) Information about their treatment. | N/A | Insufficient information restrict them to manage their health and language barrier threat their care experience. |
| 5 | Lim et al.[27] | To explore the challenges and unmet needs experienced by the Australian Chinese community affected by cancer, and understand the contexts that hindered optimal care for this community. | 1) Cultural appropriate information regarding diet.<br>2) Information about treatment option.<br>3) Psychological, community and spiritual support. | N/A | 1) Communication barriers impaired trust building with their clinicians.<br>2) Difficulty in navigating the health system lead to the delayed in treatment and long waiting time.<br>3) Cultural differences produce conflict on views about wellness, especially for the usage of traditional Chinese medicine. |
| 6 | Lim et al.[45] | To describe the levels of health literacy and experience of care coordination among Chinese migrant patients with cancer and their carers in Australia, to examine factors associated with these. | 1) Information about health condition.<br>2) Information about navigating the healthcare system. | N/A | Health literacy has a large and positive affect for care experience. |
| 7 | Hsu et al.[28] | To identify culturally appropriate means of talking about cancer that would be understood as beneficial and supportive by Chinese patients. | N/A | N/A | Patients are less disclose their diagnosis, feeling like emotionally vulnerable. |
| 8 | Butow et al.[46] | To document unmet needs, and variables associated with these, in a population-based sample of first-generation immigrants and Anglo-Australians who had survived cancer. | 1) Unmet information needs.<br>2) Understanding the healthcare system.<br>3) Immigrants who needed an interpreter had between two and four times higher unmet needs in all domains. | 1) Higher unmet needs contribute to higher levels of anxiety and depression.<br>2) Unmet needs were negatively correlated with HRQoL. These correlations were strongest for Arabic participants. | N/A |
| 9 | Ashing et al.[48] | To examine multilevel predictors of health-related quality of life among Chinese-American breast cancer survivors. | N/A | Social support, family communication, general health perception, quality of care, and life stress have significant correlations with overall HRQoL. | N/A |
| 10 | Wang et al.[29] | To understand how Chinese-American breast cancer survivors experience and cope with physical distress relative to NHW survivors. | Information about the usage of traditional Chinese medicine | Chinese immigrant breast cancer survivors expressed less psychological wellbeing compared with US-born Chinese and NHW. | Cultural values that emphasize respect for authority figures, such as doctors, may contribute to lower levels of disclosure among Chinese individuals. |

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**Table 3** (*Continued*)

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | Unmet needs | HRQoL | Care experience |
| 11 | Wong-Kim et al.[30] | To explore cancer-related beliefs and QoL among Chinese women with breast cancer. | N/A | 1) Family relationships and family support as central to a good HRQoL.<br>2) Having wealth was cited frequently as a way of achieving a high-quality life. | Chinese women with breast cancer often experience cancer-related stigma and hold fatalistic beliefs about cancer, which are prevalent within Chinese communities. |
| 12 | Wang et al.[32] | To explore similarities and differences in survivorship care concerns among Chinese American and NHW breast cancer survivors. | 1) Information about their diet after treatment;<br>2) The need of social support to adapt to life after cancer treatment. | Economic constraints affect their HRQoL. | Language barriers and the stress of immigration (eg, changes in socioeconomic status, loss of social networks) affect their care experience. |
| 13 | Levesque et al.[26] | To broadly explore the experience of breast cancer and coping strategies utilized by Chinese-Australian women. | 1) High-quality, accurate information about cancer and treatment options.<br>2) Need psychological support to assist them to cope with psychological burden.<br>3) Need written information with diverse languages.<br>4) Need for reliable and high-quality interpreter services.<br>5) Need cultural appropriate services. | N/A | Insufficient information on how to manage their health, along with difficulties accessing interpreter services, negatively affects the care experience of patients. |
| 14 | Zhang et al.[31] | To investigate factors affecting Chinese women's understanding of, and access to, breast health services, to better understand reasons for low participation in screening and their experiences of breast cancer clinic care. | 1) Chinese speaking staff.<br>2) Information related their treatment.<br>3) Information about traditional Chinese medicine. | N/A | 1) Patients with limited English proficiency reported communication difficulties during interactions with doctors and expressed distrust in interpreter services.<br>2) Chinese female with breast cancer suffer with cancer related stigma and fatalistic beliefs about cancer. |
| 15 | Lebel et al.[47] | To greater understanding of how Asian cancer survivors are affected by stigma and improve the provision of culturally-sensitive care. | N/A | 1) Asian immigrant survivors reported significantly lower levels of well-being than Western born Caucasians.<br>2) Stigma was a significant predictor of emotional distress.<br>3) Stigma was a significant predictor of well-being. | Stigma exerts a deleterious impact on care experience. |
| 16 | Wang et al.[32] | To elucidate the similarities and differences in communication with physicians between Chinese and NHW breast cancer survivors. | Information about evidence based treatment options. | 1) Socioeconomic affect their HRQoL.<br>2) Chinese immigrants are more likely to have poorer quality physician communication and more unmet needs for survivorship care than other ethnic group. | Cultural values that emphasize respect for authority figures, such as doctors, may contribute to lower levels of disclosure among Chinese individuals. And highly acculturated Chinese immigrant women are more likely to express their needs.<br>Cultural difference shaped their communication experience with their treatment team. |
| 17 | Shaw et al.[33] | To describe migrant patients' experience of care coordination to inform the development of items for inclusion in cancer care coordination questionnaire sensitive to specific cultural needs of these patients. | 1) Information about their treatment.<br>2) Information about the introduction of roles and responsibilities of their treatment team.<br>3) Need for culturally appropriate support services. | N/A | Majority of them have positive view of their hospital experience, with that adequately informed. |

(*continued on next page*)

**Table 3** (*Continued*)

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | Unmet needs | HRQoL | Care experience |
| 18 | Butow et al.[49] | To compare prevalence and severity of anxiety and depression and quality of life in a population-based sample of first generation immigrant Australian cancer survivors and Anglo-Australian born controls. | N/A | 1) Compared with Anglo-Australian, immigrants had higher levels of depression and lower levels of HRQoL.<br>2) Arabic participants had the highest levels of depression, as well as the lowest HRQoL.<br>3) Understanding the health system was associated with lower values of depression.<br>4) Good health literacy contribute to good HRQoL. | N/A |
| 19 | You et al.[50] | Investigating the associations between socioeconomic indicators and quality of life and the mediating roles of social support and social constraints in these associations among Chinese American breast cancer survivors. | N/A | 1) Annual personal income, education was positively related to HRQoL and social support.<br>2) More social support and less social constraints were associated with better HRQoL. | N/A |
| 20 | Lin et al.[34] | To explore how US-resident Chinese immigrants with metastatic cancer search for meaning at the end of their lives. | N/A | 1) Psychological suffering seriously affect their HRQoL.<br>2) Life satisfactory, good social support and personal positive attitude towards life contribute to better HRQoL. | 1) Experiencing guilt toward their family.<br>2) Social support and religious practices help them find meaning in life, fostering hope and faith.<br>3) Being open-minded about sharing their experience can empower them. |
| 21 | Leng et al.[35] | To inform a culturally and linguistically responsive adaptation of meaning-centered psychotherapy for Chinese immigrants and identify salient issues that may affect how they receive cancer care and support. | 1) Information about traditional Chinese medicine.<br>2) Information about nutrition/ dietary. | N/A | 1) Cultural values shape the communication of advanced cancer.<br>Patients with advanced cancer have cancer-related stigma and hold fatalistic beliefs about cancer, which are prevalent within Chinese communities.<br>2) Religion serves as a meaningful source for care experience. |
| 22 | Leng et al.[36] | To explore the informational and psychological needs of Chinese cancer patients to inform the development of culturally targeted support and survivorship interventions. | 1) Information about their treatment and health conditions.<br>2) Nutritional guidance, including recommendations on what foods to eat after diagnosis, during chemotherapy, and for recurrence prevention.<br>3) Both patients and family members require social and emotional support services. | N/A | 1) Language barriers and cultural values that emphasize respect for authority figures, such as doctors, may contribute to lower levels of disclosure among Chinese individuals.<br>2) Interpreter services may not as helpful as expected.<br>3) Cultural shaped the different values of the usage of traditional Chinese medicine.<br>4) Stigma exerts a deleterious impact on care experience. |
| 23 | Chou et al.[51] | To explore the cancer symptom experience, self-care strategies and quality of life among Chinese Americans during outpatient chemotherapy. | N/A | Low to moderate levels of HRQoL among Chinese immigrant patients during outpatient chemotherapy. | Patients has strong trust of the usage of traditional Chinese medicine to help them heal after treatment. |
| 24 | Warmoth et al.[37] | To explore the social needs and challenges of Chinese American immigrant breast cancer survivors. | 1) Need for sufficient family support.<br>2) Information about navigating the healthcare system and dealing with insurance issues in USA.<br>3) Need of available cultural appropriate social support services. | N/A | Chinese female breast cancer patients experienced cancer related stigma and they often put their family as priority rather than themselves. |

(*continued on next page*)

**Table 3** (*Continued*)

| ID | Study | Aim | Results | | |
|---|---|---|---|---|---|
| | | | Unmet needs | HRQoL | Care experience |
| 25 | Choi et al.[38] | To identify the challenges and strengths of immigrant young adult Chinese American breast cancer survivors. | Need for psychological and social support. | N/A | Younger Chinese female with breast cancer suffer heavy cancer related stigma and psychological burden. They were mothers of young children and commonly concerned not about themselves, but about their children's fate if they lost their mothers. |
| 26 | Sarpel et al.[39] | To identify barriers to care in treatment of hepatocellular carcinoma among affected individuals in the New York City Chinese immigrant community. | 1) Need for face to face interpreter rather than phone translation.<br>2) Information about local health system and policy. | 1) Health insurance is a factor to affect HRQoL.<br>2) Financial issues affect HRQoL. | Language is barrier to care, and patients with liver cancer has suffered with heavy stigma as public hold the misunderstanding about the transmission of hepatitis B. And patients hold fatalistic beliefs about their cancer diagnosis. |
| 27 | Tsai et al.[54] | To explore how and to what extent acculturation and immigration affect Chinese-American immigrant women's breast cancer experience. | 1) Need for social support to develop their new social networks.<br>2) Information related to their health condition. | 1) Higher level of acculturation contribute to good HRQoL.<br>2) Functional social support and supports from partner were positively associated with the level of acculturation.<br>3) The pressure of immigration had negative influences on their HRQoL. | There is a fatalistic beliefs about cancer around ethnic Chinese communities. Cultural differences between American healthcare providers and Chinese-American families contribute to challenges in the breast cancer experience. |
| 28 | Leng et al.[52] | To identify the specific support needs of Chinese immigrant cancer patients. | 1) Need for culturally appropriate services tailored for Chinese patients with cancer.<br>2) Information needs about financial and social assistance, treatment options, and health conditions. | N/A | N/A |
| 29 | Kwok and White[40] | To explore the perceptions of information needs and social support among Chinese-Australian breast cancer survivors and how these resources affected their cancer experience. | 1) Culturally appropriate information on side-effect management and recovery.<br>2) Information about diet and nutrition.<br>3) The need for culturally aware social support services. | N/A | Limited English proficiency restrict their communication with treatment team, and Chinese female patients with breast cancer has stigma of their cancer diagnosis. |
| 30 | Tara et al.[41] | To examine the experiences of Chinese American immigrant breast cancer survivors with post-treatment breast cancer care and surveillance in New York City. | 1) Information about breast cancer recurrence and long-term breast health.<br>2) Information about their disease, treatment, and post-treatment care.<br>3) Need for sufficient social support. | N/A | Language barrier restrict them to receive the good cancer care. And it was sensitive to discuss the cancer topic and there is a fatalistic beliefs about cancer around ethnic Chinese communities. |
| 31 | Kwok and White[42] | To explore Chinese-Australian women's perceptions of the meaning and experience of a breast cancer diagnosis, treatment and coping mechanism. | Need culturally and linguistically appropriate information about cancer treatment. | N/A | 1) Limited English proficiency restrict them to communicate with their treatment and understand the information.<br>2) There is a fatalistic beliefs about cancer around ethnic Chinese communities make patients suffering cancer related stigma.<br>3) Chinese female patients with breast cancer always put their family into priority. |

NHW, non-Hispanic White; HRQoL, health-related quality of life; QoL, quality of life.

an immigrant while facing a life-threatening illness such as cancer significantly impacted Chinese immigrants' HRQoL.[30,54] Arab immigrant cancer survivors showed higher anxiety, depression, and lower HRQoL than Chinese immigrants, who in turn reported lower HRQoL than Western-born Caucasians.[43,47,49]

Psychological burden was the most negative factor affecting HRQoL for Chinese and Arab immigrants, with anxiety and depression occurring more frequently.[25,34,43,49,51] Consistently across many studies, a common contributor to anxiety among Chinese immigrants was fear of cancer recurrence.[25,29,41,42] Additionally, female Chinese immigrants breast cancer survivors and Chinese patients with metastatic cancer experienced heightened psychological burden.[28,31,34-38,40] Those with metastatic cancer expressed concerns about their future,[34,35] while women with breast cancer, particularly younger women, feared the impact of their illness on their family and children, which was associated with increased depression.[38,42]

Personal income as a core component of socioeconomic status played a key role in influencing HRQoL among Chinese immigrant cancer survivors,[30,38,50,51,54] particularly in relation to functional well-being.[38,50] In the USA, access to medical insurance was another critical socioeconomic factor affecting HRQoL among Chinese immigrants[39,52] and financial difficulties were commonly reported within this group.[32,39,52]

Sufficient family and social support were considered essential for maintaining good HRQoL.[30,48,50,54] Among Chinese immigrants, participation in religious practices and community activities helped maintain social networks and was associated with better HRQoL.[25,34,42]

*Experiences of Care*

Twenty six of the 31 included papers discussed care experiences of Chinese and Arab immigrant cancer survivors living in their host countries.[24-45,47,51,53,54] Five papers reporting poorer care than Chinese or Arab immigrants receiving in their place of birth and described negative attitudes toward the care that they received in host countries.[27,31,39,41,44]

Insufficient communication with the treatment team was a significant barrier affecting care experience among Chinese and Arab immigrant cancer survivors.[24,25,29,32,36,37,39,43,44,46,53] Chinese immigrant cancer survivors disclosed less to their healthcare providers.[29,32,36,53] Within the Chinese culture, doctors are viewed as authority figures, and they subsequently followed doctors' medical decisions without question, even when they struggled with them.[32] Additionally, inadequate English proficiency contributed to this communication challenge, as it impaired trust building with healthcare providers,[26,27,31] and reduced Chinese and Arab cancer survivors' confidence and comfort in communicating.[24,39,43,44,46,53]

Cancer stigma and fatalistic beliefs, particularly among Chinese immigrant cancer survivors, had a detrimental psychological impact,[30,35,37,39,47] leading to social isolation, feelings of loneliness,[37,38,40,54] and a sense of rejection by others.[37] As a result, some survivors choose to conceal their cancer diagnosis within their networks,[37,38,54] possibly due to cancer often being viewed as a matter of fate or a consequence of bad "feng shui," interpreted as punishment for misdeeds in a past life.[30,42,54] Therefore, the open discussion about cancer was often absent within the Chinese community.[41]

While the care experiences and well-being of included immigrant cancer survivors were largely focused on the barriers toward good care experience, facilitators among Chinese immigrants were also reported, including good health literacy and acculturation.[32,45] Keeping an open-mind and adopting a positive attitude towards cancer further also contributed to a better care experience.[34,35,42] Receiving adequate social support was another key facilitator of a positive care experience,[25,26,34,35,40,41] including family support, which was shown to promote recovery following cancer treatment.[34,35,40,41] Additionally, participation in culturally specific organizational activities and religious practice enhanced the cancer experience,[25,26,34,35] with empowerment and encouragement by cultural organisations[25,26] and finding hope, having faith, and receiving spiritual support through religious practices.[34,35]

## Discussion

The current systematic review identified 31 studies involving Asian immigrant cancer survivors from Chinese and Arab backgrounds. The representation of these ethnic groups was highly imbalanced, with 25 studies focusing exclusively on Chinese immigrants and a further five studies including multi-ethnic samples that involved Chinese participants. In addition to this ethnic imbalance, the distribution of the host countries was also uneven: no eligible study was conducted in Europe, indicating a lack of region-specific evidence from European settings.

In this systematic review, cultural and linguistic factors were found to play significant roles in shaping cancer survivorship care needs and experience, influencing how this population accesses the healthcare system and manage their state of survivorship. Additionally, re-examining the role of interpreter services and accessibility and acceptability of supportive cancer care in the host country emerged as areas for future action.

Consistent with previous evidence,[55] culture emerged as a major driver of need for information. Chinese immigrant cancer survivors expressed a strong interest in receiving information related to traditional Chinese medicine and dietary guidance. This preference reflects deeply rooted cultural beliefs about health and healing.[56] In Chinese society, food holds a central role beyond simply meeting physiological needs, and certain ingredients are culturally regarded as having medicinal properties.[57] The compatibility of traditional Chinese medicine with standard anticancer treatment can be a standard query among this patient population. In the host country, where the demand for such kind of information is not met, survivorship care can be felt as not inclusive enough. Culturally appropriate, evidence-based information is needed to support informed decision-making and to honor the cultural values of patients who seek integrative approaches to care.

Certain traditional cultural beliefs, such as feudal superstitions surrounding cancer,[30] can contribute to cancer-related stigma, which can lead to negative mental health and social outcomes for cancer survivors, including anxiety, depression, and deterioration in social functioning.[58,59] Cancer is considered taboo and often viewed as a form of punishment in life among Chinese communities.[60] Arabic cultural and religious beliefs also contribute to avoidance of mental health services, as seeking such support is often associated with social stigma.[61] Cancer survivors who influenced by these cultural norms may disclose their cancer diagnosis only to their families and actively seek to keep their illness a secret,[62] which could lead to self-exclusion from potentially beneficial supportive care services.[63] Culturally appropriated initiatives that are fully integrated within the immigrant ethnic communities could help normalize conversations about cancer,[64,65] which can enable Chinese and Arab immigrant cancer survivors and their communities to work together effectively to seek, sign up and use available services in the host country.

Language is commonly seen as barrier by both Chinese and Arab immigrants in managing cancer survivorship needs.[66] Language barriers can contribute to delay in seeking care, navigating the healthcare system, difficulties in obtaining information, and ultimately resulting in poorer health outcomes.[66,67] Although interpreter services are available in very high HDI Western countries, cancer survivors often disregard them due to lack of trust in confidentiality and accuracy.[24] Previous research has shown that where the family requested for the cancer diagnosis not to be disclosed to the patient, interpreters struggled and the translation outcome led to information

feeling too vague and less accurate.[68] Dedicated training and effective integration of interpreters into multidisciplinary oncology teams can enhance patient-provider communication in this context, curb concerns around trust, and ensure accurate exchange and transmission of key information to meet patient needs and sustain patient safety.

Barriers to communication between Chinese immigrants and healthcare professionals extend beyond language proficiency to include culture norms.[69] This pattern seems to limit Chinese immigrants' involvement in medical decision-making.[32,69] Although reduced involvement has been observed among older adults in native populations,[70] the underlying reasons appear to differ. Native older adults may prefer to assume less responsibility for medical decision-making and may be less willing to engage actively in treatment choices.[70] In contrast, Chinese immigrants' lower engagement is often related to unfamiliarity with the principles of patient autonomy and empowerment, and how these align with their cultural values.[32,69] This tendency toward limited disclosure of personal needs has been reported regardless of length of residence in the host country.[71] Therefore, culturally tailored educational interventions are needed to support Chinese immigrants in understanding and engaging with patient empowerment, alongside the development of toolkits and training for healthcare professionals to better promote culturally sensitive patient engagement.

Immigrants often require substantial adaptation to function effectively in a new environment, and limited knowledge of the host country's healthcare system can hinder their ability to access and navigate care.[72] When a cancer diagnosis is confirmed, it typically involves coordination across multiple healthcare settings, which can further exacerbate the anxiety that stems from being unfamiliar with the healthcare system.[73] This can lead to reduced treatment adherence, reduced mental wellbeing and increased risk of isolation during an already challenging period.[73] To address this issue, implementing a specialist community navigator/coordinator role in which a trained individual acts as a liaison between immigrant cancer survivors and healthcare providers could be considered.[74] This role can help reduce healthcare disparities and improve the cancer survivorship experience by enabling access, enhancing knowledge and supporting ethnic minority groups in navigating complex healthcare pathways.[75] Further research could explore ways to engage immigrant cancer survivors who are socially isolated, and to investigate their attitudes toward community support and the role of a community coordinator.

### Implications for Nursing Practice

Several implications for nursing practice arise. First, the frequently mentioned unmet information requires targeted initiatives. Healthcare systems in very high HDI countries should invest in developing translated resources, employing bilingual advocates, and implementing communication aids to support nurses in caring for cancer survivors with different backgrounds. Second, oncology nurses need to receive training in cultural awareness when caring for immigrant cancer survivors. For example, nurses should take a more proactive approach in asking their needs, as some of Chinese or Arab immigrant cancer survivors may be unfamiliar with the concept of patient autonomy. Finally, given the identified importance of community roles, implementing community nurses or navigators with cultural and linguistic competence would better support immigrant cancer survivors in accessing the health care system.

### Strengths and Limitations

To the best of our knowledge, this is the first mixed-methods systematic review to focus on the unmet needs, HRQoL, and care experiences of Asian immigrant cancer survivors living in very high HDI Western countries. The reporting of this mixed-methods systematic review was grounded in the substantive findings, enabling an integrated narrative synthesis of quantitative and qualitative evidence. All included evidence was treated as contributing to the same research questions, providing an in-depth and comprehensive understanding of the topic.

Limitations should also be acknowledged. In terms of methods, study screening and data extraction were primarily conducted by one reviewer (lead author), with verification and consultation provided by the second and third authors. Although this approach is commonly adopted in resource-constrained reviews, it may increase the risk of selection bias and data extraction errors, potentially affecting the reliability and reproducibility of the findings. Limiting the search to three core databases might have missed a few relevant studies, particularly from discipline-specific databases such as PsycINFO. However, the use of citation tracking and searching online may have partially mitigated this limitation. In terms of the findings themselves, most participants in the included studies were women with breast cancer. The findings should be carefully considered when applied to other cancer types. Moreover, the evidence regarding immigrants' places of origin was markedly imbalanced, with 30 studies providing evidence on survivors of Chinese heritage, compared with only six reporting on Arab survivors. This imbalance limits the generalizability of the findings of this systematic review to the broader Asian immigrant population. It also highlights a significant gap in the literature and emphasizes the need for increased research attention to cancer survivorship among other Asian ethnicity immigrant groups such as from Southeast population living in very high HDI settings. Furthermore, of the six studies involving Arab cancer survivors, only two reported participants' specific countries of origin. Arab populations may originate from both North Africa and Western Asia (the Middle East); however, this information was not clearly specified in most studies. As a result, the applicability of these findings to Arab immigrants from Western Asia remains uncertain. Finally, no study was conducted in Europe, thus not allowing safe conclusions to be made about the care experiences of Chinese and Arab immigrant cancer survivors in the European very high HDI territory.

### Conclusion

To promote health equity in cancer survivorship, evaluating and reshaping clinical recommendations to align with diverse cultural norms is equally important. Healthcare systems in very high HDI Western countries need to address the information needs of ethnic minority populations and provide support to help patients navigate complex healthcare systems. While communication challenges are often attributed to limited language proficiency, limited familiarity with concepts of patient autonomy also plays a significant role. Furthermore, the prevalence of cancer-related stigma and reported cancer taboos highlights the need to improve health literacy within these communities. Despite the broader initial aim of this systematic review, the identified evidence relates predominantly to Chinese immigrant cancer survivors living in the USA and Australia, and secondarily to Arab survivors, thus reflecting the disparities of research involving Asian immigrant populations from other Asian ethnicity groups and within territories such as Europe.

### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

### CRediT authorship contribution statement

**Lin Cheng:** Writing – review & editing, Writing – original draft, Methodology, Funding acquisition, Formal analysis, Data curation,

Conceptualization. **Grigorios Kotronoulas:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Deborah Cairns:** Writing – review & editing, Supervision, Methodology, Conceptualization.

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## Supplementary materials

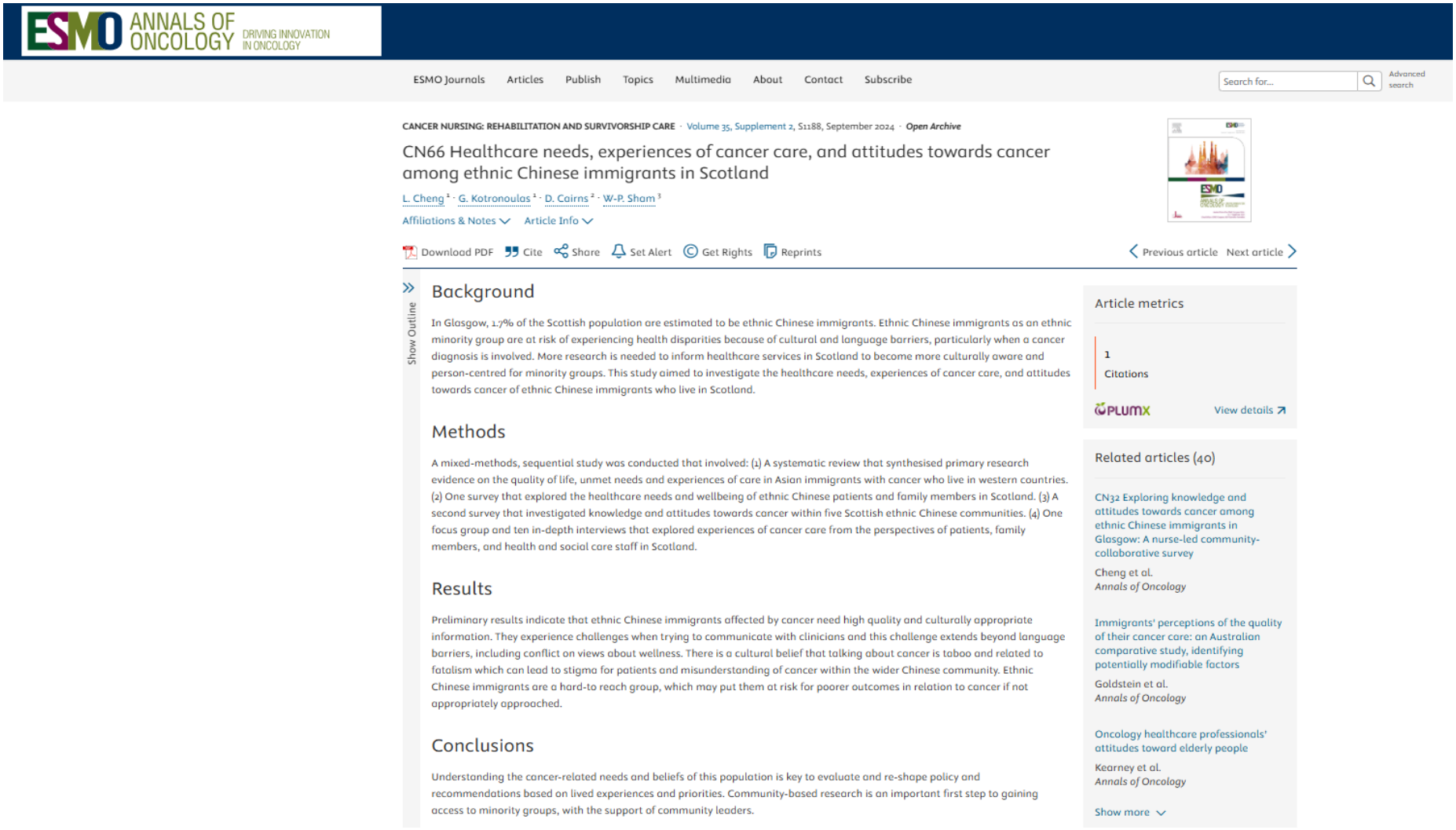
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**The abstract for the Phase 2 to 4 (Chapter 6 to 8)**



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# CN66 Healthcare needs, experiences of cancer care, and attitudes towards cancer among ethnic Chinese immigrants in Scotland

L. Cheng [1] · G. Kotronoulas [1] · D. Cairns [2] · W-P. Sham [3]

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## Background

In Glasgow, 1.7% of the Scottish population are estimated to be ethnic Chinese immigrants. Ethnic Chinese immigrants as an ethnic minority group are at risk of experiencing health disparities because of cultural and language barriers, particularly when a cancer diagnosis is involved. More research is needed to inform healthcare services in Scotland to become more culturally aware and person-centred for minority groups. This study aimed to investigate the healthcare needs, experiences of cancer care, and attitudes towards cancer of ethnic Chinese immigrants who live in Scotland.

## Methods

A mixed-methods, sequential study was conducted that involved: (1) A systematic review that synthesised primary research evidence on the quality of life, unmet needs and experiences of care in Asian immigrants with cancer who live in western countries. (2) One survey that explored the healthcare needs and wellbeing of ethnic Chinese patients and family members in Scotland. (3) A second survey that investigated knowledge and attitudes towards cancer within five Scottish ethnic Chinese communities. (4) One focus group and ten in-depth interviews that explored experiences of cancer care from the perspectives of patients, family members, and health and social care staff in Scotland.

## Results

Preliminary results indicate that ethnic Chinese immigrants affected by cancer need high quality and culturally appropriate information. They experience challenges when trying to communicate with clinicians and this challenge extends beyond language barriers, including conflict on views about wellness. There is a cultural belief that talking about cancer is taboo and related to fatalism which can lead to stigma for patients and misunderstanding of cancer within the wider Chinese community. Ethnic Chinese immigrants are a hard-to reach group, which may put them at risk for poorer outcomes in relation to cancer if not appropriately approached.

## Conclusions

Understanding the cancer-related needs and beliefs of this population is key to evaluate and re-shape policy and recommendations based on lived experiences and priorities. Community-based research is an important first step to gaining access to minority groups, with the support of community leaders.

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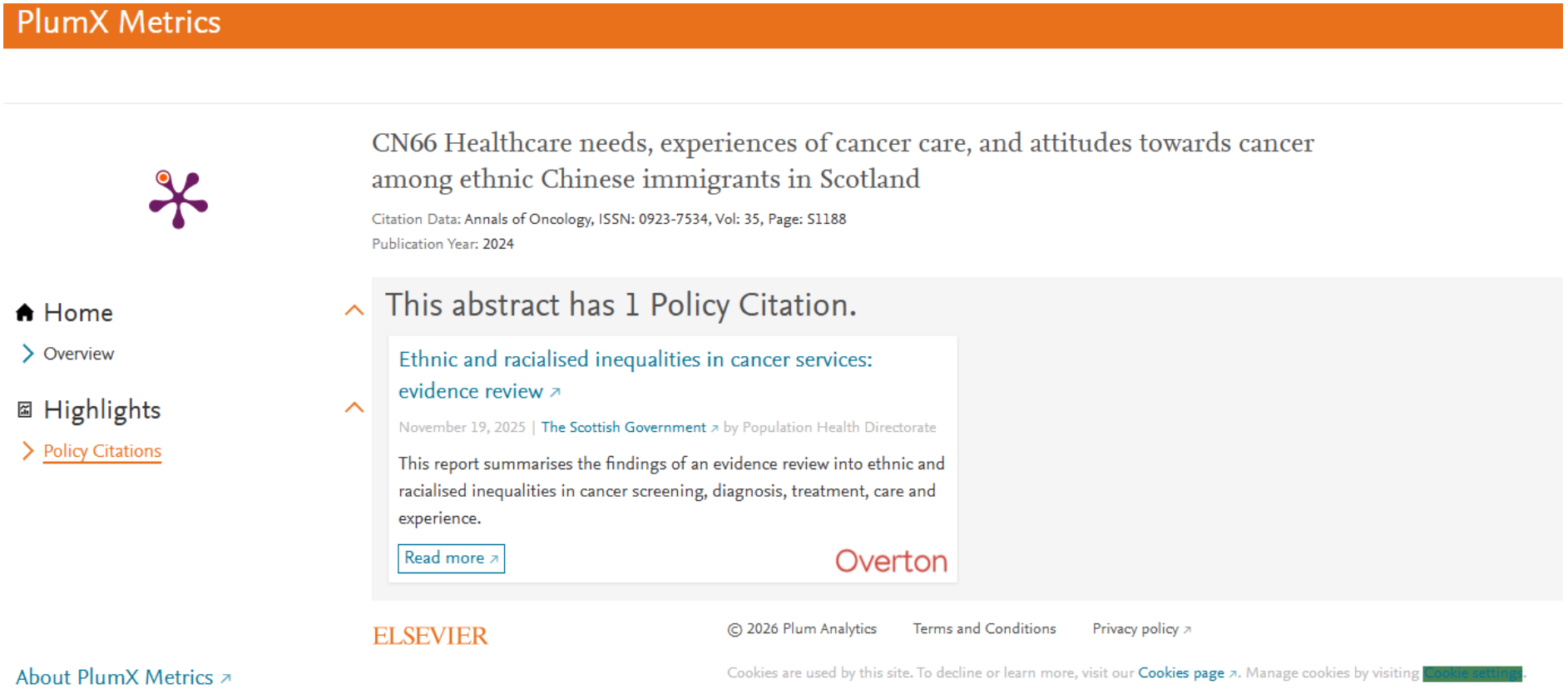
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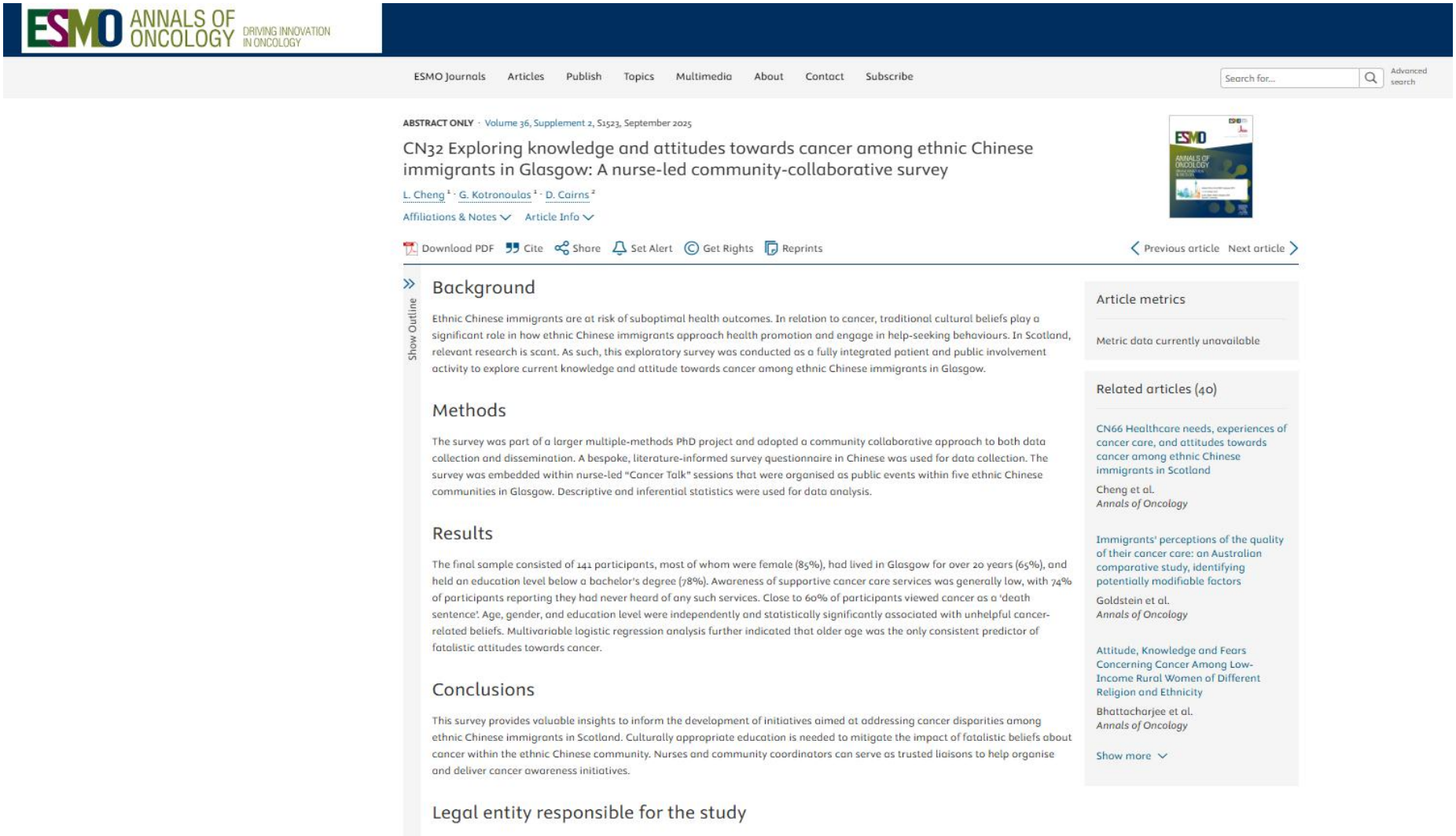
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# CN32 Exploring knowledge and attitudes towards cancer among ethnic Chinese immigrants in Glasgow: A nurse-led community-collaborative survey

L. Cheng [1] · G. Kotronoulas [1] · D. Cairns [2]

Affiliations & Notes Article Info

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## Background

Ethnic Chinese immigrants are at risk of suboptimal health outcomes. In relation to cancer, traditional cultural beliefs play a significant role in how ethnic Chinese immigrants approach health promotion and engage in help-seeking behaviours. In Scotland, relevant research is scant. As such, this exploratory survey was conducted as a fully integrated patient and public involvement activity to explore current knowledge and attitude towards cancer among ethnic Chinese immigrants in Glasgow.

## Methods

The survey was part of a larger multiple-methods PhD project and adopted a community collaborative approach to both data collection and dissemination. A bespoke, literature-informed survey questionnaire in Chinese was used for data collection. The survey was embedded within nurse-led "Cancer Talk" sessions that were organised as public events within five ethnic Chinese communities in Glasgow. Descriptive and inferential statistics were used for data analysis.

## Results

The final sample consisted of 141 participants, most of whom were female (85%), had lived in Glasgow for over 20 years (65%), and held an education level below a bachelor's degree (78%). Awareness of supportive cancer care services was generally low, with 74% of participants reporting they had never heard of any such services. Close to 60% of participants viewed cancer as a 'death sentence'. Age, gender, and education level were independently and statistically significantly associated with unhelpful cancer-related beliefs. Multivariable logistic regression analysis further indicated that older age was the only consistent predictor of fatalistic attitudes towards cancer.

## Conclusions

This survey provides valuable insights to inform the development of initiatives aimed at addressing cancer disparities among ethnic Chinese immigrants in Scotland. Culturally appropriate education is needed to mitigate the impact of fatalistic beliefs about cancer within the ethnic Chinese community. Nurses and community coordinators can serve as trusted liaisons to help organise and deliver cancer awareness initiatives.

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**Award with Young & Early Career Cancer Nurses (YECCN)**



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