University of Wollongong
Research Online

University of Wollongong Thesis Collection 2017+

University of Wollongong Thesis Collections

2023

Development, implementation and evaluation of the acceptability and feasibility of a shared cancer follow-up model of care

Tiffany Sandell

Follow this and additional works at: https://ro.uow.edu.au/theses1

University of Wollongong
Copyright Warning
You may print or download ONE copy of this document for the purpose of your own research or study. The University does not authorise you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site.
You are reminded of the following: This work is copyright. Apart from any use permitted under the Copyright Act 1968, no part of this work may be reproduced by any process, nor may any other exclusive right be exercised, without the permission of the author. Copyright owners are entitled to take legal action against persons who infringe their copyright. A reproduction of material that is protected by copyright may be a copyright infringement. A court may impose penalties and award damages in relation to offences and infringements relating to copyright material. Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.

Unless otherwise indicated, the views expressed in this thesis are those of the author and do not necessarily represent the views of the University of Wollongong.

Research Online is the open access institutional repository for the University of Wollongong. For further information contact the UOW Library: research-pubs@uow.edu.au

Development, implementation and evaluation of the acceptability and feasibility of a shared cancer follow-up model of care

Tiffany Sandell

Primary supervisor: Dr Heike Schütze
Co-supervisors: Professor Andrew Miller and
Associate Professor Rowena Ivers

This thesis is presented as part of the requirement for the conferral of the degree:
Doctor of Philosophy

This research has been conducted with the support of the Australian Government Research Training Program Scholarship and the Illawarra Shoalhaven Local Health District Radiation Oncology Clinical Research Fellow Scholarship

University of Wollongong
Faculty of Science, Medicine and Health
Graduate School of Medicine

March 2023

Abstract

Background The increasing incidence of cancer, coupled with improved survivorship, has increased the demand for cancer follow-up care and the need to find alternative models of care. International and national guidelines advocate for including general practitioners (GP) in cancer follow-up care. Barriers to implementing shared care into practice include having clinical assessment protocols for GPs, and suitable health technology to allow two-way communication to enable oncologists to continue overseeing care. To address these barriers, this thesis aimed to develop and implement a novel shared cancer follow-up model of care, and evaluate the model's acceptability and feasibility to patients, GPs and radiation oncologists (RO).

Methods Following a systematic review, this research employed a concurrent triangulation mixed methods methodology. Participants were patients on radiotherapy follow-up care, their GP and RO. The intervention included patients' visiting their GP twice and the GP completing a clinical assessment protocol, which was transferred with novel health technology to the RO in real-time to oversee care. The quantitative component included a cross-sectional population survey and two concordance studies. Data were analysed using frequencies, Cohen's Kappa, Fleiss Kappa, logistic regression, and odds ratio. The qualitative component included semi-structured interviews, which were analysed thematically using the Theoretical Framework of Acceptability. Results were then synthesised to answer the overarching thesis' aim.

Results Four-hundred and fourteen surveys were returned (45% response rate) for the population survey. Acceptance for radiation oncology shared cancer follow-up care was high (80%). High Intervention Coherence and a positive Affective Attitude were significant predictive factors in accepting shared care. Eighty-three patient-RO dyads completed the remote monitoring concordance study. The lower-than-ideal response rate and fair to moderate patient-RO concordance meant results could not be used to support the model. Fifteen GP-RO dyads completed the follow-up clinical assessment concordance study, with moderate to almost perfect agreement, indicating the feasibility of the clinical assessment tool. Thirty-two pre-intervention and 28 post-intervention interviews were performed. This shared cancer follow-up model of care was acceptable and feasible for patients, GPs and ROs. Central to the acceptance was the clinical assessment protocol with an in-built rapid referral option, the health technology used to transfer the results securely from the GP to allow the RO to oversee care in real-time and collect outcome data. Acceptability and feasibility rely on the patients' understanding of the benefits of shared care, the patients' relationship with their GP, the oncologists' endorsement of the model, the clinical assessments, and the health technology that allows the oncologist to continue to oversee care.

Conclusion This thesis has shown a novel shared cancer follow-up model of care that is acceptable to patients, GPs and ROs, and feasible in practice. To support implementing this shared cancer follow-up model of care into practice, there is a need to review funding models, have continued support for health technology interfaces, support to ensure GPs have adequate recall systems in place, initial and ongoing support for GPs and oncologists in the form of a shared care coordinator, and support normalising the model into practice for all agents.

Acknowledgements

At the beginning, I recall a conversation I had with Andrew, a Radiation Oncologist I worked with. He told me that doing a doctorate was like walking in the forest…..blindfolded. Whilst navigating through the forest was mostly solo and, at times, a lonely stroll, I would like to acknowledge the support of those who helped navigate me past the low-lying logs, the head height branches, and safely through the forest.

Over the past four years, many individuals have supported and encouraged me. My supervisors, Dr Heike Schütze, Prof Andrew Miller and A/Prof Rowena Ivers. Thank you for supporting this journey. There have been many ups and downs with jobs, faculty, and life changes.

Heike, when I first met you, you were nothing but enthusiastic and supportive of this research and willing to give me a chance even with my 'corporate hat' on. You have graciously guided me with patience, kindness, and selflessness through the highs and lows of my candidacy (and life). Your expertise and guidance have been invaluable to me as an early career researcher and the overall thesis. I appreciate all the time that you have donated, even many late nights over different time zones! You really went above and beyond and have been an excellent teacher and supervisor.

Special thanks to Andrew, the first person I spoke with about my research idea and who wholly supported the research and me. Thank you for the many hours in the car visiting clinics, and the countless 'spottos' and 'punch buggies' (I believe Andrew had the highest tally). Thank you for the many hours of educational and life advice, you provided invaluable counsel in this research. I would also like to express my gratitude for the guidance provided by Rowena. Your ability to balance the research, clinical and practical worlds has given this work a unique richness. Thank you for your invaluable advice and continuous support.

A very special mention to Marianna at ISLHD Research Central. Thank you for your guidance and ability to help problem solve whilst maintaining the broader perspective and keeping me on track. I gained a great deal from your mentorship, wisdom and clarity of purpose and motivating me through some of the parts of the foggy forest when it felt like there was no direction forward. Thank you to the team on level 8 for providing statistics support, presentation feedback, life advice and friendship: Jose, Tiana, Janaye, Kimberly, Emily & Jean.

I would like to acknowledge all the patients, general practitioners and radiation oncologists involved in this research. I also extend my acknowledgements to all the radiation oncologists at ISLHD. Thank you for your support, your feedback and direct involvement. Dr Elias Nasser, I owe so much to you for your kind words and continual encouragement from the day I started working at the cancer centre. Thank you to my work colleagues, Anne S, Belinda, Beck, Alexis, Liz and Anthony, for your encouragement and support over the years.

Thank you to a few others for working silently behind the scenes on the technical side of PROsaiq and MOSAIQ. Thank you, Janet, for helping create, test, and automate clinical letters and quality control checklists; always willing, able, and keen to help. Thank you to Ashley for supporting the PROsaiq system in the background and rebooting at a moment's notice. Thank you, Rebecca, from Coordinare, for supporting the processing of continuing professional development points.

I must also thank the amazing support from my friends who have helped me push through the downs and celebrate the ups. MJ thank you for your beautiful words of encouragement. Anna thank you for making me laugh. Thank you, Tina, Kate, Jess A, Kelly R, Rachel B, Melissa, Brooke, Jess D, Emma W, Sophie, Morgan, Julia & Åse, for being my cheer squad and a source of strength.

Thank you to my parents for instilling the importance of higher education in our family. As dedicated teachers, you've modelled the importance of continually learning and that there is no end to learning. To my sisters, Melanie and Alex, thank you for helping me make sense of my thoughts and for listening, supporting, and believing in me.

Finally, my family. The encouragement from Christofer. His passion for research and philosophy was infectious (something he gets from his sister, Michaela), and led me to where I am today. No words can capture my gratitude for your encouragement, patience, and unwavering belief in me. Thank you for walking with me through the forest, being the ear and shoulder I needed, and bandaging me up along the way. Tomorrow, we start a new path, through another forest, but hopefully not blindfolded this time. During the past four years, as a family, we have learnt the importance of investing in life experiences and that health is real wealth. Most importantly, the biggest adventure of life is learning.

Certification

I, *Tiffany Sandell*, declare that this thesis is submitted in partial fulfilment of the requirements for the conferral of the degree *Doctor of Philosophy* from the University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. This document has not been submitted for qualifications at any other academic institution.

Tiffany Sandell
March 2023

COVID-19 Impact Statement

The COVID-19 pandemic substantially disrupted academic research, with fieldwork largely suspended (1). Two separate government-enforced stay-at-home lockdowns in NSW in 2020 and 2021 delayed data collection by 12 months.

During the first stay-at-home lockdown, medical consultations in the study region provided limited face-to-face consultations between patients, their radiation oncologists, and many GPs. Telehealth consultations were instead implemented rapidly to continue patient care. This first lockdown resulted in a nine-month delay in the initial recruitment as we could not request patients attend their specialist and GP face-to-face.

As there was no known timeframe for the delay, the thesis was revised to include an additional cross-sectional study for remote follow-up monitoring of patients when neither the oncologist-led model nor the shared care model was available face-to-face for patients. This was also an opportunity to test the health technology proposed for the shared care intervention.

The second stay-at-home lockdown in NSW coincided with redeployment to the Public Health contact tracing team, the roll-out of the COVID-19 vaccinations, and phase two of the intervention. As vaccinations were the priority, some GPs further delayed their involvement in this research. However, as vaccination uptake in NSW increased, GPs were able to schedule the follow-up appointment with their patient. This second lockdown resulted in a three-month delay in final data collection.

Thesis style

Thesis by compilation was chosen to publish the evidence in a timely manner to help facilitate how cancer follow-up care is offered to patients sooner. This thesis format follows the University of Wollongong guidelines.

The journal articles in Chapters 3-8 have been reformatted to Vancouver referencing style for consistency within the thesis as per the UOW guidelines. Unless otherwise stated in the chapter overview, permission to reproduce all or part of an article to be used in this thesis was not required.

Publications during candidature

Published

Sandell T, Schütze H. Factors influencing the translation of shared cancer follow-up care into clinical practice: A systematic review. BMJ Open. 2022;12(8). (**Chapter 3)**

Sandell T, Schütze H, Miller A. A shared cancer follow-up model of care between general practitioners and radiation oncologists for patients with breast, prostate, and colorectal cancer: Protocol for a mixed methods implementation study. JMIR. 2021;10(1). (**Chapter 5)**

Sandell T, Miller A, Schütze H, Ivers R, Vijayakumar V, Dinh L. Patient self-reported follow-up for radiation oncology patients during COVID-19: Feasibility and patient-clinician agreement. JROI. 2023;12(2). (**Chapter 6)**

Sandell T, Miller A, Schütze H. Concordance between general practitioners and radiation oncologists for cancer follow-up cancer. IJERPH. 2023;20(1). (**Chapter 7)**

Accepted

Sandell T, Schütze H, Miller A, Ivers R. Patients' acceptability of shared cancer follow-up model of care: A population-based survey using the Theoretical Framework of Acceptability. BMC Primary Care. 2023. (**Chapter 4)**

Under review

Sandell T, Schütze H, Miller A. Acceptability of a shared cancer follow-up model of care between general practitioners and radiation oncologists: A qualitative evaluation. Health Expectations. (**Chapter 8)**

Peer-reviewed conference presentations during candidature

Sandell T, Miller A, Schütze H, Ivers R, Vijayakumar V and Dinh L. Radiation oncology patient self-reported follow-up during the COVID-19 pandemic, Australian Public Health Conference, Supporting and Re-energising Public Health in a Disrupted Word, 23-24 September 2021, Canberra (virtual presentation).

Sandell T, Schütze H, Miller A, Ivers R. Shared cancer follow-up care - Shaping an optimal care pathway between general practitioners and radiation oncologists, PC4 Scientific Symposium, Shaping Optimal Care Pathways around Australia, 25 May 2021, Melbourne, Australia.

Sandell T, Schütze H. A systematic review: The barriers and enablers to shared cancer follow-up care, 16th World Congress on Public Health, 12-16 October 2020, Rome, Italy (virtual presentation).

Statement of contributions of others

Table 1. Authorship and contributions for studies included in this thesis

Chapter	Contributions
Chapter 3 Factors influencing the translation of shared cancer follow-up care into clinical practice: A systematic review	• Tiffany Sandell[1,2]: conceptualisation, study design, data collection, data analysis, writing: original draft, review and editing • Dr Heike Schütze[1, 3]: supervision, conceptualisation, study design, data analysis, writing: review and editing.
Chapter 4 Patients' acceptability of shared cancer follow-up model of care: A population-based survey using the Theoretical Framework of Acceptability	• Tiffany Sandell[1,2]: conceptualisation, study design, ethics, data collection, data analysis, writing: original draft, review and editing • Dr Heike Schütze[1, 3]: supervision, conceptualisation, study design, ethics, writing: review and editing • Professor Andrew Miller[2]: supervision, conceptualisation, writing: review and editing. • Associate Professor Rowena Ivers[1]: supervision, writing: review and editing
Chapter 5 A shared cancer follow-up model of care between general practitioners and radiation oncologists for patients with breast, prostate, and colorectal cancer: Protocol for a mixed methods implementation study	• Tiffany Sandell[1,2]: conceptualisation, research design, methodology, writing: original draft, review and editing. • Dr Heike Schütze[1, 3]: supervision, conceptualisation, research design, methodology, writing: review and editing. • Professor Andrew Miller[2]: supervision, conceptualisation, writing: review and editing.
Chapter 6 Patient self-reported follow-up for radiation oncology patients during COVID-19: Feasibility and patient-clinician agreement	• Tiffany Sandell[1,2]: conceptualisation, study design, ethics, data collection, data analysis, writing: original draft, review and editing • Professor Andrew Miller[2]: conceptualisation, supervision, writing: review and editing • Dr Heike Schütze[1, 3]: supervision, ethics, conceptualisation, writing: review and editing • Associate Professor Rowena Ivers[1]: supervision, writing: review and editing • Dr Vivega Vijayakumar [2]: data collection, writing: review and editing • Dr Lincoln Dinh[2]: data collection, writing: review and editing
Chapter 7 Concordance between general practitioners and radiation oncologists for cancer follow-up cancer	• Tiffany Sandell[1,2]: conceptualisation, study design, ethics, data collection, data analysis, writing: original draft, review and editing • Professor Andrew Miller[2]: conceptualisation, supervision, writing: review and editing. • Dr Heike Schütze[1, 3]: supervision, conceptualisation, study design, ethics, writing: review and editing
Chapter 8 Acceptability of a shared cancer follow-up model of care: A qualitative evaluation	• Tiffany Sandell[1,2]: conceptualisation, study design, ethics, data collection, data analysis, writing: original draft, review and editing • Dr Heike Schütze[1, 3]: supervision, conceptualisation, study design, ethics, analysis, writing: review and editing • Professor Andrew Miller[2]: supervision, data collection, writing: review and editing.

1. Faculty of Science, Medicine and Health, Graduate School of Medicine, University of Wollongong, NSW, Australia
2. Department of Radiation Oncology, Cancer Services, Illawarra Shoalhaven Local Health District, NSW, Australia
3. Faculty of Medicine, School of Medicine University of New South Wales, NSW, Australia

All authors hereby agree with the authors' contributions statement:

Tiffany Sandell, 17 March 2023

Dr Heike Schütze, 16 March 2023

Prof Andrew Miller, 15 March 2023

A/Prof Rowena Ivers, 17 March 2023

Table of Contents

List of Figures

List of Tables

List of abbreviations

ASCO	American Society of Clinical Oncology
COVID-19	Coronavirus caused by the SARS-CoV-2
CROSS	Consensus-based checklist for reporting of survey studies
GP	General practitioner
HREC	Human Research Ethics Committee
ID	Identification
IOM	Institute of Medicine
ISLHD	The Illawarra Shoalhaven Local Health District
JBI	Joanna Briggs Institute
NCCN	National Comprehensive Cancer Network
NICE	National Institute for Healthcare and Excellence
NSW	New South Wales
OCP	Optimal Care Pathways
PhD	Doctor of Philosophy
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
PROSPERO	Prospective register of systematic reviews
RO	Radiation oncologist
TFA	Theoretical Framework of Acceptability
UOW	University of Wollongong

CHAPTER 1: Introduction

Chapter overview

This chapter provides the overall context for this thesis. First, the researcher's position and the research setting are presented. Section two provides background information on cancer follow-up care: what a cancer survivor is, the impact of treatment, the need for follow-up care, and the different types of follow-up care models, followed by presenting evidence for change. Finally, the thesis aim and objectives are presented, along with the theoretical framework and significance of this research. The structure of the thesis and how each chapter relates to the objectives are presented in table format.

1.1 Overview

1.1.1 Position of researcher

I have worked for over 10 years in the public health system, predominantly in cancer services, where my focus as an employee was to lead clinical practice improvements. Throughout numerous clinical practice projects, I listened to patients disclose their heartfelt stories, challenges, and suggestions for improving the cancer service. Secondary to this, I monitored how many patients attended the Wollongong and Shoalhaven cancer centres for treatment and follow-up consultations. I was acutely aware that as more people started treatment, more were finishing their treatment and entering the follow-up phase for many years. I saw the service demand increase over the years and knew this would continue based on the increasing incidence of cancer diagnoses.

Having a public health and project management background, I embarked on a search to find a possible solution to address this. I spoke with many radiation oncologists and medical oncologists and appreciated their open views. I researched possible follow-up models that placed the patient at the centre of the care. I realised more research was needed, and there were gaps in the evidence for change. I felt almost ready to tackle a PhD after two Masters degrees and a decade of practical experience. I sought a primary supervisor with a skillset who could help guide me during the research process, and together with support from the Illawarra Shoalhaven Local Health District (ISLHD) research program, I embarked on my PhD. I did not set out to change the health care system or revolutionise the way cancer follow-up care was delivered, I wanted to create a more person-centred approach to improve access to cancer follow-up care, whilst considering the hospital resources. After this, I hope that any patient can have an open and informed shared decision-making discussion with their oncologist and GP and have the option to choose where and who provides their follow-up care based on their values and preferences.

Previous experience using qualitative and quantitative data to support projects led me to understand and appreciate combined methods to gain a more complex understanding of the phenomenon and the desire to learn more. I was eager to read, explore and understand my ontological and epistemological position. I recognised my position aligned with critical realism as the paradigm seeks explanations "in the complexity of everyday life, those explanations may draw on different social theories" (2 p.113). Conceptualising the study as mixed methods within this paradigm allowed me to see the phenomenon as ontologically real, but my research tools as epistemologically relativist.

1.1.2 Research setting

The ISLHD is south of Sydney in New South Wales (NSW), Australia, and stretches over a 250-kilometre coastal catchment area (see Figure 1). The ISLHD provides public health services to over 400,000 people (3), and cancer services (medical oncology, haematology, and radiation oncology) to over 10,000 people annually. Radiation oncology outpatient services are provided in a regional area at Wollongong Hospital, and a rural area at the Shoalhaven District Memorial Hospital (see yellow stars in Figure 1).

Figure 1. Map of the local health district regions in NSW and the hospitals that comprise the ISLHD

The ISLHD radiation oncology service treats more than 1500 patients with radiotherapy and performs close to 6000 follow-up consultations annually (in 2022) (3). The service experienced a 20% increase in follow-up consultations over the 5-year period between 2018-2022 (including telehealth consultations during COVID-19), and treatment activity is projected to increase by 18% by 2031 (ISLHD department meeting, 2022, personal communication, 15 March). Breast, colorectal, and prostate cancer account for a substantial proportion of radiotherapy treatment at each site (3).

Funding of healthcare in Australia

Before presenting the current cancer follow-up model of care, it is important to understand how healthcare is funded in Australia. Australia's universal healthcare system, Medicare, is financed through general tax revenue and a government levy. Health expenditure accounted for 10.2% of the gross domestic product in 2019-20 (4). Medicare enrolment is open to Australian and New Zealand citizens, permanent residents, some temporary residents, and citizens of nations that offer reciprocal benefits (5). Medicare provides access to public hospitals with no copayment and considerable coverage for medical services, pharmaceuticals, and other health services. In addition, approximately half of the Australian population have private health insurance and can choose their treating doctor and elect to be treated in a public or private hospital.

Each state and territory in Australia have a range of private and public radiation therapy providers. Only public radiation therapy providers are available in the Illawarra and Shoalhaven region. Therefore, patients eligible for Medicare do not have copayments for radiation therapy treatment or consultations.

The term ‘general practitioner’ is used in many Commonwealth countries and refers to a licenced medical doctor, usually in the community setting, who treats acute and chronic conditions to patients of all ages and provides preventative care and health education. Other countries may refer to a general practitioner as a primary care physician, specialist general practitioner, family doctor, family physician, or family medical practitioner. For the purposes of this thesis, the term general practitioner or GP is used.

Under Medicare, the Australian government provides rebates to all patients for GP consultations. GPs can set their fees above the Medicare rebate, and some charge patients a copayment (6). There are reported differences in how many practices do not charge a copayment, ranging from 16% (6) to 43% (7). The practice of copayments varies across Australia, with people living in metropolitan areas less likely to be charged copayments (7), and people in regional and rural areas more likely (6), with the average copayment for a 15-minute consultation being $40 (7). Fifty percent of GPs have indicated that the current funding model is financially unsustainable (8), with more patients expected to pay copayments and at an increasing amount in the future (9).

Access to general practitioners

In Australia, patients are not allocated to a specific general practice clinic or an individual GP. Patients can choose their GP, with a reported 79% of the population having a usual or preferred GP, and 75% stating they could always see their preferred GP when needed (10). Australia has an average of 119.6 full-time equivalent GPs per 100,000 population (2021) (8); however, this varies across the states and territories. Major cities have 122 GPs per 100,000, inner regional areas 114.3 per 100,000, and outer regional, remote and very remote areas 94.3 per 100,000 (11).

Comparatively, Portugal has an average of 273 GPs per 100,000 (2021); Ireland 179; Canada 115 (2015) (12); the United States of America 111.7 (2019) (13); the Netherlands 90.9 (2021) (12); Germany 71.9 (2021) (12); and the United Kingdom 59.6 (2021) (14).

Health professionals communication

In Australia, a government initiative, *MyHealth Record,* is an online summary of an individual's health information. It was developed to allow doctors, hospitals and other health professionals involved in patient care to access health information. Although there are 23 million registered individuals, the use of *MyHealth Record* has been limited. Whilst 18% of patients who presented to an emergency department had their file accessed by a pharmacist (15), fewer than 2% had their file accessed by a nurse or doctor (2020-21) (15). Ninety-nine percent of GPs are registered and have used *MyHealth Record*; in comparison, 31% of specialists are registered, and only 13% have used it.

The primary method of communication between health professionals is via letters, delivered by mail, fax or secure messaging system. There is no consistent communication method between health professionals, and it varies across states, territories and health services. In this study setting, the two hospitals upload oncology consultant letters to the *MyHealth Record*, and the letter is also sent either electronically or via mail to the patient's GP. When GPs refer a patient to the oncology service, this is primarily via a hard copy letter the patient presents to the oncology service. However, local projects are improving the uptake of electronic referrals. Besides patient referrals, GPs do not have a streamlined method to communicate or inform an oncologist if they have managed a patient regarding any cancer-related treatment side effects.

1.2 Cancer follow-up care

Cancer survivorship

The term cancer survivor refers to any individual living with cancer or who has had cancer (16). The survivorship phase refers to a cancer survivor navigating life after their diagnosis and usually after treatment (17). Cancer survivors who have had active treatment, such as chemotherapy, surgery, radiation oncology, and/or immunotherapy, usually transition to routine follow-up care for many years (18). Follow-up care aims to assess and treat short- and long-term side effects, monitor for recurrence, and provide psychosocial support (19–21).

Once cancer survivors have completed active treatment, many cancer survivors experience physical and psychosocial symptoms (20,21,22), as discussed in the next section. After treatment, adjusting to life with less medical involvement can take months or years (22). During this phase, many cancer survivors reconstruct their identity and adapt their life plans as they take greater personal responsibility in managing their follow-up care (23–25).

The impact of cancer treatment on physical health and psychosocial health

Although cancer treatments have improved cancer survival rates, they can also cause a range of physical side effects and psychosocial effects (26). Physical side effects after cancer treatment can include fatigue, constipation, diarrhoea, incontinence, nausea and vomiting, pain, sexual dysfunction, skin problems, sleep problems, secondary cancers, etcetera (26–29). These physical side effects can develop during treatment and remain for months to years, whereas late side effects may appear years later. Risk factors for late side effects vary by diagnosis, the type of treatment, age, time since treatment, genetics and other psychosocial factors. Therefore, consistent and comprehensive long-term follow-up care is needed to prevent, minimise and manage these side effects (30).

Most cancer survivors adjust well to their pre-diagnosis life by reintegrating into the workplace and family roles; however, many experience psychosocial health concerns (31–33). Psychosocial health refers to a “person's sexual, emotional, social, environmental, cognitive, religious, moral and spiritual satisfaction” (34 p.395). The impact of cancer treatment on psychosocial health may include body image and self-esteem changes, depression, fear that cancer will return, difficulty finding meaning in life, grief, guilt, loneliness, difficulty navigating relationships, seeking or rejecting spirituality, and stress (35). The standard follow-up routine leaves many cancer survivors with unmet psychosocial needs (36,37).

The fear of cancer recurrence may last for years or even a lifetime (38). Known as 'Damocles syndrome', this phenomenon is one where the person feels a heightened sense of mortality due to the chance of cancer recurrence (39). It is based on the Greek mythological figure, Damocles, who was seated at a feast, but under constant peril from the sword hanging above him attached by a single hair (see Figure 2).

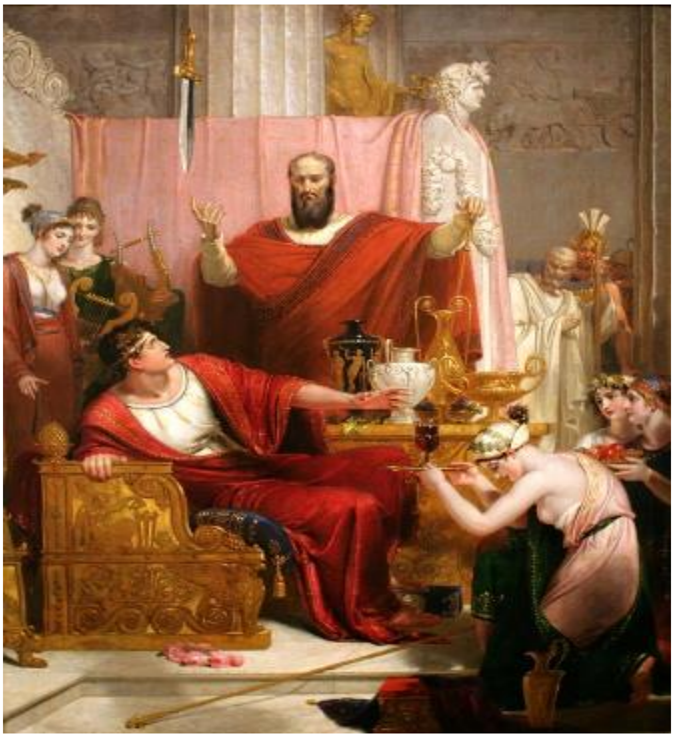


Figure 2. Greek Mythology figure of Damocles, illustrating the Damocles Syndrome (source: 40)

Managing physical and psychosocial health for cancer survivors

The physical and psychosocial effects of cancer diagnosis and treatment require follow-up care to monitor, treat and provide strategies for health behaviour changes to improve overall outcomes (41). Cancer survivors are considered an at-risk population based on their cancer diagnosis and treatment and face additional risks of morbidity and reduced quality of life (20). Additionally, maladaptive health behaviours, such as a sedentary lifestyle or unhealthy eating habits, have led to poor health-related outcomes in cancer survivors (42). Fortunately, cancer survivors want to know how to improve their overall health and reduce their chance of cancer recurrence (43). They do this by seeking support from their oncologists and GPs for guidance concerning their physical and psychosocial health (38,41). This is an opportunity for health providers to intervene in the follow-up phase to positively impact the cancer survivor's health outcomes (44).

Routine assessment of cancer survivors' level of psychosocial health has been consistently recommended as part of cancer care to meet the needs of cancer survivors beyond treatment-related physical difficulties (45,46). “Cancer survivors often prefer psychosocial care by their GP, and GPs generally consider they are well placed to provide this care” (47 p.444). However, GPs have been minimally or not involved in the evaluation of psychosocial intervention outside of the hospital setting (47). When only a GP was involved in psychosocial interventions, results showed no positive or negative difference in the patient's psychosocial symptoms (48–52). However, positive changes to psychosocial symptoms were accomplished by psychosocial interventions that were administered by multidisciplinary teams, such as a shared care arrangement (53–55).

The demand for cancer follow-up care

Given cancer treatments' physical and psychosocial impacts, there is a need for ongoing cancer follow-up care, and the demand for follow-up care is growing. The increased demand for cancer follow-up care is attributed to an ageing population, increasing incidence and prevalence of cancer worldwide, and improved patient screening and treatment options (56). As a result, the projected number of new cancer cases worldwide by 2030 is estimated to be 21.7 million, an increase from 14.1 million in 2012 (56). This equates to a global increase of 35% in new cancer cases over an 18-year period.

Incidence rates in Australia have followed the same trend, increasing 38% over 18 years (85,231 in 2000, projected 138,321 in 2018) (57). Although survival data varies by cancer type stage, the global five-year survival rate for all cancers has increased from 50% in 1990-1977 to 67% in 2007-2013 (58), and from 48% in 1984-1988 to 70% in 2013-2017 in Australia (59). Australia has one of the best relative survival rates; consequently, there is a growing need to review cancer follow-up care.

Guidelines for cancer follow-up care

Australian oncologists are generally guided by the National Institute for Clinical Excellence (NICE), the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) guidelines. These guidelines are used regarding the frequency and timeframe for follow-up care and are summarised in Table 2.

The ASCO and NCCN guidelines acknowledge a report from the Institute of Medicine (IOM) that saw cancer care was in crisis and urgently needed change. The IOM concluded that “cancer care is often not as patient-centred, accessible, coordinated or evidence-based as it could be” (60 p.20). This report from the IOM has formed the basis for change internationally and made a recommendation for four distinct phases of survivorship care:

> “1. Prevention and detection of new cancers and recurrent cancer; 2. Surveillance for cancer spread, recurrence, or second cancers; 3. Intervention for consequences of cancer and its treatment; and, 4. Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met” (60 p.366).

Although the health systems of the United States of America and Australia differ, the recommendation to include the GP in the follow-up phase is echoed internationally (61–64). The Clinical Oncology Society of Australia does not have specific guidelines; however, they have a position statement for survivorship care. This position statement highlights the need to enhance the coordination and integration of care and access to equitable services (65). Similarly, Cancer Australia's survivorship principles state that survivorship care needs to be person-centred, evidenced-based, coordinated and integrated across the healthcare settings (66).

Cancer Australia is due to release its first national cancer plan in April 2023, adopting Optimal Care Pathways (OCP). The OCPs present “key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality, evidence-based care, including in the survivorship phase” (67 p.76) (see Table 2). Transitioning from active treatment to survivorship, the OCPs present several follow-up models for consideration (shared care, GP-led, nurse-led, and telehealth – discussed in more detail below). The OCPs recognise that whilst some cancer survivors will require ongoing oncologist-led follow-up care, for others, a shared care arrangement with their GP may be appropriate (67). Whilst the OCPs highlight the need for ongoing communication between GPs and oncologists for shared care (67), they do not specify how this communication would work in clinical practice.

Table 2. ASCO, NCCN, NICE Guidelines to cancer follow-up care

	American Cancer Society / American Society of Clinical Oncology,		**National Comprehensive Cancer Network**		**National Institute for Clinical Excellence**	**Australia – Optimal Care Pathways, Step 5: Care after initial treatment and recovery**	
	Breast 2016 (68)	**Prostate, 2014** (69)	**Not tumour specific 2022** (18)	**Breast** (18)	**Breast, 2018** (70)	**Breast 2016** (68)	**Prostate, 2014** (71)
Target audience	Primary care providers, medical oncologists, radiation oncologists, and other clinicians caring for breast cancer survivors.	Primary care providers, medical oncologists, radiation oncologists, and other clinicians caring for prostate cancer survivors.	Oncology and primary care practices.		Healthcare professionals, Commissioners and providers of breast cancer services, people with early and locally advanced breast cancer, their families and carers.	Both health professionals and a synthesised version for patients, carers and families.	
Surveillance	Physical examination every 3-6 months for 3 years. 6-12 months for the following 2 years, then annually. Annual mammogram. MRI only if high risk.	Measure PSA every 6-12 months for the first 5y, then annually. Refer to oncologist if rising PSA. Perform an annual digital rectal exam in coordination with the specialist to avoid duplication.	N/A	History and physical exam 1-4 times per year for 5y and then annually. Annual mammogram.	Annual mammogram.	Physical examination every 3-6 months for 3 years. 6-12 months for the following 2 years, then annually. Annual mammogram. MRI only if high risk.	Measure PSA every 6-12 months for the first 5y, then annually. Refer to oncologist if rising PSA. Perform an annual digital rectal exam in coordination with the specialist to avoid duplication.
Long-term management	Assessment and management of physical and psychosocial long-term and late effects of breast cancer and treatment e.g. body image, fatigue, bone pain, lymphoedema, cardiotoxicity	Assessment and management of physical and psychosocial long-term and late effects of prostate cancer and treatment. E.g. anaemia, bowel dysfunction, cardiovascular and metabolic effects, distress/depression/ anxiety, fracture risk, sexual dysfunction/body image, sexual intimacy, urinary dysfunction, and vasomotor symptoms.	Assessed for cardiovascular disease risk. Assessed for anxiety, depression, trauma and distress. Assess cognitive function, fatigue, lymphoedema, pain, hormone-related symptoms, sexual function, sleep disorders. Psychosocial effects: fear of recurrence, employment and return to work, financial burden.	Endocrine therapy.	Provide information on psychological support.	Assessment and management of physical and psychosocial long-term and late effects of breast cancer and treatment e.g. body image, fatigue, bone pain, lymphoedema, cardiotoxicity	

Health promotion/ health behaviour	Educate the patient on signs and symptoms. Assess patient information needs. Discuss obesity, physical activity, nutrition, smoking, sexual health	Assess information needs. Discuss obesity, physical activity, nutrition, and smoking.	All survivors should be encouraged to set incremental as well as ultimate goals for diet, physical activity, and weight management. At a minimum, all survivors should be encouraged. Healthy lifestyles, physical activity, nutrition and weight management, supplement use, health behaviour change, immunisations and prevention of infections.	Educate, monitor and refer for lymphoedema management.	Provide advice on healthy lifestyle; weight, alcohol, regular physical activity, and smoking.	Encourage and support the patient to reduce modifiable risk factors for recurrence as well as other chronic diseases (smoking, healthy diet, sun smart, limit alcohol, be physically activity, maintaining healthy body weight).	
Coordination	Have a treatment summary or care plan. Communicate with oncology team.	Treating specialist to provide treatment summary to GP. Primary care clinicians and treating oncology specialists should confer regarding the survivorship care plan components and determine roles and responsibilities.	Coordination of care between the primary care provider and specialists is encouraged.		Need a written care plan. People have the right to be involved in discussions and make informed decisions about their care.	Responsibility for follow-up care should be agreed between the lead clinician, the GP, relevant members of the multidisciplinary team and the patient. Supports written treatment summary, including: diagnostic tests and results, diagnosis including stage and prognosis, tumour characteristics, treatment received and dates, current toxicities and side effects and expected outcomes, treatment plans for side effects, follow-up schedule and contact information.	
Screening	Assess risk and offer family genetic counselling. Cervical, every 3y, ages 30-65 every 5y. Colorectal, from age 50. Lung, if current of former smoke, from age 5.	Screen for colorectal cancers. Refer if bleeding, pain other symptoms. If haematuria, perform evaluation to rule out bladder cancer.	Screening for subsequent new primary cancers. Breast annually from age 30 or 8 years after radiation. Annual skin check. Colorectal from age 30 or 5y after radiation.	Genetic screening	N/A	Annual mammogram. Genetic screening and update family history.	Assess risk and offer family genetic counselling. Cervical, every 3y, ages 30-65 every 5y. Colorectal, from age 50. Lung, if current of former smoke, from age 50.

Person-centred care

Before describing the different models of care, a discussion of person-centred care is valuable. Person-centred care is a term that is becoming increasingly familiar and important in healthcare and refers to placing the patient at the centre of care (72). There is no universally agreed-upon definition of person-centred care; however, it supports patients in making informed decisions, managing their health and care, and deciding when representatives may act in their stead (73). Furthermore, person-centred care requires a collaborative effort from services to adapt to changes in an individual's needs, concerns, family situation, social circumstances, lifestyles and preferences (74).

In the traditional biomedical healthcare model, medical practitioners instruct and prescribe healthcare treatment with little consultation from patients and families (75). The shift to a person-centred care approach creates flexibility in providing healthcare services and is tailored to meet the individual's needs (75). Person-centred care enhances healthcare quality and has become an independent measure of quality (74). Cancer follow-up guidelines acknowledge that new models of care should incorporate person-centred care principles and recognise the importance of patient involvement in designing healthcare (74,76,77). This thesis engages with patients to help foster a better working partnership and evaluate the model of care to assess if the model meets the patient's needs, preferences and values.

Cancer follow-up models of care

“As the number of cancer survivors increases worldwide, there have been many efforts to define and advocate for quality survivorship care, with the ultimate aim to improve survival, physical symptoms, psychosocial effects and quality of life” (30 p.197). A model of care generally describes how healthcare services are provided and:

> “…outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place” (78 p.7).

As the understanding of side effects and the long-term management of cancer survivors has increased, different cancer follow-up care strategies have developed over the past 20 years.

Oncologist-led model of care

Oncologists are the specialists that diagnose, stage, and treat cancer and monitor cancer survivors for late side effects and recurrence. In Australia, an oncologist completes an additional six years of training after graduation as a doctor. There are different types of oncologists: medical oncologists, radiation oncologists, haematologists and surgical oncologists. Depending on a cancer survivor's cancer and treatment, patients may be cared for by one or all of these oncologists, each taking the lead at different times during the treatment pathway.

The oncologist-led model of care is the most common and accepted model internationally (79–90) and is the current model used in Australia. In Australia, the oncologist-led model of care may occur in the public or private setting. The oncologist manages patient care throughout the disease by explaining the cancer diagnosis, establishing the disease stage, discussing treatment options, overseeing treatment delivery and managing symptoms and side effects of delivered treatment (21). The oncologist-led model of care is usually parallel to a patient's GP being involved in other facets of the patient's health and well-being (91).

General practitioner-led

A GP is a doctor who treats common medical conditions, manages chronic conditions in the community, and coordinates care by referring patients to hospitals and specialists as required (92). A GP completes a three-year specialist training program after a residency in the hospital setting. The GP focuses on the patient's whole health, combining psychological and social contributions to health, therefore applying bio-psychosocial-semiotic approaches to patient management (93).

GPs are usually the first point of contact when cancer is suspected or diagnosed. Routine cancer follow-up care in general practice is not standard (94). Studies have transferred care entirely from the oncologist to the GP, and results show no difference between recurrence and quality of life (95). GP-led care may be suitable for low-risk patients or patients who live in rural or remote areas with impeded access to specialist care (96). However, barriers to adopting a GP-led model can be attributed to the perception of some oncologists and cancer survivors that GPs lack sufficient cancer-specific skills (97,98) and prefer traditional models of care (97,99,100). Another factor highlighted is that some oncologists report that if GPs were to conduct follow-up care, there is currently no mechanism for them to report back to the oncologist (Miller A, 2023, personal communication, 15 March).

Oncology nurse-led

A nurse is a licensed healthcare professional trained to care for people and provide health education; medical practitioners usually supervise them. Oncology nurses have the requisite training and expertise to detect and manage short and long-term side effects and refer to appropriate services (96). An oncology nurse-led cancer follow-up model of care can occur in a primary or non-primary healthcare setting and be face-to-face or via telehealth. Studies have demonstrated the effectiveness, safety, acceptability, cost-effectiveness of oncology nurse-led clinics (101–103) and decreased clinic waiting times (104).

Nurse-led cancer follow-up care has been reviewed as an option for fulfilling person-centred care principles for cancer survivors (105). However, there are conflicting studies regarding cancer survivors' preference between a GP and a nurse for follow-up care. For example, two studies in Australia with breast cancer survivors found that follow-up care with a breast care nurse was preferred to a GP (106,107). This is similar to lung cancer survivors in the United Kingdom (104). However, it was also found that if a physical examination were needed, as it is with breast cancer, they would prefer their GP over the breast care nurse (107). Although this model appears feasible and acceptable, it still requires the GP or oncologist participation to oversee the care and refer for specific tests and medicines (107).

Technology-enabled care

Technology-enabled care is the umbrella term for healthcare services using health technology such as telehealth, digital health, virtual video care, e-health services, self-care apps to support care (108) and is an ongoing area of research and development. The setting varies for technology-enabled care and may be self-administered by the patient or administered and monitored by the nurse, GP or oncologist. Technology-enabled care is useful for administering healthcare to patients who are geographically separated from providers (109). Prior to the COVID-19 pandemic, technology-enabled care was not widely adopted for cancer follow-up care (110). During COVID-19 many cancer follow-up consultations used telehealth to reduce the risk of infection to the cancer survivor and to protect the healthcare staff. Although a relatively new concept and an emerging research area, cancer survivors stated that telehealth could never totally replace physical follow-up consultations (111), some oncologists are concerned about telehealth's impact on survival (112).

Shared care

A shared cancer follow-up model of care is distinct from the sole transfer or discharge of care from one care provider to another. A shared cancer follow-up model of care harnesses the expertise of various health professionals (113) and involves explicit sharing of information and coordination of follow-up care (64), usually between a GP and a specialist (for example, a surgeon, medical oncologist, and radiation oncologist). The realisation of shared care as a possible model for cancer follow-up care aligns with emerging perceptions of cancer as a chronic condition (41). Additionally, shared care is prevalent for managing antenatal care and some chronic health conditions, such as heart disease, diabetes and asthma (114–117).

Shared cancer follow-up care is safe and offers no differences in recurrence rates or quality of life compared to the oncologist-led model (51,118,119). Shared cancer follow-up care facilitates comprehensive care as a possible benefit to cancer survivors (120). However, for health services to be person-centred, they need agility and integration to meet patients' needs, values and preferences (75).

1.3 Problem statement

The increasing incidence of cancer, coupled with improved survivorship, has increased the demand for cancer follow-up care and the need to find alternative models of care, including ones that place the patient at the centre of the care whilst also satisfying the needs of the involved clinicians (GPs and oncologists). International and national clinical guidelines advocate for including GPs in the follow-up phase for cancer patients in a shared care model.

A wealth of international evidence has demonstrated that when a GP is involved in cancer follow-up care, there is no difference in the recurrence rate detected between oncologists and GPs, no difference in quality of life, and it is cost-effective. Furthermore, many patients welcome their GP having a more prominent role in their cancer follow-up care, and GPs want to have this expanded role; they both emphasise the need for ongoing support from the oncologist (121–123).

However, the adoption and implementation of shared cancer follow-up care is limited. For shared care to be truly shared, the GP and the oncologist must be involved in each episode of care. There is no shared cancer follow-up model of care in Australia where the GP performs routine cancer follow-up care, and the oncologist continues to oversee the care in real-time. There is a need to identify tangible barriers and facilitators to implementing shared cancer follow-up care and address them using evidenced-based research methods.

1.4 Thesis aim and objectives

The overarching aim of this thesis was to develop and implement a novel shared cancer follow-up model of care and evaluate the acceptability and feasibility to patients, general practitioners and oncologists. The objectives were:

1. To identify the barriers and facilitators for shared cancer follow-up care between general practitioners and oncologists.
2. To determine the level of acceptance for shared cancer follow-up care in the ISLHD cancer patients.
3. To develop a shared cancer care follow-up model of care.

> **3a**. To test the model and determine the concordance in clinical data between patients and oncologists completing the follow-up clinical assessment in the radiation oncology setting.
> **3b.** To test the model and determine the concordance in clinical data between GPs and oncologists completing the follow-up clinical assessment in the radiation oncology setting.
> **3c.** To evaluate the acceptability of the model to patients, GPs and ROs.

1.5 Theoretical Framework

Chapter 1 has presented the researcher's position and setting, background information on cancer follow-up care, evidence for change and the thesis aim and objectives. This section provides the theoretical framework informing this research.

Developing and embedding new models of care in health services is complex (124). Models of care should consider the people involved and the organisational context to evaluate the ability to sustain and establish the change. Theoretical frameworks provide the rationale for conducting the research and are used to make research findings meaningful and generalisable (125). The theoretical framework used to guide the design and interpretation of some of the studies in this thesis was the Theoretical Framework of Acceptability (TFA).

The TFA is a multi-construct theoretical framework created to support the evaluation of the acceptability of healthcare interventions. It centres around the perspectives of the people involved in the intervention and those who administer the intervention (126). “The TFA is a multi-faceted construct, represented by seven component constructs: affective attitude, burden, perceived effectiveness, ethicality, intervention coherence, opportunity costs, and self-efficacy” (126 p.9) (see Figure 3).

The TFA can be used prospectively, concurrently and/or retrospectively. That is, a healthcare intervention's acceptability can be assessed before engaging in the intervention. For this thesis, the TFA was used to guide the analysis of the quantitative population survey, the qualitative interviews, and the mixing of the results.

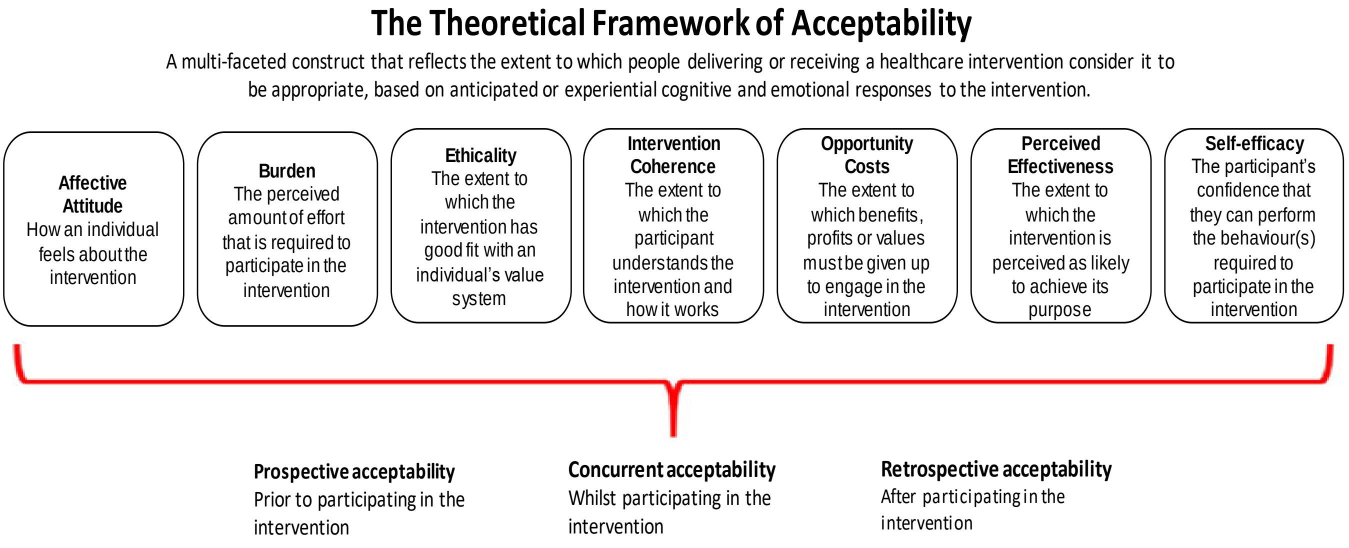


Figure 3. The constructs of The Theoretical Framework of Acceptability (source: 126)

1.6 Significance of the research

The proposed research is significant as it seeks to address an identified gap in allowing the GP to perform routine cancer follow-up care whilst the oncologist continues to oversee the care in real-time at each episode of care. Figure 4 presents the proposed two-way communication transfer between the oncologist and the GP. This research seeks to contribute to the growing body of literature on shared cancer follow-up care.

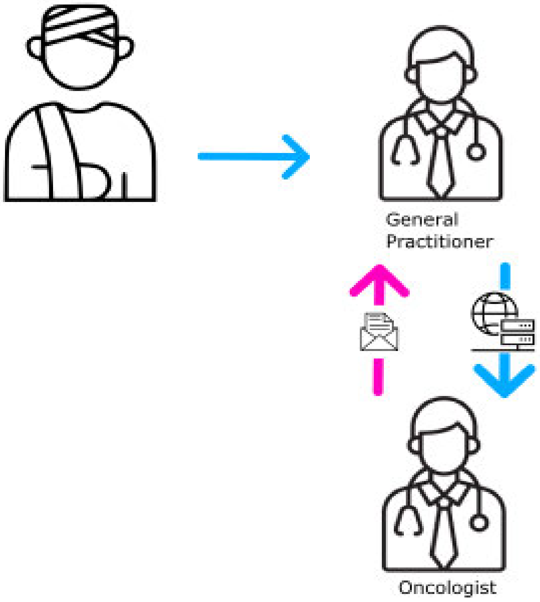


Figure 4. Diagram of the proposed communication path between the oncologist and general practitioner for the shared cancer follow-up model of care

1.7 Thesis outline

This thesis is structured into nine chapters, including the current introduction chapter (Chapter 1). Chapter 2 details the methodology and methods used in this thesis. More specific details for each study are included in the Methods section of Chapters 3-8.

Table 3 provides an outline of the structure of this thesis, stating which chapters address the thesis objectives. The final chapter, Chapter 9, synthesises the qualitative and quantitative results, positions the findings of this thesis and outlines future implications to policy and organisations.

Table 3. Overview of thesis structure

Chapter		Objective the chapter addresses
1	Introduction and background	-
2	Methodology and Methods	-
3	Factors influencing the translation of shared cancer follow-up care into clinical practice: A systematic review	Objective 1. To identify the barriers and facilitators for shared cancer follow-up care between general practitioners and oncologists.
4	Patients' acceptance of a shared cancer follow-up model of care between general practitioners and radiation oncologists: A population-based questionnaire using the Theoretical Framework of Acceptability	Objective 2. To determine the level of acceptance for shared cancer follow-up care in the ISLHD cancer patients.
5	A shared cancer follow-up model of care between general practitioners and radiation oncologists for patients with breast, prostate, and colorectal cancer: Protocol for a mixed methods implementation study	Objective 3. To develop a shared cancer care follow-up model of care.
6	Patient self-reported follow-up for radiation oncology patients during COVID-19: Feasibility and patient-clinician agreement	Objective 3a. To test the model and determine the concordance in clinical data between patients and oncologists completing the follow-up clinical assessment in the radiation oncology setting.
7	Concordance between general practitioners and radiation oncologists for cancer follow-up care	Objective 3b. To test the model and determine the concordance in clinical data between GPs and oncologists completing the follow-up clinical assessment in the radiation oncology setting.
8	Acceptability of a shared cancer follow-up model of care between general practitioners and radiation oncologists: A qualitative evaluation	Objective 3c. To evaluate the acceptability of the model to patients, GPs and ROs.
9	Discussion and Conclusion	-

Chapter summary

Chapter 1 introduced the reader to the researcher's position and described the research setting. It provided an overview of cancer follow-up care, described the different models of care, and presented the need to develop new care models to help address capacity issues and person-centred care domains. The chapter concludes by presenting the aim and objectives, the theoretical framework, the significance of the research, and an outline of this thesis.

CHAPTER 2: Methodology and Methods

Chapter overview

This chapter provides the researcher's philosophical viewpoint and discusses how mixed methods research design is the most suitable methodological approach to address the aim and objectives. Following this, rigour and ethical considerations are presented.

2.1 Philosophical paradigm

Research paradigms are sets of commonly held beliefs and assumptions and are a way of thinking. A research paradigm reflects the researcher's beliefs about the world and how they see it and interpret acts within it. The parameters for a research paradigm are defined by:

1. Ontology - What constitutes the properties of reality?
2. Epistemology - What is the relationship between the researcher and what is being studied?
3. Methodology - How can the researcher ascertain what they believe can be known? (127)

The first chapter (Section 1.1.1) adopted the position of critical realist research. Critical realism “combines a realist ontology (there is something to find out about) with a relativistic epistemology (different people will come to know different things in different ways)” (2 p.113). Critical realism is a paradigm that views the real world and the observable world as distinct entities (2). What is observable in reality is socially constructed with structures and agency based on our perceptions and experiences that are under constant internal influence; that is, what we can observe is less than what is real. From an ontological perspective, structure and agency are “distinct and yet equally real” (128 p.74). Research techniques that adhere to this paradigm use strategies that concentrate on “who is doing what, with whom and for which reasons” (129 p.640) to explain structure properties and understand agency as it relates to structures.

Ontologically, critical realism proposes a stratified reality into three domains: real, actual and empirical (130). Critical realists understand that the research will not be able to capture all the nuances of their experiences, and it describes a social world that presents opportunities to implement interventions and affect change. Bhaskar (131) understood reality as complex overlapping layers with their own distinctive characteristics. These layers are depicted in Figure 5; at the base of the iceberg, the real domain is where everything exists but cannot be seen. In the middle is the actual domain, where mechanisms generate observed and unobserved events. At the top is the empirical domain, that is, what we as researchers observe (132). Bhaskar's stratified approach can be applied to the natural, biological, and physical worlds, making it ideal for healthcare.

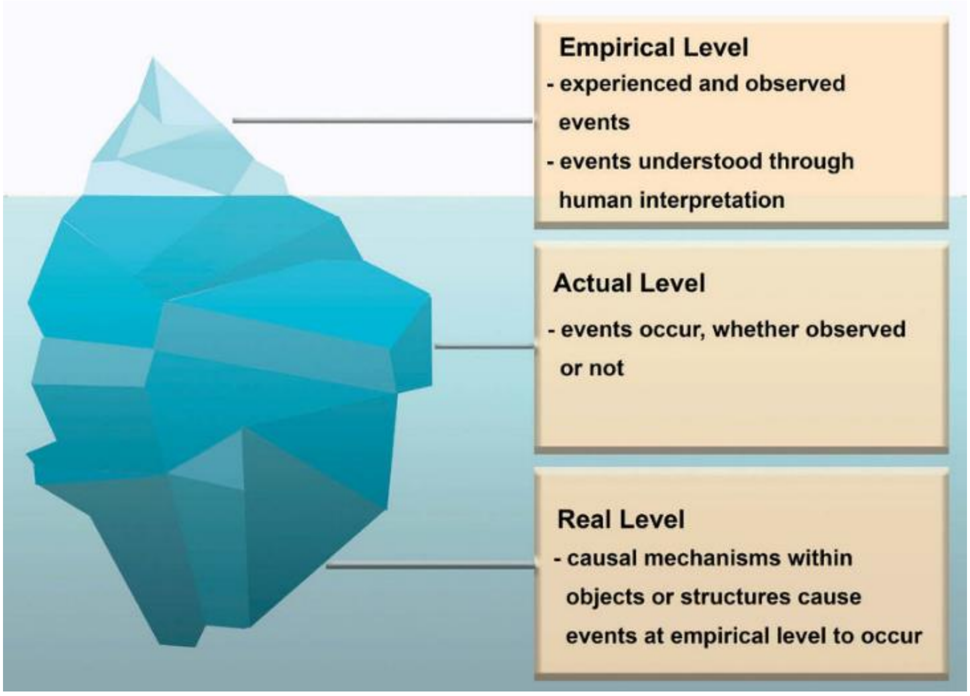


Figure 5. An Iceberg Metaphor for critical realism ontology (source: 133)

In relation to Figure 5, the critical realist recognises the real domain of structures as hidden. Changes in structure, such as changes in health technology mechanisms (presented on the next page), affect changes in the actual domain, and some of the results and changes to the altered communication are perceived in the empirical domain. While attempting to answer the how and why of certain events or phenomena, critical realism can be utilised to inform the research method to explain outcomes and events (134). That is, critical realism acknowledges that emergent mechanisms make up interventions and systems. (135).

The agents in this thesis are the patients, GPs and ROs. While they offer viewpoints that are subjectively significant at the empirical level (thus valuable for research), these viewpoints cannot be compared to and do not govern objective reality (136). Critical realism aims “to develop and provide deeper levels of explanation and understanding of causal or generative mechanisms” (137 p.1210). The structure and agency interaction shapes human life and society.

Structures such as hospitals precede the agents who use them and work in them and outlast the agents. However, the hospital can only exist as a hospital, not an empty building, through the activities of the agents who use it. The interdependence of structure and human agency is central to critical realism:

> “Social structures provide resources that enable individuals to act, as well as placing limits on individual behaviour. However, the behaviour of human agents is not exclusively determined by social structures, as agents are also able to transform social structures by responding creatively to the circumstances in which they find themselves” (138 p.413).

Critical realist-informed research is important in explaining social behaviour by identifying the agent-agent and agent-structure relationship. These relationships can be influenced or triggered by mechanisms. The health technology mechanisms implemented within this thesis at the actual level elicit an observable change in the empirical domain. These are listed below in Table 4:

Table 4. Health technology mechanisms used within the intervention

	What is it?	How is it used in the intervention?
Clinical assessments	Cancer follow-up clinical questions for patients on radiation oncology follow-up. A copy of the clinical assessments is available in Section 7.3, Table 17 and 18.	GPs access the clinical assessment, complete the set of prescribed questions, and the results are returned to the oncologist. The clinical assessment includes a rapid referral option for patients in the shared care model.
HealthPathways	HealthPathways is a frequently used website platform for GPs, containing local referral and treatment guidelines developed collaboratively by Local Health District clinicians and primary care clinicians.	For the intervention, GPs can navigate to Oncology Care and select a weblink to access the shared cancer follow-up clinical assessment for breast, prostate and colorectal cancer.
PROsaiq	PROsaiq® is a webserver that processes the clinical assessments in MOSAIQ to produce a webpage and which can then be presented as a weblink on HealthPathways.	The webform contains placeholders for patient identifiers, and when the form is submitted by the GP, the webserver securely imports the file into the patient's oncological medical record in MOSAIQ®.
MOSAIQ®	MOSAIQ® is the oncology information system used at the hospital cancer centres.	Includes an internal alert system (QCL) for the oncologist to review the patient file when the GP has submitted the clinical assessment. Clinical outcome data available can be viewed by the RO and remains in the patient's oncological medical record.
Argus	Argus is a secure electronic messaging system used to transfer electronic letters and referrals between providers to communicate confidential patient-related information in line with privacy standards.	Once the RO has reviewed the patient's clinical assessment in MOSAIQ from the GP, this triggers the creation of an autogenerated letter, that is then sent via Argus to the GP. If the general practice does not use Argus, a physical copy of the letter is posted.

Critical realism can be used to understand *how* and *why* hidden structures influence healthcare interventions operating within the context of primary healthcare settings (134). That is, given that critical realism holds that no single truth is observable, mixed methods methodology allows several different perspectives to observe a phenomenon. This integration of methods fosters the understanding of the complexity of reality (139). A critical realist can synthesise and discuss convergences and divergences from the quantitative and qualitative data legitimately using mixed methods. Collecting perceptions and reflections-based data and analysing the relationships is helpful in evaluation studies. This paradigm is applicable as this thesis evaluated perceptions of a healthcare intervention.

Additionally, critical realists think that we must embrace epistemic relativism and that we cannot be naive about our knowledge and experience. Epistemic relativism recognises that there is no guarantee that our knowledge corresponds to how things are (140). Critical realism acknowledges the difficulty of achieving objectivity and that the real world exists independently of human perception (131). As such, a critical realist attempts to achieve objectivity by recognising and understanding their own bias and, like many other paradigmatic views, approaches the subject from numerous angles to create a well-rounded understanding of the subject. This enables researchers to view the field broadly without being constrained by their own biases and preconceptions (131).

2.2 Methodological approach

Quantitative research allows for larger sample sizes and includes methods to minimise confounding factors, allowing the results to be generalised (141). The population survey (Chapter 4) and concordance studies (Chapters 6 and 7) provide local and robust closed-ended information about the research problem. The quantitative methods allow researchers to evaluate the content of the healthcare intervention.

Conversely, qualitative methods allow the evaluation of the context of the healthcare intervention as it allows the researcher to understand a phenomenon in context and usually uses smaller representative sample sizes (142). Therefore, qualitative inquiry is appropriate for this thesis as it depicts the participants' (patients, GPs and ROs) experience and views at the empirical level of the healthcare intervention (143).

From a critical realist perspective, quantitative studies alone are inadequate for explaining the complex open systems of the social world in a meaningful way (144). Critical realists understand that to correctly identify and explain the structural mechanisms that contribute to social phenomena, they require qualitative empirical evidence to explain mechanisms that generate the social phenomena. Therefore, a balance of quantitative and qualitative studies was required.

This thesis used a concurrent triangulation mixed method research design where it integrated quantitative and qualitative data to answer the thesis aim (see Figure 6). Mixed methods are increasingly recognised as crucial for implementation in health services (145) and reduce potential biases that may be present in either qualitative or quantitative research alone (143).

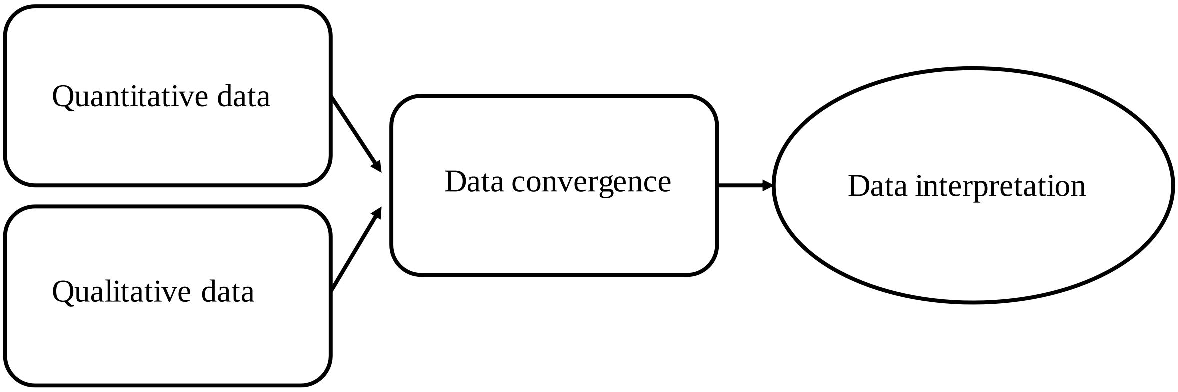


Figure 6. Diagram of concurrent triangulation mixed methods

2.3 Study design and methods used in this thesis

A design framework establishes how data is collected and analysed to answer a particular research problem (146). The overarching methodological approach and research aim will determine the type of research study design. This thesis utilised a cross-sectional study design, described further below. A systematic review is a secondary research design used to inform other research designs and will be described first.

2.3.1 Study designs

Systematic review

A systematic review is a secondary study design used to summarise the results of several primary research studies and is transparent and replicable (147). A systematic review is important to synthesise the current evidence and identify gaps. Systematic reviews have a formulated question and follow a rigorous method to select, appraise, and analyse the data from the studies. The gold standard for systematic reviews is to follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methods (148), which includes a 27-item checklist and a four-phase flow diagram (149).

A systematic review with a critical realist perspective looks beyond the findings' concepts and relationships. It aims to provide a retroductive response to the question of what actual phenomena led to the empirical observations and what underlying mechanisms or structures were necessary to produce the latter (150). The systematic review included in this thesis, Chapter 3, aimed to identify the barriers and facilitators for shared cancer follow-up care between general practitioners and oncologists. The findings from the systematic review were important in informing the development of the shared cancer follow-up model of care.

Cross-sectional study design

A cross-sectional study is a primary study design and is a type of observational design used on a defined population and conducted at a single point in time (151). Cross-sectional study designs are used for population-based surveys and can be used before planning a cohort or longitudinal study. Participants are selected based on the study's inclusion and exclusion criteria. As it is at one point in time, it is challenging to derive causal relationships during analysis. In this thesis, Chapters 4, 6, 7 and 8 employ a cross-sectional study design. Chapter 4 is a population-based survey, with Chapters 6 and 7 based on patient-reported and clinician-reported data.

Chapter 8 uses a repeat cross-sectional study design: interview data were collected at two time points over a one-year period. Pre-intervention, participants were asked about their views on the current follow-up care model, presented with the shared cancer follow-up model, and asked about their views on shared care. Post-intervention, the participants were asked about their experience and overall views on shared care. This study design allowed an evaluation to determine if there was a change in perception.

2.3.2 Data collection methods

Survey

Surveys are used to examine or question a sample of respondents to extract information about their opinions, behaviour or knowledge (152). Surveys can be quantitative and/or qualitative using open-ended and/or closed-ended questions (153). Common types of surveys are questionnaires, administered either face-to-face or telephone or via electronic methods (email or website).

This thesis employed a cross-sectional quantitative survey to evaluate the acceptability of a shared cancer follow-up model of care. A 32-point survey was developed and comprised four sections: demographics, health and cancer-related information, access to healthcare, and acceptance of shared care, described in more detail in Chapter 4.

Healthcare data

Healthcare professionals are responsible for their patients' medical history data and other clinical and medical data. Previously, medical data was in the form of handwritten or typed notes (154). Clinical examinations and medical records are now routinely and widely digitalised in the healthcare system (155). Healthcare facilities have their own data repository where patient data is stored.

For this thesis, data was entered and transferred into the oncology information system by the patient (patient-self report), the GP (transferred from the GPs' clinic) and manually entered by the radiation oncologist directly into the oncology information system. The three data types were extracted from the oncology information system for analysis. The extracted data was used to inform Chapter 6 for the remote monitoring model of care assessing the patient-RO concordance and Chapter 7 to determine the GP-RO concordance.

Interviews

Interviewing is a standard method used across many paradigms and is a form of inquiry that gives the researcher direct access to the interviewees' points of view regarding attitudes and their account of the experience. The interview involves the construction of meanings and the potential for the joint construction of knowledge about experiences, events and activities (156).

Critical realists utilise data from qualitative interviewing methods to explain the phenomena of the social (137). The phenomena of interest serve as the starting point for a critical realism inquiry model and aim to explain empirical events and structures. A critical realist approach to interviews focuses on the individual's experience (empirical) and the actual and real domains of structure and agency that are usually hidden from the researcher, producing new objective knowledge (137,157).

This thesis used semi-structured interviews using an interview guide (see Appendix F), and the results are presented in Chapter 8.

2.3.3 Data analysis methods

Quantitative

Quantitative methods incorporate standardised measures and statistical techniques. From a critical realist perspective, understanding the quantitative observations at an empirical level is important to postulate the underlying structures and mechanisms that explain the phenomena involved (158). Quantitative techniques used within this thesis include descriptive statistics, Cohen's Kappa, Fleiss Kappa, Logistic regression and posthoc analysis.

Qualitative

Qualitative analysis allows the researcher to interpret, organise, and structure their observations and interpretations to construct meaningful theories based on the data extracted through qualitative methods. In addition, qualitative analysis enables the researcher to be rigorous, critical and reflexive with the findings.

Some critical realists use a grounded theory approach to data analysis (159,160). However, it has been argued that using a grounded theory approach may not be ideal for a critical realist perspective (133). Grounded theory and critical realism engage with theory differently. Although grounded theory is guided by existing theory, during the analysis process, it does not engage actively with existing theory (133). Grounded theorists frequently use inductive coding, where the researcher derives the codes from the data. Whereas the deductive approach applies a set of codes to the data, a top-down approach. This set of coding may be based on the research questions or from an existing research framework or theory. It can be argued that the critical realist finds the most effective way to explain reality is to interact with existing theories about reality (133). Therefore, using existing theories relevant to reality is important to critical realism. It is possible to be deductive and inductive and combine the approaches, where a deductive approach using a priori of codes are employed, and inductively review and analyse the data with the codes to develop new codes.

The systematic review used an inductive thematic analysis and was dual-coded, whereas the interviews were analysed using a dualistic deductive (template coding) and inductive thematic analysis technique. The dualistic technique draws codes from an existing framework, the Theoretical Framework of Acceptability.

Template coding is not dissimilar to a grounded theory methodology where the text analysis allows the researcher to find answers by repeatedly coding, reviewing and refining the coding process (161). Codes are defined by the researcher, whether by developing their own codes based on the data or choosing a priori of codes drawn from research and theory. Template coding was also a way to acknowledge my reflexivity during the research process. When researchers analyse data, “they construct a cognitive model of the data according to the perspective of the person who is reporting the data” (162 p.338). It is important to have at least one other researcher code the data to address subjectivity and rigour with thematic analysis; therefore, there were two coders for both the systematic review (Chapter 3) and the qualitative analysis of the interviews (Chapter 8).

2.4 Rigour

Triangulation

Triangulation is a strategy to improve rigour in research (163–165). It attempts to minimise inherent bias in any particular source and relies on convergent information from different sources (166). Triangulation may be in the form of method, investigator, theory or data source triangulation (166). This research employed method triangulation, investigator triangulation, and data source triangulation, outlined below.

Methodological triangulation is the use of multiple methods to study a phenomenon (166). The use of a population survey, concordance studies and interviews allow the results from one method to be used to enhance, augment and clarify results from one another.

Investigator triangulation uses more than one investigator in a study. The credibility of the findings can be greatly increased by the capacity to confirm findings across investigators (166). Investigator triangulation was used in the systematic review and the analysis of the qualitative interviews.

In social and evaluation research, data source triangulation collects data from different types of people or groups and is used to enhance the reliability and validity of the findings (167). Data source triangulation between patients, GPs and ROs assisted in gaining multiple perspectives, validating the data, and providing complementary insights into the same empirical phenomenon (168).

TAPUPASM

In addition to triangulation, measures of validity, trustworthiness or rigour are crucial in health research and should be guided by the philosophical perspective adopted by the researcher (169). From a critical realism perspective, rigour is evaluated with the acronym TAPUPASM: Transparency, Accessibility, Propriety, Utility, Purposivity, Accuracy, Specificity and Modified objectivity (170).

Transparency

Transparency considers how the researcher came to the research question, aim, objectives and methods and being explicit about their philosophical approach (171). This can be demonstrated in this thesis in Section 1.1.1 where the researcher's position was presented, including personal experiences and assumptions about cancer follow-up care.

Transparency is further demonstrated by review and approval from the Human Research and Ethics Committee and registration with the Australia New Zealand Clinical Trials Registry. The publication of the research protocol also further demonstrates transparency (Chapter 5).

Accessibility

Accessibility involves the dissemination and implementation of findings (172). It requires the researcher to consider who the recipient of the research is and if the people in the context can apply the findings or access them. The outcomes of this research will be presented here in this thesis, at national and international conferences, and published in peer-reviewed journals that are open access for easier clinician access. At a local level, a summary of the findings will be disseminated to GPs via the Local Public Health Networks and presented at the hospital Grand Rounds. Participants involved in the intervention were able to indicate on the Consent Form if they would like a summary of the results.

Propriety

Propriety requires research to be ethical and legal. Accordingly, an ethics application was approved by the joint University of Wollongong and Illawarra Shoalhaven Local Health District Human Research Ethics Committee. This application addressed confidentiality, informed consent, and data protection. Additional information on ethical considerations is below in Section 2.5.

Utility

Utility is similar to Accessibility above. When discussing utility, it's important to consider whether the knowledge produced is useful to health professionals and whether the findings directly address the issue (172). The methods, data collection, analysis and synthesis of the findings present knowledge locally at the hospital level, nationally and internationally through presentations and publications. Chapter 9 provides implications and recommendations to health organisations.

Purposivity

Purposivity refers to the methods of inquiry and whether the methods will achieve the aim and objectives of the research. Mixed methods were used in this thesis to answer the thesis aim by reducing potential biases present in either qualitative or quantitative research.

Accuracy

Claims of knowledge should reflect the participant's perceptions and experiences. Out of respect for the time participants had already given to the study, they were not asked to review the interpretations of the interview transcripts (a procedure known as member checking or participant validation) and because doing so for the pre-intervention interviews could have influenced the intervention.

Based on the critical realist paradigm, the empirical level of information is collected from participants. This was evidenced by using verbatim quotes from participants to demonstrate their views. However, some elements are not directly identified during data collection. The final discussion chapter finds the real level during the merging and synthesising of different data types in Chapter 9. Triangulation ensures accuracy during the analysis process and assists the researcher in finding real knowledge.

Specificity

Specificity refers to if the knowledge generated meets source-specific standards. As part of the systematic literature review, sources were identified as those involved in the cancer follow-up process, the patient, the GP and the oncologist. The identified barriers in the systematic review justified the study design for the intervention study.

Modified objectivity

Modified objectivity asserts there is one reality, and that reality may not always be fully comprehended. For example, patients, GPs, and oncologists may feel and experience the impact of the shared care intervention (the actual). The researchers measure and observe the intervention (empirical). However, the combination of the actual and empirical may explain what is real. The iceberg analogy may better explain this in Section 2.1 and Figure 5.

2.5 Ethical considerations

According to the National Health and Medical Research Council, research that involves human participants in public organisations like universities and government hospitals must be approved by an accredited HREC. The purpose of the HREC is to protect the welfare and rights of the participants in the research (173).

The ISLHD has a primary duty to protect the rights and interests of research participants. It must make sure that human research is conducted in accordance with accepted ethical and scientific standards, follows agreed-upon ethical and legal guidelines, does not jeopardise participants' rights and interests, and has a robust and open process for participant consent. Only those with the required scientific expertise and credentials may conduct research, whether it involves patients or healthy volunteers, and only when they are working under the direction of an ISLHD clinician who is competent and meets the necessary requirements (174).

As this research was in partnership between the UOW and the ISLHD, an ethics application was submitted to the joint UOW and ISLHD HREC. As a result, ethical clearance for studies presented in Chapters 4, 6, 7 and 8 was approved in May 2020 (2020/ETH00301) and June 2020 (2020/ETH01427), and subsequent site-specific approval was granted. The research was conducted according to ethical research guidelines such as merit and integrity, justice, beneficence and respect (173), discussed below.

Merit and integrity

Merit is justifiable if the research has potential benefits and may contribute to knowledge and understanding. There is also merit when the research contributes to the skills and expertise of researchers (173). This research has merit as it identifies barriers and facilitators to implementing shared cancer follow-up care and contributes to a new knowledge area. The research also has merit as it facilitated the development of research expertise to a novice researcher overseen and supported by supervisors with extensive academic and clinical research experience.

Integrity is when research is conducted by researchers who commit to searching for knowledge and understanding (173). As presented in Section 1.1.1, the researcher described their personal interest in public health and cancer services, describing the need to search for knowledge with the desire to enhance follow-up care options for cancer survivors. Honest research practices, positive or negative dissemination of findings, and contribution to public knowledge and understanding are some examples of integrity. The style of this thesis, by compilation, further demonstrates the integrity to contribute to public knowledge and understanding.

Justice

Justice in research is about fairness. Fairness refers to the recruitment of research participants; there was no unfair burden on participants and a fair distribution of benefits (173). The two hospitals presented in the research setting are the only two in this specific health district that provide radiation oncology follow-up services. The opportunity to participate and the purpose, benefits and risks of participating were explicit on the patient information sheets provided to the patients, GPs, and ROs. Participants were given ample time to read the study information, and for two studies, patients received a phone call to discuss and answer any questions or concerns the potential participant may have had. In one study, consent was tacit upon completing the questionnaire, and the participant information sheet explaining their response was anonymous.

In addition to the participant information sheet explaining that the interview would be recorded, participants were asked verbally at the beginning of the interview if they consented to it being recorded. As an acknowledgement of participation in the interviews, participants were presented with a $30 gift voucher. Participants were not aware of the gift voucher until after the interview to avoid coercion.

Beneficence

Beneficence is the term for the intended advantages of the study that must outweigh any harm to participants (173). The likely benefit may be to the participants and/or the wide community. Research with people treated for cancer requires the researcher to be aware of the risk of cancer recurrence and emotional distress. For the intervention study, the research was designed to minimise risk by selecting participants that were three years post-treatment. The participant information sheets advised that they could withdraw from the study at any time and provided the number for Cancer Council helpline should they become distressed.

Respect

Participants must be treated with respect to maintain public trust and confidence in human research (175). Respect in human research refers to the value of respect for individual autonomy and enables people to make meaningful decisions about participation (175). Respect calls for the researcher to show consideration for the participants' welfare, beliefs, perceptions, practices, and cultural heritage (173). A valid process for consent is essential in human research. Participants were provided with participant information sheets informing of the aim, process, and information dissemination plans. They were informed that the research was voluntary, and if they participated, they could withdraw. Participants who were involved in the interviews were presented with a $30 gift voucher to show appreciation for their involvement; there was no coercion, as participants were not aware of the gift card during recruitment. During the interviews, participants were given the time to share their experiences; they were shown respect by attentive listening and empathy and informed there were no right or wrong answers. After the interviews, participants were thanked verbally for their valuable contributions.

2.6 Confidentiality and privacy

The confidentiality of participants was maintained by assigning unique participant identification numbers (ID). The research team used the UOW Cloudstor shared folder, password-protected and only accessible to the research team. After interview recordings were downloaded to a shared folder, the recordings were deleted from the Dictaphone. Then, the researcher transcribed the recordings; the participants' names and identifying features were omitted before the transcripts were uploaded to the research team folder according to the participant ID. Data collected from the hospital system remains part of the patient's oncological medical file. The data extracted from the hospital system was de-identified and saved to the shared folder.

Chapter summary

The chapter discussed the researcher's philosophical underpinnings of critical realism, which provided the rationale for a mixed methods approach. The individual methods, rigour and ethical considerations were presented. As this thesis is by compilation, more detail about specific research design, sample size and ethical considerations are included in the Methods section of each chapter.

CHAPTER 3: Factors influencing the translation of shared cancer follow-up care into clinical practice: A systematic review

Chapter overview

This chapter is a systematic review that explores the factors that influence the implementation of shared cancer follow-up care into clinical practice. This systematic review aimed to address Objective 1 of this thesis: To identify the barriers and facilitators for shared cancer follow-up care between general practitioners and oncologists.

Findings from this study were published in BMJ Open. BMJ Open is a Q1 journal with an impact factor of 3.007. A component of this paper was presented at the World Congress on Public Health virtual conference.

The systematic review protocol was registered with PROPERO:
https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020191538

Citations:

Sandell T, Schütze H. Factors influencing the translation of shared cancer follow-up care into clinical practice: a systematic review. BMJ Open. 2022;0:e055460

Sandell T, Schütze H. A systematic review: The barriers and enablers to shared cancer follow-up care, 16th World Congress on Public Health, (virtual), Rome, Italy, 12-16 October 2020

3.1 Abstract

Background The increasing incidence of cancer, coupled with improved survivorship, has increased demand for cancer follow-up care and the need to find alternative models of care. Shared cancer follow-up care in general practice is a safe option in terms of quality of life and cancer recurrence; however, there are barriers to translating this into practice. This review aimed to identify factors that influence the translation of shared cancer follow-up care into clinical practice.

Methods Systematic review. Seven electronic databases: MEDLINE, Science Citation Index, Academic Search Complete, CINAHL, APA Psychinfo, Health Source: Nursing/Academic Edition, and Psychology and Behavioural Sciences Collection, were searched for published papers between January 1999 to December 2021. The narrative review included papers if they were available in full-text, English, peer-reviewed, and focused on shared cancer follow-up care.

Results Thirty-eight papers were included in the final review. Five main themes emerged: 1. Reciprocal clinical information sharing is needed between oncologists and general practitioners, and needs to be timely and relevant; 2. Responsibility of care should be shared with the oncologist overseeing care; 3. General practitioners skills and knowledge to provide cancer follow-up care; 4. Need for clinical management guidelines and rapid referral to support general practitioners to provide shared follow-up care; 5. Continuity of care and satisfaction of care is vital for shared care.

Conclusion The acceptability of shared cancer follow-up care is increasing. Several barriers still exist to translating this into practice. Work is required to develop a shared-care model that can support general practitioners whilst the oncologist can oversee the care and implement two-way communication between general and oncologists' clinics. The move towards integrating electronic health care records and web-based platforms for information exchange provides a promise to the timely exchange of information.

PROSPERO Registration
Reg No: CRD42020191538

3.2 Introduction

After active cancer treatment is complete, patients require ongoing follow-up care to treat late side effects, monitor recurrence, and provide psychosocial care (19–21). The duration and frequency of follow-up care depend on the type and stage of cancer and the treatment. Cancer follow-up models of care fall into sequential, parallel or shared-care models (91,176). Sequential care is when one provider delivers all healthcare. Parallel care is when the specialist manages cancer-related issues (oncologist-led), and the general practitioner manages non-cancer-related health matters. Parallel care that is oncologist-led is the current most common model of care (177,178) and is usually provided in a hospital setting (179). Shared care is a partnership between health professionals that improves the quality of patient care by integrating the delivery within and across the health service and enhances communication between providers (180).

The Institute of Medicine (IOM) states that "cancer care is often not as patient-centred, accessible, coordinated or as evidenced-based as it should be" (60 p.2). They emphasised the urgent need for new cancer models of care where health professionals work together to ensure that every patient receives care tailored to their particular situation (60). The IOM developed a conceptual framework to address the identified deficiencies that aimed to place the patient at the centre of care in a system that supports patients in making informed medical decisions consistent with their needs, values, and preferences. The framework highlighted the need for adequately trained staff, a coordinated workforce, evidence-based cancer care, and information technology to improve cancer care quality and patient outcomes.

Due to the growing number of cancer survivors and increased demand for follow-up consultations, the sustainability of oncologist-led parallel care has been questioned (100,181–183). There has been limited progress in developing cancer follow-up models of care that address the person-centred care domains of respect for patients' preferences, coordination and integration of care, information and education, continuity and transition, and access to care (184).

The evidence for the benefits of shared cancer follow-up models of care is growing (51,120,185–187). Randomised controlled trials have shown no difference in the recurrence rate or quality of life when a general practitioner provides cancer follow-up care compared to an oncologist (95,119,188,189). Despite acknowledging the benefits of general practitioners' playing a greater role in cancer follow-up care, there are barriers to translating shared cancer follow-up care into practice. The specific research question for this systematic review was, "What factors influence translating shared cancer follow-up care into clinical practice?

3.3 Methods

A protocol with defined objectives, study selection criteria and approaches to assess study quality was developed and registered with PROSPERO. This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) format (190) and checklist (Appendix A): i) development of inclusion/exclusion criteria; ii) extraction and coding of study characteristics and findings; and iii) data analysis and synthesis of findings. Both quantitative and qualitative papers were included in this narrative systematic review. This systematic review was part of a larger study on shared cancer follow-up care, approved by the Illawarra Shoalhaven Local Health District and University of Wollongong Human Research Ethics Committee (2020ETH00301).

Eligibility criteria

Inclusion criteria: (a) general practitioner, patient, and/or oncologist perceptions of shared cancer follow-up care; (b) general practitioner involvement in cancer follow-up care (not a substitution for care); (c) intervention with the general practitioner involved in cancer follow-up care; (d) adults patients in the follow-up period; and (e) papers peer-reviewed, published in English between January 1999 and December 2021.

Exclusion criteria: (a) commentary, editorial, literature review, protocol; (b) patients on active treatment; (c) palliative care; (d) surgical only treatment; (e) paediatric; (f) skin cancer, melanoma or blood cancer (these were excluded as the follow-up regime varies to solid tumour follow-up).

Information sources and search strategy

The search was conducted in the following seven electronic databases: MEDLINE, Science Citation Index, Academic Search Complete, CINAHL, APA Psycinfo, Health Source: Nursing/Academic Edition, and Psychology and Behavioural Sciences Collection. To ensure relevant results were obtained, search terms were developed using a modified version of the PICO (Population, Interest, Comparison and Outcome) Framework (191). The search terms were constructed and agreed upon by both authors. The second author is a skilled academic who teaches literature searching and research methods at the postgraduate level and has experience conducting systematic reviews, and a university librarian was also consulted. Alternative keywords for each search term (see Table 5) were combined using the Boolean operator 'OR' to ensure all possible variations were captured; the search was then refined by combining the searches with 'AND'. The wildcard '*' was used to allow for word truncations. The search string is attached as Appendix B.

Table 5. Systematic review search terms

PICO	Search terms
Population	"general practitioner" OR "primary care physician" OR "family physician" OR "family practitioner" OR GP OR doctor OR specialist OR oncologist
	AND
Interest	"model of care" OR "shared-care" OR "shared care" OR "follow-up care" OR "follow up care"
	AND
Outcome	Cancer OR oncolog* OR neoplasm

Study selection

Papers were imported into Zotero reference management software, and duplicates were removed. Both authors independently used a stepwise procedure to identify relevant papers. Risk of bias was systematically assessed by two researchers using separate checklists. TS performed the initial search and screened the titles and abstracts against the inclusion/exclusion criteria; the remaining texts were retrieved in full and screened against the inclusion/exclusion criteria. HS independently checked the results and compared her findings with the first author. The authors met with the final list of included/excluded papers and resolved any disagreement by discussion and consensus. A third reviewer from the broader research team was available in case consensus could not be reached between the first two reviewers. Reasons for exclusion were recorded.

Data collection and quality appraisal

The following data were extracted into a Microsoft Excel spreadsheet: first author, year, country, study type, aim, sample, methods, results and conclusion. The rigour of each included study was assessed by both authors using the Joanne Briggs Institute (JBI) Critical Appraisal tools checklists (192) that use a three-point grading system: include, exclude and seek more information. These grades are based on desirable and undesirable effects, quality of evidence, values and preferences, and costs (192). The JBI suite was selected as it contains 13 checklists that provide consistency in reviewing the different types of papers without using different tools with different grading/scoring systems.

Data synthesis

TS summarised the results, discussion and conclusion of the included papers into one Microsoft Excel document. Both authors then synthesised the findings into themes using Braun and Clarke's six-step thematic analysis framework (193). Disagreements regarding the allocation of themes were resolved by discussion and consensus; the thematic analysis results are presently narratively.

Patient and public involvement

Patients and members of the public were not involved in this study. We intend to engage the public in disseminating our results, including social media engagement, newsletters and conferences.

3.4 Results

The initial search yielded 1145 papers after duplicates were removed. After reviewing the abstracts against the inclusion criteria, 1047 were removed as they did not meet the inclusion criteria. The full text of the remaining 98 papers was examined in full, and a further 59 were removed. The remaining papers' reference lists were scanned to capture any additional papers that may have been missed in the initial search. The resultant 39 papers were assessed for quality using the JBI critical appraisal tools, resulting in 1 paper being excluded due to poor methodological quality, bringing the final total to 38 papers (see Figure 7).

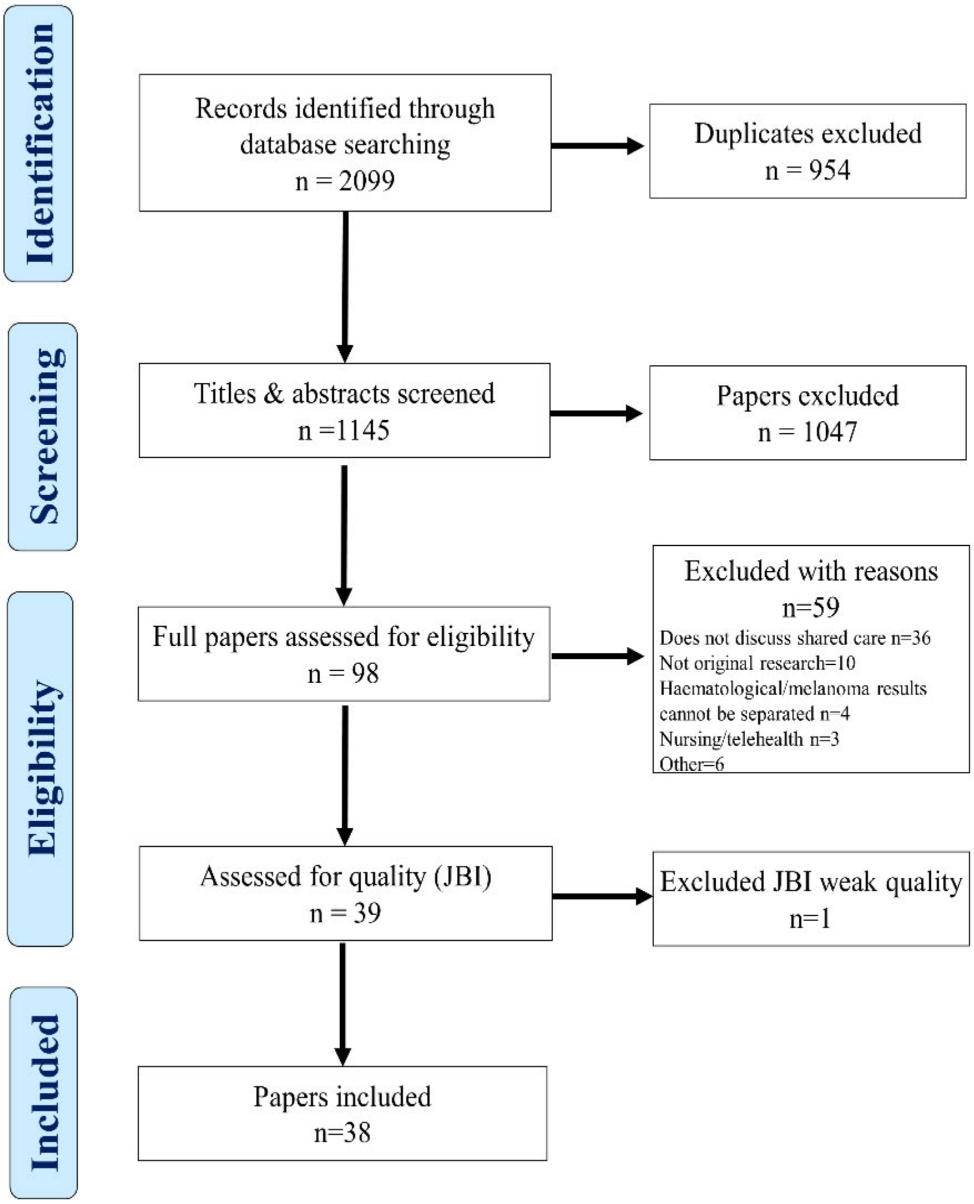


Figure 7. PRISMA Flowchart

Study characteristics

Of the 38 included papers, eleven were from the United States, nine from Australia, six from Canada; the remaining papers were from the United Kingdom, The Netherlands, Denmark, Norway, Italy, Singapore, Germany and France (see Table 6). Half of the papers were published in the last five years, with the sample sizes ranging from 20 to 2,159. There were 20 quantitative, 17 qualitative and one mixed-methods paper.

Table 6. Summary of included papers in the systematic review

First Author, Year Country	Study aim, methodology & methods	Results/Conclusion	Themes
Anvik, 2006 (121) Norway	To explore patient, relatives and GP views of the GPs role during initial cancer follow-up. Qual- Int, FG.	Patients have trust in the GP. GP require good access to specialists. Follow-up plans will improve the care and cooperation. Hospitals to initiate a stronger collaboration.	CC, G
Aubin, 2010 (122) Canada	To describe the actual and expected role of a GP in the different phases of cancer. Quant- Quest.	Patients prefer oncologists to maintain overall responsibility. Patients would like their GP to be more involved, requires better communication and collaboration.	Res
Aubin, 2012 (91) Canada	To compare patient, GP and specialist expectations of involvement during cancer phases. Quant- Quest.	Differing views of GP role. GPs perceived themselves as involved in shared care; GP responsibility to be clearly outlined, and effective communication implemented.	Res, Inf
Berkowitz, 2018 (194) United States	To explore preferences and knowledge of GPs in the care of head and neck cancer survivors. Quant- Quest.	32% of GPs felt confident they could manage late/long-term side effects; 30% believed they were responsible for care after one year, and 81% after five years.	Res, Sk
Brennan, 2010 (80) Australia	To explore follow-up practices and attitudes to alternative models of cancer care. Quant & Qual- Quest.	Specialists are supportive of sharing follow-up care. Survivorship care plan would improve care. 96% of specialists felt GPS needed more training.	Inf, Res, Sk
Brennan, 2011 (123) Australia	To explore experiences with follow-up care and attitudes to alternative models of cancer care. Qual- Int	Patients relied on their specialist, but open to their GP playing a role. Communication seen as a barrier. Positive view on care plans.	Inf, CC
Cheung, 2013 (195)United States	To assess how physician attitudes & self-efficacy affect preferences for cancer models of care. Quant- Quest.	51% GPs support shared care. 59% specialists preferred a specialist-led model. 57% GPs able to perform routing follow-up care. Prior involvement increases willingness.	Sk, Inf, Res
Coschi, 2021 (196) Canada	To assess oncologists' attitudes and beliefs regarding sharing/transitioning survivorship care. Quant- Quest.	There is a current lack of routine sharing. Absence of formal policies & guidelines. Patient preference and loss of patient outcome data are barriers.	FG, Inf, Res
Crabtree, 2020 (197) United States	To understand how GPs perceive their role to cancer survivors. 38 GPs. Qual- Int.	The majority of GPs felt follow-up care was within their role. Some GPs did not feel adequately educated about the needs of cancer survivors.	Res, SK
Dahlhaus, 2014 (198) Germany	To examine German GPs views on their involvement in the care of cancer patients. Qual- Int.	GPs are well placed for follow-up care. GPs want to stay involved in cancer care. Slow or non-existent information sharing is a barrier to shared cancer care.	CC, Inf, Sk
Del Giudice, 2009 (199) Canada	To determine GP willingness and timeframe for GP-led follow-up model. Quant- Quest.	GPs willing to take over responsibility of routine follow-up care after two to three years. Require a letter, follow-up guidelines, rapid referrals.	G
Dicicco-Bloom, 2013 (200) United States	To provide a better understanding among GPs, patients, and oncologist through cancer care. Qual- Int.	GPs want regular updates of their patients, and are well placed for care. GPs wanted guidance about follow-up screening and side-effects and better information sharing.	G, Inf
Doose, 2019 (201) United States	To examine patient & health system factors in shared care & quality of cancer care. Quant- Quest.	No significant relationships between shared care and quality indicators of cancer care. Survivorship care plans may improve the quality of cancer care.	Inf
Fidjeland, 2015 (202) Norway	To explore GP experiences and view providing cancer follow-up and taking a greater role. Quant- Quest.	78% GPs felt confident in their knowledge and skills to provide follow-up care. Some GPs (42%) were more willing to take on follow-up care after three years	G, Res Sk
Fok, 2020 (203) Singapore	To explore GP perspectives of a shared-care programme with oncologists. Qual- Int, FG.	GPs willing to share the care but recommended role definition, training, clinical protocols, resources and access to oncologist's consultation.	Res, Sk

First Author, Year Country	Study aim, methodology & methods	Results/Conclusion	Themes
Hall, 2011 (204) United Kingdom	To explore the opinions and experiences of patients and GPs involved in shared care. Qual- Int.	Most patients support shared cancer care, if there is robust support from specialist. GPs and patients have concerns about the GP gaining and maintaining clinical skills.	G, Res, Sk
Hanks, 2008 (205) Australia	To identify and compare the roles of GPs & colorectal cancer management in Australia. Qual- Int.	Shared cancer follow-up care is influenced relationships. Improvement in GP and specialist relationship and communication could lead to better shared care.	CC, G, Inf, Res
Haq, 2013 (206) Canada	To document information needs of breast cancer patients, GPs, & oncology specialists. Qual- FG, Int.	GPs feel ill-equipped and felt unsure of their role. The care plan made the GP feel more engaged. Guidelines gave GPs more confidence in cancer follow-up care.	G, Inf
Hudson, 2012 (207) United States	To examine patient perspectives and preferences on GP roles in their cancer follow-up care. Qual-Int.	Most patients prefer follow-up care with the specialists. Barriers identified was GP lack of expertise, limited involvement during treatment, lack of continuity of care.	CC, Sk
Hudson, 2016 (208) United States	To explore cancer survivors' experiences of follow-up care provided by GPs and oncologists. Quant- Ques.	Patients rated GPs higher for coordination of care & comprehensive care. Prostate patients rated GPs higher for all items, compared to breast patients.	CC
Klabunde, 2013 (209)United States	To assess GPs and oncologists' roles in providing cancer follow-up care. Quant- Quest.	Over 50% of GPs reported co-managing with an oncologist. GPs had a preference for a shared model care, and receipt of treatment summaries from oncologists.	Res, Inf, Sk
Klabunde,2017 (210)United States	To explore factors that affect cancer patients follow-up communication & coordination. Quant- Quest.	Half the oncologists communicated with the GP. Oncologists' reliance on written correspondence to communicate with GPs may be a barrier to care coordination.	Inf
Lang, 2017 (63) Germany	To assess the role of GPs in German cancer care from patients' perspective. Quant- Quest.	Patients want their GP to play an active role. A shared care model where the GPs are supported by the specialists and have extra training is recommended.	CC, Res
Laporte, 2017 (62) France	To examine how women experienced the post-treatment & perceived the role of the GP. Qual- Int.	Patients felt abandoned at the end of treatment. Patients accepted follow-up care with their GP provided there was a close working relationship with the specialist.	CC, Res
Lawn, 2017 (211) Australia	To explore cancer survivors' views on shared care: what cancer survivors need. Qual- G.	Patients need to be at the centre of the care. Information sharing between health professionals is important. It was perceived the GPs lacked the skills for shared care.	Inf, Sk
Lizama, 2015 (212) Australia	To investigate GPs perceptions about communication when providing cancer care. Quant- Quest.	GPs want to be kept in the loop and want follow-up information. Timely transfer of relevant information between primary care providers and specialists is essential.	CC, G, Inf
Nielsen, 2003 (61) Denmark	To determine the effect of shared care on the attitudes of cancer patients towards the healthcare system and their health-related quality of life. Quant- RCT, Quest.	Young people rated GPs knowledge higher than the control group. No significant difference in quality of life between the intervention group and control group.	G, Inf
Potosky, 2011 (97) United States	To compare GPs & oncologists' knowledge, attitudes, and practices for follow-up care. Quant- Quest.	Specialists believe GPs lack the skills. Effective communication between GPs and specialists can increase GP confidence in their ability to perform follow-up care.	Res, Sk
Puglisi, 2017 (213) Italy	To investigate the views of oncologists, GPs, and patients about surveillance strategies. Quant- Quest.	Most GPs claim that cancer follow-up care should be shared with oncologists. Most GPs and oncologists have a poor relationship and patients report poor collaboration.	SK, Inf, Res
Roorda, 2013 (214) The Netherlands	To explore the discharge of breast cancer patients to GPs & the experiences and views of GPs. Quant-Quest	The barriers to shared care were communication, patient preference, & GPs knowledge & skills. Development of guidelines would facilitate shared follow-up.	G, Inf, Res

First Author, Year Country	Study aim, methodology & methods	Results/Conclusion	Themes
Schütze, 2017 (215) Australia	To explore the views of cancer survivors, oncologist and GPs, about GPs involved in follow-up care. Qual- Int.	It was important for GPs to have knowledge and an interest in cancer. It was important for the specialist to oversee the care and maintain overall responsibility.	G, Res, Sk, Inf,
Sisler, 2012 (216) Canada	To examine how patients evaluate the continuity & quality of their follow-up care with GP. Quant- Quest.	Patients evaluate the GP favourably; patients with complex issues rated their specialist higher. Role clarification between providers is needed.	CC, Res
Tan, 2018 (217) Australia	To explore how non-English and English-speaking patients perceive care to be coordinated. Qual- Int.	Both groups described similar barriers to care, but non-English-speaking participants described additional communication difficulties and perceived discrimination.	Res, Inf
Taylor, 2020 (218) United Kingdom	To examine the experiences of patients and healthcare professionals of follow-up in primary care. Qual- Int.	There is a lack of clear policies and practices. Disparities in knowledge, understanding, processes and pathways. Unclear roles and responsibilities.	Res, Inf
Vuong, 2020 (219) Australia	To explore views on patient suitability for long-term colorectal cancer shared care. Qual- Int.	Stronger systems such as cancer-specific training, survivorship care protocols, shared information systems, care coordination and navigational supports are needed.	Inf, G
Walter, 2015 (220) United Kingdom	To determine the current practice & views of GPs in England about cancer survivorship care. Quant- Quest	GPs felt that cancer follow-up care can be shared, with the specialist maintaining overall responsibility. GPs felt confident in their ability to provide follow-up care.	G, Res
White, 2021 (221) Australia	To explore shared follow-up care model to understand information needs. Qual- FG	Women need evidence for the effectiveness of shared follow-up care. Clear descriptions of GP and specialist roles is needed.	Inf, Sk
Weaver, 2014 (222) United States	To describe survivors' perception of provider involvement in follow-up care. Quant- Quest.	Care is more likely to be rated as high quality when one main provider is identified & an oncology specialist is involved.	Inf

LEGEND: CC, continuity of care; FG, focus group; G, follow-up guidelines; GP, general practitioner; Inf, information sharing; Int, interview; Qual, qualitative; Quant, quantitative; Quest, questionnaire; Res, responsibility; Sk, GP skills.

Thematic Analysis

Five themes were identified and are discussed below. Themes are ordered from the highest number of instances of articles within each them; however, frequency does not necessarily equate to order of importance (193).

Reciprocal clinical information sharing

Twenty-three papers referred to the importance of timely and quality sharing of clinical information between health professionals. Information sharing within healthcare is complex and fundamental for effective and efficient shared care (206,210,212). The primary method to share clinical information between doctors and patients was face-to-face verbal communication (200); between oncologists and general practitioners, it was written correspondence, followed by phone, integrated electronic health records and email (206,210).

Despite written communication being the primary method for information sharing, general practitioners were not provided quality and timely clinical information from oncologists to manage cancer follow-up care (123,198,200,212,214). One paper found that only half of the oncologists said that they directly shared clinical information about their patients to the general practitioner (210); another reported that around half of general practitioners received the transfer of clinical information from the oncology clinic (214). Not sharing clinical information with general practitioners results in many general practitioners not having clear instructions on follow-up and how to act in case of complications (212,214,218) and leaves patients to be the conduit to transfer clinical information verbally between the oncologist and general practitioner (123,211).

Due to inefficiencies with written correspondence, survivorship care plans (a record of cancer, treatment follow-up care plan) were developed to improve the transfer of information between the patient, general practitioner, and oncologist (80,206,214). Survivorship care plans may effectively address some of the information needs of both breast patients and their general practitioners (206), and the provision of a plan from the oncologist to the general practitioners is associated with a higher likelihood of sharing follow-up care(209). However, the use of electronic medical records between general practice and oncologists was identified as being more valuable than survivorship care plans (200,212).

Using verbal and written correspondence for information sharing during shared care follow-up positively affected the patient evaluation of the cooperation between the general practitioners and oncologists (61). This was achieved by providing a summary with structured details of the investigation, treatment, physical, psychological, and social problems, and specific information about what the oncologists expected the general practitioner to do during the follow-up period (61). Direct phone contact with the oncologist was available for further clarification on the written correspondence if required (61) .

Seven papers discussed issues with one-way information sharing: written information from the oncologist to the general practitioner (198,200,205,206,210,212,213). Shared cancer follow-up care relies on the two-way transfer of information between all health professionals involved in patient care (200), as there is a need for oncologists to receive important clinical outcome data about the patient from the general practitioner (196). Five papers highlighted the need to further develop health information technology to assist the two-way information sharing process and improve the timeliness and quality of information between general practitioners and oncologists (61,211,212,219,221). There is a need for shared information systems that are connected between the oncologist and the general practitioner to support care, and fast-track options to the hospital system when patients are unwell (219). Additionally, it was important for patients to know that both care providers could see the results of a follow-up consultation and act upon if needed (221).

Responsibility for follow-up care

Twenty-two papers discuss responsibility for follow-up care (62,63,80,91,97,122,194–197,202–205,213–218,220). There was a preference from patients, general practitioners and oncologists, for oncologists to maintain overall responsibility for cancer follow-up care (97,122,195,196,213,215). Oncologists were more likely to prefer an oncologist-led model instead of a shared-care or general practitioner-led model, as oncologists felt that they had the specialised knowledge for follow-up care (195), and general practitioners did not (97,195,213). However, oncologists were receptive to sharing care with general practitioners taking a greater role in the more standardised aspects of follow-up care (80). Oncologists felt that improved collaboration between themselves and general practitioners was required for shared cancer follow-up care (50) and that defined roles would be needed for shared care to be feasible (215,218). However, oncologists preferred that they maintain primary responsibility for the patient's care, even if they were sharing the care of the patient with the general practitioner (97,195,213,215).

General practitioners reported that they were already involved in the care of their cancer patients from the initial work-up of diagnostic tests and diagnosis, monitoring pathology results, and coordinating long-term screening (91,195,220), and welcomed a greater role in cancer follow-up care (97,195,202,215). General practitioners viewed shared care positively (197,204) and preferred a shared model compared to the oncologist-led model (97,195). General practitioners perceived that they could provide an important role in the follow-up phase for their patients and provide a more person-centred care approach (198) and help address unmet psychosocial needs (203). However, general practitioners felt that oncologists should maintain overall responsibility and provide overarching support to general practitioners and oversee the patient's results and progress (62,63,204,215,220).

Patients identified oncologists as having the primary responsibility in their current cancer journey, except when cancer progressed to an advanced phase and palliation (where the general practitioner became more involved in their partnership with a palliation team) (122). Many patients preferred the oncologist-led follow-up model and a parallel approach to follow-up care where the oncologist managed cancer-related issues and the general practitioner non-cancer-related health matters (91,122). Despite the limited involvement of general practitioners in cancer follow-up care, patients indicated that they would appreciate their general practitioners taking a greater role in their long-term care if the oncologist remained involved (63,122,215). Additionally, patients were more likely to accept a shared-care model if the general practitioner was directly supported by their oncologist (63), as this reassured patients that they remained directly linked into the hospital system (215).

General practitioners' knowledge and skills

Fifteen papers discussed the knowledge and skills of general practitioners for shared care (80,97,194,195,197,198,202–204,207,209,211,213,215,221). Perceptions differed regarding general practitioners' skills and abilities to take a greater role in cancer follow-up care, and in some cases, limited acceptance for the general practitioners to be involved in cancer follow-up care (197,207,221). Many general practitioners stated they felt confident in their skills to provide cancer follow-up care (97,209) and reported that they could provide routine cancer follow-up care by detecting and arranging diagnostic testing pathology and offer psychosocial support (198,202). Some general practitioners highlighted their essential role in providing holistic care and how their involvement could generally improve overall cancer care (198). General practitioners who agreed they had the skills to provide follow-up care were more likely to prefer a shared care model (209). However, other general practitioners had concerns about gaining and maintaining the clinical skills needed to conduct cancer follow-up care (194,195,203,204). Some oncologists and patients also felt that general practitioners did not have the specialised knowledge of specific treatment side effects and how to manage these and felt that general practitioners required upskilling to take on shared care (97,213,215).

Patients, general practitioners, and oncologists confidence in shared cancer care increased if general practitioners received extra training on short-term and long-term side effects (80,204,207). Another method identified to upskill general practitioners was integrating the general practitioner earlier in the patients' care (202,207). General practitioners are usually involved in the initial screening and diagnosis, then again as cancer progresses to late-stage and palliative care. Earlier engagement of the general practitioner during active treatment would upskill them in managing acute side effects, which will help in the long-term follow-up period (80). Regardless of the extra training, general practitioners still wanted ongoing support from oncologists (215).

Need for clinical management guidelines and rapid referrals

Fourteen papers discussed the need for clear clinical management follow-up guidelines to support general practitioners in shared follow-up care (61,121,196,199,200,202,204–206,212,214,215,219,220). The lack of clear guidelines was a barrier to transitioning follow-up care between the oncologists and the general practitioner (196). However, general practitioners were more willing to take a greater role in follow-up care if they were provided appropriate follow-up clinical management guidelines (199,214) and more guidance about follow-up screening and side effects of cancer treatment (220). Specific follow-up guidelines (121), specifically templates (220), could be in the form of a printable checklist or using validated instruments (206) and would reassure general practitioners that they were addressing aspects critical for the particular patients' care. The use of clear guidelines could address perceived knowledge deficits for general practitioners interested in being involved in shared care (219).

Clinical management guidelines that were best-practice or written by the oncologists would provide a safety net for recurrence or other serious events (215). Any clinical management guidelines that a general practitioner completed would need to be sent to the oncologist to oversee and continue to monitor the patient's progress and to be able to address any issues that arose quickly (215). Patients have shown positive results for not feeling “left in the limbo” (54 p.267) when the oncologist has supplied specific follow-up details to the general practitioners.

Two papers (199,205) highlighted that for general practitioners to play a greater role in cancer follow-up care, along with the provision of clinical management guidelines, they also need assurance of a rapid referral back to the oncologist if recurrence is detected.

Continuity of care and satisfaction of care

Ten papers referred to the importance of continuity of care, satisfaction of care and accessibility (62,63,121,123,198,205,207,208,212,216). Continuity of care for cancer patients refers to having the same health professional providing the care and having an ongoing doctor-patient relationship (62,123). Many patients reported having developed a relationship with their oncologist during the diagnosis and active treatment phase and subsequently felt “dumped” (53 p.155) when experiencing a high turnover of oncologists due to registrar involvement. Some patients found this lack of continuity of care during the follow-up phase distressing (62,212). Additionally, some general practitioners felt disconnected from their patients during the follow-up care stage (198) and felt excluded (123).

A patient's relationship with their general practitioner and oncologist influences their acceptance and readiness for shared cancer follow-up care (208). Patients had a stronger relationship with their general practitioner than their oncologist (198) and had stronger feelings of trust because of their long-standing relationship (62). Breast cancer patients were the only tumour group that felt they had a stronger relationship with their oncologist and would prefer their oncologist to maintain follow-up (123,208).

Continuity of care is strongly associated with patients' satisfaction of care (208,216). Most patients are satisfied when their general practitioner becomes more involved in their cancer follow-up care (216). Additionally, the distance a patient travels for their follow-up care influenced continuity of care and satisfaction. General practitioners in rural areas and some urban areas were found to provide improved continuity of care to their patients (205). In a rural setting that provided cancer follow-up care, general practitioners reported that care was strengthened by a good working relationship with the oncologist (205).

3.5 Discussion

This systematic review analysed both qualitative and quantitative studies to provide a comprehensive picture of factors that influence the translation of shared cancer follow-up care into clinical practice for solid tumours (for example breast, prostate, colorectal, lung). We found reciprocal clinical information sharing, responsibility for follow-up care, general practitioners' skills and knowledge, need for clinical management guidelines and rapid referral, and continuity of care and satisfaction of care were important factors. Whilst some themes we identified are similar to the findings of a recently published systematic review (223), we add to the knowledge base by highlighting the need for reciprocal, two-way communication and establishing a mechanism for the oncologist to maintain overall responsibility for overseeing the follow-up care.

The need for reciprocal two-way communication is supported by a recent study that reviewed current e-care plans between cancer centres and general practices (224). They did not identify a system that integrated general practice systems and hospital systems to address two-way communication (224). This highlights the need for infrastructure to support the transfer of information between general practitioners and oncologists for successful shared cancer care. Whilst a current randomised controlled trial protocol exists to explore shared cancer care for colorectal patients (225). This protocol does not specify how this transfer of information to the hospital oncologist will be achieved. The one study that has trialled and reported on the secure transfer of clinical information into the hospital with cancer patients to collect patient-reported outcomes (226), used a web-based platform PROsaiq (227), where the patient could complete a clinical assessment from home. The information subsequently transferred into the patients' hospital medical record and allowed the oncologist to monitor the patients' progress (226). This web-based health technology has been evaluated as feasible and secure to use in the clinical setting (226) and offers promise for a technological platform for reciprocal information sharing.

We found that oncologists, patients, and general practitioners want and need the oncologist to maintain responsibility and oversee the patient's cancer follow-up care. This is a challenging barrier to address due to medical legalities. The health professional that provides the consultation is legally responsible for the appointment outcome; therefore, a general practitioner that provides cancer follow-up care is responsible for that consultation. This issue is similar to cancer multi-disciplinary team meetings with clinicians holding concerns about the legal framework, despite the known benefits of multi-disciplinary care (228). Consequently, it would be challenging to establish a shared care follow-up model, where the oncologist is responsible without establishing a legal framework. However, finding a mechanism for the oncologist to be involved and oversee the patient's follow-up care may be more feasible, provided there is a strong administrative and organisational infrastructure to support coordinated efforts (214). This would depend on the successful transfer of information from general practice to the hospital.

The need for follow-up clinical management guidelines and rapid review also depends on the reciprocal transfer of information. General practitioners using follow-up guidelines developed by oncologists have shown positive results (206). Patients believed the follow-up consultation was more detailed and comprehensive than oncologist-led follow-up (229,230). Despite the efforts to develop and utilise follow-up guidelines, there needs to be health technology infrastructure or better integration for general practitioners to access any guidelines developed.

One notable finding was that despite the evidence that cancer follow-up care in general practice is safe (94,231), perceptions still exist that general practitioners do not have the necessary skills and knowledge for cancer follow-up care. This may be in part due to medical hegemony and power differentials (232), where the general practitioner is viewed as inferior in the medical hierarchy to the oncologist. Perception plays a powerful role in health psychology and is a determinant of behaviour (233) and can influence the patient’s, general practitioners and oncologists preference for cancer follow-up care.

Another factor that will determine shared cancer follow-up is the relationship (either positive or negative) the patient has with their general practitioner and oncologist and if they have continuity of care. Higher levels of satisfaction of care with having their general practitioner involved have been reported for both breast cancer patients (95) and colorectal cancer patients (234). A shared cancer follow-up model of care will not suit everyone, and any decision a patient makes about their follow-up care will be based on their own circumstances, perceptions, experience, values and needs.

This review was undertaken with a rigorous systematic methodology and has identified some important enablers for shared cancer follow-up care. The review included quantitative and qualitative studies and comprehensively captures the available evidence. This review has some limitations. The selected databases searched were chosen as they contained the most relevant and up to date information on the topic. However, it is possible that some papers catalogued on other databases could have been missed. Whilst two reviewers independently screened the results against the inclusion/exclusion, Cohen’s Kappa value was not used to calculate the inter-rater agreement so the precision of the inclusion criteria is unknown. There was limited data captured from oncologists which may make it difficult to define the extent of barriers to shared care from their perspective. Only published peer-reviewed literature was included and may therefore be subject to publication bias. Papers were limited to those in English, and there may be papers available in other languages that were not captured. Given that healthcare practices vary internationally, this review may not reflect all practices. This review was limited to adult patients and excluded skin and blood cancers; therefore, the results may not be extrapolated to paediatrics and all cancer types.

3.6 Conclusion

Shared care is an alternative model to the oncologist-led cancer follow-up model of care. The model is dependent on the patients’ personal preferences and relationship with their health care providers. A shared cancer follow-up model of care relies on the oncologist maintaining overall responsibility and overseeing the care, effective two-way information sharing between general practitioners and oncologists, and the provision of follow-up guidelines. Oncologists and general practitioners support a shared-care model of care; however, any model developed needs to be evaluated for feasibility and acceptability. The barriers to a shared cancer follow-up model of care between general practitioners and oncologists are complex and require a multifaceted approach. To improve the acceptability and feasibility of shared cancer follow-up care, researchers and health professionals in both primary and secondary care need to work collaboratively to address the barriers and translate the research into practice. Further research is required to better understand the use of health technology to bridge the information-sharing gap and explore the feasibility and acceptability of shared cancer follow-up care for oncologists, general practitioners, and patients.

CHAPTER 4: Patients' acceptance of a shared cancer follow-up model of care between general practitioners and radiation oncologists: A population-based questionnaire using the Theoretical Framework of Acceptability

Chapter overview

This chapter presents a local population survey to evaluate the acceptability of a radiation oncology shared cancer follow-up model of care. This population survey aimed to address Objective 2 of this thesis: To determine the level of acceptance for shared cancer follow-up care in the ISLHD cancer patients.

Findings from this study have been accepted in the BMC Primary Care journal, a Q1 journal with an impact factor of 2.634.

A copy of the survey is presented in Appendix C.

4.1 Abstract

Introduction International and national guidelines highlight the need for general practitioner involvement during and after active cancer treatment and throughout long-term follow-up care. This paper aimed to evaluate patients' acceptance of a shared cancer follow-up model of care using the Theoretical Framework of Acceptability (TFA).

Methods This cross-sectional study was conducted at two cancer care centres in the Illawarra and Shoalhaven region of Australia. A sample of patients scheduled for a radiation oncology follow-up consultation in 2021 were sent a 32-point self-complete paper-based survey. Data were analysed using descriptive, parametric and non-parametric statistical analysis. This paper followed the Checklist for Reporting of Survey Studies (CROSS).

Results Of the 414 surveys returned (45% response rate), the acceptance for radiation oncology shared cancer follow-up care was high (80%). Patients treated with only radiotherapy were 1.7 times more likely to accept shared follow-up care than those treated with multiple modalities. Patients who preferred follow-up care for fewer than three years were 7.5 times more likely to accept shared care than those who preferred follow-up care for five years. Patients who travelled more than 20 minutes to their radiation oncologist or to the rural cancer centre were slightly more likely to accept shared care than those who travelled less than twenty minutes to the regional cancer centre. A high understanding of shared care (Intervention Coherence) and a positive feeling towards shared care (Affective Attitude) were significant predictive factors in accepting shared radiation oncology follow-up care.

Conclusion Health services need to ensure patient preferences are considered to provide patient-centred cancer follow-up care. Shared cancer follow-up care implementation should start with patients who prefer a shorter follow-up period and understand the benefits of shared care. However, patients' involvement needs to be considered alongside other clinical risk profiles and organisational factors. Future qualitative research using the TFA constructs is warranted to inform clinical practice change.

4.2 Introduction

Once cancer patients complete active treatment, they require long-term follow-up to monitor for treatment-related side effects, recurrence, and psychosocial support (19–21). The usual model of care is the hospital-based oncologist-led model (177,178). There is usually little formal involvement with the patient's general practitioner in this model of care (215,235). While the oncologist-led model suits many patients, it may not always meet patients' physical and psychosocial needs (236,237). For some patients, a shared care model might be more appropriate, tailored to their tumours, treatments, locality (metropolitan, regional or rural), access to specialists, and specific physical and emotional needs and preferences (67).

Shared care differs from the partial or whole transfer of care, where aspects of care are wholly transferred from the oncologist to another provider, such as a general practitioner. A shared cancer follow-up model of care harnesses the expertise of health professionals (113) and involves the explicit sharing of information and coordination of follow-up care (64). Shared care is widely used in antenatal care and for managing patients with asthma, diabetes and ischaemic heart disease (114–117).

There is a growing body of evidence supporting the benefits of shared cancer follow-up models of care (51,120,185–187). Randomised controlled trials have shown no difference in cancer recurrence rates or quality of life when a general practitioner is involved in follow-up care (95,119,188,189). A shared cancer follow-up model of care offers several advantages to patients, health providers and health services. Patients generally find general practitioner appointments are more accessible than specialist appointments (217,238); there are fewer duplication of tests and clinical questions; reduced travel time; and more accessible parking (204,223). Benefits for general practitioners include increased knowledge and awareness of their patient's overall health (198), addressing their patient's unmet psychosocial needs (203), and improving relationships with specialists (212). A shared care model benefits oncologists by allowing more time for newly diagnosed patients, patients on active treatment, advanced-stage and complex patients (239), and involvement in research and development activities. Additionally, the cost of shared cancer follow-up care to the health system is less than standard oncology follow-up care (49,240).

A shared cancer follow-up model of care may vary for each medical discipline (medical oncology, radiation oncology, haematology, surgical) and tumour type (breast, prostate, head and neck, abdomen, lung, etcetera). For example, in one model for shared care for colorectal patients, the general practitioner and oncologist alternate the appointments quarterly (225). In another model specific to radiation oncology shared follow-up care for breast, prostate and colorectal cancer patients, the radiation oncologist consultations cease entirely after three years after treatment, and patients see their general practitioner (3). In that model the general practitioner follows a prescribed clinical follow-up assessment, and the radiation oncologist oversees and reviews the consultation results; this model is reliant on health technology and the two-way transfer of clinical information in real-time (3).

A core principle of shared cancer follow-up care is the acceptability of all parties: the oncologist, the general practitioner and the patient (241). General practitioners are willing to accept a greater role in cancer follow-up care if there is improved information sharing and they are provided with clear clinical follow-up guidelines or protocols (62,200,220). However, increased workload concerns remain (214,242,243). Oncologists are more likely to prefer an oncologist-led model instead of a shared-care or general practitioner-led model, as they feel they have the specialised knowledge for follow-up care (195). However, oncologists are receptive to general practitioners taking a greater role in the more standardised aspects of follow-up care for low-risk patients (215), such as managing long-term and late side effects, blood tests and physical examinations. Several qualitative studies have found that patients appreciate their general practitioners taking a greater role in their long-term care (62,121,204,207,237).

Despite increasing evidence of the effectiveness of shared cancer follow-up care, data on implementation is limited. Treatment types (chemotherapy, immunotherapy, radiotherapy, surgery, etcetera) cause different short-term and long-term side effects (244), and differences in acceptance based on treatment type may help inform implementation. However, there is limited quantitative research on patients' acceptance of a shared cancer follow-up model of care, specific to radiation oncology patients to allow generalisability to larger samples. This study aimed to evaluate patients' acceptance of shared cancer follow-up care model of care between their general practitioner and radiation oncologist using the Theoretical Framework of Acceptability, in the Illawarra Shoalhaven Local Health District.

4.3 Methods

Study design, setting and participants

The Checklist Reporting of Survey Studies (CROSS) guided this study (Appendix D). This cross-sectional study used a purpose-developed survey and was set in one regional, Illawarra Cancer Care Centre, and one rural, Shoalhaven Cancer Care Centre, Australia. This region provides health services for around 400,000 people, including radiotherapy-related services for over 6,000 distinct people for treatment and consultations annually. The study population was patients on a radiation oncology follow-up regime at one of these cancer centres in 2021.

In Australia, oncologists are guided by the American Society of Clinical Oncology, the National Comprehensive Cancer Network, and the National Institute for Clinical Excellence guidelines for follow-up care. Follow-up care is between five to 10 years, however, the actual frequency depends on the individual patient's health, stage, and treatment.

Data sampling and data collection

In 2021, there were 6,036 distinct patients scheduled for radiation oncology follow-up appointments in the study sites. We calculated that three-hundred and sixty-two completed surveys were required to obtain a 95% confidence interval, with a 5% margin of error. We anticipated a 40% response rate. This was assumed because paper-based surveys obtain response rates of 46% compared to online surveys of 36% (245), and we were using a mixture of the two. A proportional stratified random sampling approach was employed based on years since treatment. Years since treatment strata were divided into <1 year, 1-2 years, 3-4 years, 5 years, 6-10 years and >10 years. The sample from each stratum was randomly selected using a Microsoft Excel formula to generate the participant list. Therefore, we sent 950 paper-based surveys and patients could elect to return the paper survey in the prepaid envelope provided or complete the survey online using the provided Quick Response Code or weblink.

Survey

A 32-point survey was developed by the authors and comprised four sections: demographics, health and cancer-related information, access to healthcare, and acceptance of shared care. The options in the demographics, health and cancer-related information, and access to healthcare sections were adapted based on previous survey designs (80,246,247), and are described below.

Demographics: These included age, sex, postcode, country of birth, primary language spoken, ethnicity, relationship status, level of education, housing situation, employment status, and income.

Health and cancer-related information: The cancers with the highest incidence (244) (breast, prostate, lung, colorectal, pelvis and head and neck) were included, as well as an 'Other' option. Additional information included: the staging at diagnosis, the primary hospital where radiation oncology treatment was received, other treatments received, and years post active treatment. A five-point scale ranging from 'Excellent' to 'Poor' based on World Health Organisation recommendations (245) was used to measure self-reported health status.

Access to healthcare: Questions included whether the patient had a regular general practitioner, how often they visited their different doctors, the time required to travel to their doctors and the primary mode of transport, and how often they would like a consultation for their radiation oncology follow-up care, and how many years they would prefer follow-up care.

Acceptability of shared cancer follow-up care: Acceptance of shared care was based on the Theoretical Framework of Acceptability (TFA) (126). The TFA is a multi-construct theoretical framework designed explicitly to assess the acceptability of healthcare interventions from the perspectives of the people who receive the intervention and those who deliver it (126). The TFA can be applied quantitatively or qualitatively and used prior to a health intervention to form judgments about whether the participants expect the intervention to be acceptable or unacceptable. Assessment of anticipated acceptability prior to participation can highlight which aspects of the intervention could be modified to increase acceptability and thus, participation (126). The seven constructs of the framework used to determine overall acceptability are Affective Attitude, Burden, Ethicality, Intervention Coherence, Opportunity Costs, Perceived Effectiveness and Self-efficacy. Questions were developed based on these constructs and measured using a five-point Likert scale from 'Strongly disagree' to 'Strongly agree' (see Table 7 for example).

The survey was refined with feedback from four general practitioners and two radiation oncologists. The survey included as few questions as possible to reduce the burden on patients and improve the response rate (248). Readability was scored at Year Nine level, which is slightly higher than the Australian desired standard of Years Six to Eight (249). The survey was piloted on ten follow-up patients and ten cancer centre staff for content validity. The average completion time was 4.5 minutes. The final version was available in printed form and online using Qualtrics XM.

Table 7. Theoretical Framework of Acceptability constructs and example statements used in the survey

TFA Constructs	Definition	TFA questions on 5-point Likert scale (Strongly disagree to Strongly agree)
Affective Attitude	Anticipated Affective Attitude: how an individual feels about the intervention, prior to taking part.	I would be **satisfied** for my radiation oncology follow-up care to be shared with my general practitioner, so long as the radiation oncologist is still involved.
Burden	Anticipated burden: the perceived amount of effort that is required to participate in the intervention.	It is **easier** to get to my general practitioner than the hospital. (Transport, time, parking, accessibility)
Ethicality	The extent to which the intervention has good fit with an individual's value system.	I would **value** my radiation oncologist and general practitioner working together to share my follow-up care.
Intervention Coherence	The extent to which the participant understands the intervention and how it works.	I **understand** that shared radiotherapy follow-up care will benefit me, my doctors and the health system.
Opportunity Costs	Anticipated opportunity cost: the extent to which benefits, profits, or values must be given up to engage in the intervention.	In order to have shared follow-up care, I would **need to give up** some of my time or my values on shared-care.
Perceived Effectiveness	Anticipated effectiveness: the extent to which the intervention is perceived to be likely to achieve its purpose.	I **believe** that shared radiotherapy follow-up care will benefit me, my doctors and the health system.
Self-efficacy	The participant's confidence that they can perform the behaviour(s) required to participate in the intervention.	If I had the choice: a. I would choose to have my follow-up care with **only** my radiation oncologist. b. I would choose to have **shared** follow-up care with my general practitioner so long as my radiation oncologist is involved. c. I have **confidence** in my choice above.

Reliability and Validity

Internal consistency reliability estimates how much total test scores would vary if slightly different items were used (250). The reliability across the seven constructs was assessed by computing Cronbach's α, with the minimum acceptable value of α=0.70. The coefficients for the constructs totalled α=0.78, indicating an acceptable level of internal consistency (251,252). Table 8 shows that the reliability would slightly improve if the Opportunity Costs construct were removed; however, the research team deemed the improvement small and did not delete it. The construct validity of the TFA constructs (that is, how accurately the constructs measure what they say they do) (253) was calculated with Pearson's correlation coefficient of the patient's responses to an item with their total scores. A validity coefficient above 0.35 is strongly valid (254), and all constructs were positively associated.

Table 8. Reliability and validity analysis of acceptability constructs

TFA Construct	Corrected item total correlation	Cronbach's Alpha if item deleted	Pearson correlation	Sig (2-tailed)
Affective Attitude	0.603	0.727	0.684	<.001
Burden	0.182	0.819	0.373	<.001
Ethicality	0.756	0.699	0.764	<.001
Intervention Coherence	0.753	0.704	0.787	<.001
Perceived Effectiveness	0.772	0.695	0.796	<.001
Opportunity Costs	0.281	0.803	0.523	<.001
Self-Efficacy	0.373	0.771	0.413	<.001

Statistical analysis

Data were analysed using the statistical software package SPSS version 29 (255). Frequencies and percentages were calculated for categorical variables and reviewed for normality. Two forms of acceptance scores were generated. For the first, an average score across all TFA constructs, with opportunity scores reversed to align from a negative to a positive scale. A patient's summated score was divided by the number of constructs constituting the scale, thereby creating a mean that falls within the range of the values for the response continuum options. All items comprising the construct's scale were assumed to have equal weight when calculating a summated score. The second form of acceptance score was achieved by dichotomising the data into 'Accept' and 'Not Accept'. The Accept score was generated from the 'Strongly agree' and 'Agree' response categories, and the Not accept score was generated from 'Neither agree/disagree', 'Disagree' and 'Strongly disagree'. The dichotomised data were used to understand whether acceptance could be predicted based on any of the TFA categorical constructs (logistic regression).

Parametric tests included multinomial and ordinal logistic regression. If requirements for parametric test procedures were not met, non-parametric tests were used: Chi-Square, Kruskal Wallace Test and posthoc analysis. All tests were 2-sided; statistical significance was defined as $p \leq 0.05$. Weighted adjustments were used to compensate for missing data.

Ethical consideration

Ethical approval for this study was obtained from the Joint University of Wollongong and Illawarra Shoalhaven Local Health District Human Research Ethics Committee. Patients were provided with a participant information sheet about the study's aim and procedures and informed that consent was tacit upon completing the survey and that responses would be anonymised. Patients did not receive payment or an honorarium.

4.4 Results

Of the 950 surveys sent, 414 were returned (response rate of 45%); 371 had no missing data. Twenty-eight surveys were returned to sender (26 were no longer at that address, and two stated that the patient was deceased). Most (383 of 414) surveys were returned via post (92%). Patient demographics, health characteristics and healthcare access are presented in Table 9. Age and sex did not significantly influence a patient's preference regarding their choice of follow-up care, and there were no significant socio-demographic variables on the acceptance for shared care.

One-third of the patients (n=141, 34%) were treated with only radiotherapy, and two-thirds (n=273, 66%) were treated with radiotherapy and chemotherapy and/or surgery. More patients reported their health as either 'Excellent' or 'Very good' (43.5%), followed by 'Good' (36.6%) and 'Fair' or 'Poor health' (19.9%). Almost all patients had a regular general practitioner (98%); 90% lived within a 20-minute drive of their general practitioner, and 40% lived within a 20-minute drive of their radiation oncologist.

Table 10 shows a high acceptance of radiation oncology shared care across the different tumour types. However, no statistically significant results were found with patient acceptance of shared care between the tumour group, cancer staging, or years since treatment.

Table 9. Demographics of radiation oncology respondents

	N (%)		N (%)
Sex		**Cancer**	
Male	171, (41.3)	Breast	193, (46.6)
Female	243, (58.7)	Colorectal	9, (2.2)
		Head/Neck	54, (13)
		Lung	25, (6)
		Prostate	91, (22)
		Pelvis	9, (2.2)
		Other	33, (8)
Age		**Stage at diagnosis**	
<40	5, (1.2)	I	91, (22)
41-50	38, (9.5)	II	76, (18.4)
51-60	13, 2(32.9)	III	57, (13.8)
61-70	201, (50.1)	IV	25, (6)
>71	25, (6.2)	Not known	165, (41.1)
Education		**Treatment**	
Year 10	126, (31.2)	Only radiotherapy	141, (34.1)
Year 12	42, (10.4)	Radiotherapy and other	273, (65.9)
Certificate	117, (29)		
Undergraduate	43, (10.6)		
Postgraduate	52, (12.9)		
Prefer not to say	24, (5.9)		
Relationship		**Years since treatment**	
Married	278, (67.5)	Less than 1 year	122, (29.8)
Single	25, (6.1)	1-2 years	82, (20)
De-facto	13, (3.2)	2-3 years	59, (14.4)
Divorced	37, (9.0	3-4 years	51, (12.5)
Widow	53, (12.9)	4-5 years	45, (11)
Prefer not to say	6, (1.5)	5-10 years	43, (10.5)
		> 10 years	7 , (1.7)
Housing		**Health**	
Rent	48, (11.7)	Excellent	46, (11.3)
Own	341, (82.8)	Very good	131, (32.2)
Other	14, (3.4)	Good	149, (36.6)
Prefer not to say	9, (2.1)	Fair	68, (16.7)
		Poor	13, (3.2)
Employment			
Casual	15, (3.7)	**Main hospital treated at**	
Part-time	40, (9.8)	Illawarra Cancer Centre	262, (64)
Full-time	32, (7.8)	Shoalhaven Cancer Centre	147, (36)
Unable to work	18, (4.4)		
Retired	295, (72.1)		
Prefer not to say	9, (2.2)		
Income		**Travel time (one way) to General practitioner**	
<$15,000	58, (15.2)		
$15,000-29,999	97, (25.5)	0-20 minutes	361, (90.5)
$30,000-49,000	63, (16.5)	21-40 minutes	27, (6.7)
$50,000-74,999	46, (12.1)	> 40 minutes	11, (2.8)
$75,000-100,000	23, (6)		
>100,000	10, (2.6)		
Prefer not to say	84, (22)		

	N (%) cont.		N (%) cont.
Country of birth		**Travel time (one-way) to Radiation oncologist**	
Australia/New Zealand	324, (78.3)	0-20 minutes	156, (40.1)
United Kingdom	46, (11.1)	21-40 minutes	159, (40.9)
Europe	31 (7.5)	41-60 minutes	51, (13.1)
Africa	5 (1.2)	> 1 hour	12, (3.1)
Asia	5 (1.2)	> 2 hours	11, (2.8)
Canada	3 (0.7)		
Primary language		**Preferred radiation oncology frequency**	
English	404, (97.6)	Every second month	11, (2.8)
Other	10, (2.4)	Every three months	48, (12.1)
		Every six months	108, (27.3)
		Once a year	167, (42.2)
		No more visits wanted	62, (15.7)
Identifies as Aboriginal and/or Torres Strait Islander		**Preferred year for follow-up**	
No	398 (98)	No follow-up wanted	38, (9.6)
Yes	9 (2)	For 1 year	67, (17)
		For 3 years	32, (8.1)
		For 5 years	174, (44.1)
		For 10 years	47, (11.9)
		For lifetime	37, (9.4)

Table 10. Acceptance for radiation oncology shared follow-up care

	Accept Shared Care N (%)	**Do not accept shared care N (%)**	**N**
Total average acceptance	**325, (80%)**	**79, (20)**	**405**
Breast	149, (79)	39, (21)	188
Colorectal	7, (78)	2, (22)	9
Head/Neck	44, (83)	9, (17)	53
Lung	20, (83)	4, (17)	24
Prostate	74, (82)	16, (18)	90
Pelvis	9, (100)	0, (0)	9
Other cancer	23, (72)	9, (28)	32

Theoretical Framework of Acceptability Constructs

Table 11 shows patients' acceptance for shared follow-up care across each construct in the Theoretical Framework of Acceptability. For Affective Attitude 85% agreed that they would be satisfied for their follow-up care to be shared with their general practitioner as long as the radiation oncologist was still involved. Ethicality: 88% agreed a shared cancer follow-up model fits with their values. Intervention Coherence: 88% agreed that they understood the benefits of shared cancer follow-up care for themselves, their doctors and the health care system. Perceived Effectiveness: 87% agreed that shared care was likely to achieve its purpose. Self-Efficacy: 75% elected to have shared follow-up care; sub-analysis showed 97% had confidence in their choice (p=<0.001).

Table 11. Acceptance for radiation oncology shared follow-up care according to the Theoretical Framework of Acceptability constructs

TFA Constructs	Agree	Disagree
Affective attitude	85%	15%
Burden	30%	70%
Ethicality	88%	12%
Intervention Coherence	88%	12%
Perceived Effectiveness	87%	13%
Opportunity Costs	33%	77%
Choose Shared Care	75%	15%
Self-Efficacy	93%	7%

Acceptance and preferences for follow-up care

Patients treated with only radiotherapy were associated with an increase odds of accepting shared care, odds ratio 1.707 (95% CI 1.051-2.773), Wald $\chi^2(1)=4.668$, $p<0.031$. Additionally, patients who self-reported 'Very good' health had a statistically significant higher acceptance of shared care than those who self-reported their health as Good (p=0.008). However, health status was not a strong predictor of accepting shared care ($\chi^2(4)$, 7.951, $p=0.093$).

The majority of patients preferred to have their radiation oncology follow-up reviews for five years (44%). However, patients who preferred follow-up care for one year were 2.9 times more likely to accept shared care ($p=0.025$), than those who wanted follow-up care beyond five years; and those who preferred follow-up care for three years were 7.5 times more likely to accept shared care ($p=0.012$) than those who preferred care beyond five years.

Patients treated at the regional hospital were 1.8 times more likely to want follow-up care to continue for over 10 years ($p=0.027$), and five times more likely to want follow-up for life ($p=<0.001$), compared to patients treated at the rural hospital. These results align with travel time. Patients who travelled less than 20 minutes one-way to their radiation oncologist had a slightly lower acceptance for shared care (mean rank=186.08, $p=0.025$) than those who travelled more than 20 minutes (mean rank=207.15, $p=0.025$).

Although not significant, patients treated at the rural hospital had a slightly higher average acceptability score of shared care (3.94/5 compared to 3.86/5 from the regional hospital).

Logistic regression predicted patients' acceptance of shared care (see Table 12). Patients with a high understanding of shared care (Intervention Coherence) were predicted to be seven times more likely to accept a shared cancer follow-up model of care; those with a high Affective Attitude were predicted to be three times more likely; those with a high Ethicality were two and half times more likely; and those with high Self-Efficacy were three times more likely. Other constructs were not significant in predicting acceptance of shared care.

Table 12. Odds ratio of Theoretical Framework of Acceptability and shared care acceptance

TFA Construct	df	Sig.	OR
Affective Attitude	1	<0.001	3.231
Burden	1	0.306	1.131
Ethicality	1	0.031	2.497
Intervention Coherence	1	<0.001	7.111
Opportunity Costs	1	0.162	0.824
Perceived Effectiveness	1	0.781	1.129
Self-Efficacy	1	0.007	3.467

4.5 Discussion

This multi-centre cross-sectional study evaluated patients' acceptance of a shared cancer follow-up model of care between their general practitioner and radiation oncologist using the Theoretical Framework of Acceptability (TFA). We found that 80% of patients accepted a radiation oncology shared follow-up model of care, and 75% would choose shared care compared to the oncologist-led model if given a choice. Patients treated only with radiotherapy were more likely to accept shared follow-up care, and patients who preferred follow-up care for fewer than three years were more likely to accept shared follow-up care. The TFA constructs of Intervention Coherence, Affective Attitude and Self Efficacy were significant predictors of acceptance for shared cancer follow-up care.

Previous qualitative research has found that patients are willing to accept shared cancer follow-up care if their oncologist remained remains involved and can oversee their care (215). Although previous research does not distinguish between patients treated with only radiation therapy or other modalities, this study confirms that most radiation oncology patients would accept shared cancer follow-up care provided their radiation oncologist was still involved. However, the extent to how the oncologist was to remain involved was not explicitly addressed. It has been suggested that for the oncologist to remain involved and oversee the patient's care, there is a need for improved two-communication and linkage of medical records between health professionals (215,219).

Some patients require follow-up appointments with multiple specialists: radiation oncologist, medical oncologist, surgeon (for example, urologist, breast surgeon), and shared care has been highlighted as beneficial in reducing the number of appointments and duplication of assessments (215,256). However, our results found that patients who only received radiotherapy treatment were more likely to accept shared follow-up care, and no significant difference with years since treatment was found. This is an interesting result, as patients treated with only one modality have fewer follow-up consultations than those treated with multiple modalities (who would be more likely to benefit from having fewer appointments). The higher acceptance for patients treated with only radiotherapy may be due to other unknown factors, such as long-term toxicity and treatment side effects and warrants further investigation.

To our knowledge, this is the first quantitative study to apply the TFA, which helped determine factors that may predict a patient's acceptance of a radiation oncology shared follow-up model of care. Patients with good Intervention Coherence, Affective Attitude and Self-Efficacy were significantly more likely to accept a shared care model. Additionally, these constructs were also useful in predicting acceptance and could be useful for health services to undertake readiness assessments. This finding is also supported by the Social Cognitive Theory that goes beyond the individual behaviour (Health Belief Model and Theory of Reasoned Action/Planned Behaviour) and considers interactions with social and environmental influences. According to Bandura (257), if people lack awareness of how their lifestyle habits affect their health, they have little reason to change; conversely, knowledge creates the precondition for change (257). Therefore, the knowledge and understanding (Intervention Coherence) regarding the benefits of shared cancer follow-up care is important to consider before transferring the care of patients to their general practitioner in a shared care model. This finding is also supported by a recent study that found women need to be provided with the evidence that shared follow-up care is effective, so they can form a thorough understanding (Intervention Coherence) of what shared is, who is responsible for what and to understand that shared care will not negatively impact their health outcomes (221). The TFA allows researchers and health services to determine which constructs require further attention to increase acceptance before implementing health interventions.

Although there are several system barriers to implementing shared cancer follow-up care (such as the need for defined health professional roles (215), protocols, evidence-based guidelines (121,200,206) and communication tools (223), acceptability to patients is fundamental. Our results support that shared cancer follow-up care needs to be individualised based on the patient's cancer type, treatment type, current health, and personal preferences (80). The American Society of Clinical Oncology suggested that “models of risk are needed to stratify survivors into different levels of intensity and setting for follow-up care. Components needed in such a model include risk recurrence, the persistence of moderate to severe toxicity or therapy, risk of serious physical late effects and psychosocial status” (258 p.634). Another form of stratification to select appropriate patients for a shared care model beyond the clinical paradigm is to evaluate the patient's acceptability toward shared care.

In addition to the risk stratification for cancer patients, essential elements for shared care include improved communication between the general practitioner and oncologist (205,212,259). It is equally important to provide patient-centred care, including engaging with patients and understanding their needs and preferences (260). We show that patients with a strong understanding (Intervention coherence) of the benefits of shared care are seven times more likely to accept a shared care follow-up model.

Study limitations

To our knowledge, this was the first study that used the Theoretical Framework of Acceptability quantitatively, and there is limited guidance on applying the framework in survey format. The study was specific to radiation oncology follow-up; some patients may have confused this with their medical oncology or surgical oncology follow-up. Although this study had a good response rate, there is no information about the 55% who declined to participate. It is possible that those who did not respond were less likely to accept shared cancer follow-up care, and response bias may be present. The authors were unable to conduct a non-report analysis. Additionally, there were few responses from colorectal cancer patients; this may be due to fewer colorectal cancer patients being treated with radiotherapy compared to breast and prostate patients. Finally, this study was conducted across a regional and rural population and may not be generalisable to the metropolitan population. However, based on our results, patients who travel less than 20 minutes to their oncologist were slightly less likely to accept shared care and may produce similar results in a metropolitan area where people live closer to cancer centres. The lead author is a critical realist researcher and acknowledges that many unobservable structures and events may influence the results.

4.6 Conclusion

There is a need to normalise shared cancer follow-up care into practice. However, normalising shared cancer care requires a multifaceted approach and support from specialists, general practitioners and patients. Based on the findings of this study, informing patients about the concept and benefits of shared care is important to foster acceptance. Follow-up care should be based on individual clinical risk and patient preference for follow-up care. Further investigation is needed to establish how the oncologist is to remain involved and oversee care in a shared care model, and to qualitatively research the acceptance among radiation oncologists, general practitioners and patients using the TFA constructs to inform clinical practice change.

CHAPTER 5: A shared cancer follow-up model of care between general practitioners and radiation oncologists for patients with breast, prostate and colorectal cancer: Protocol for a mixed methods implementation study

Chapter overview

This chapter presents the research protocol and addresses Objective 3: To develop a shared cancer care follow-up model of care. This chapter describes the components of the model in more detail. The clinical assessment is in Chapter 7, and the model of care diagram is in Chapter 8.

This chapter has been published in the Journal of Medical Internet Research. This journal is a Q1 journal with an impact factor of 7.52. A component of this paper was presented at the Primary Care Collaborative Cancer Clinical Trials Group Scientific Symposium.

Citations:

Sandell T, Schütze H, Miller A. A shared cancer follow-up model of care between general practitioners and radiation oncologists for patients with breast, prostate, and colorectal cancer: Protocol for a mixed methods implementation study, Journal of Medical Internet Research, 2021 Jan 19;10(1).

Sandell T, Schütze H, Miller A, Ivers R, Shaping an optimal care pathway between general practitioners and radiation oncologists, The Primary Care Collaborative Cancer Clinical Trials Group Scientific Symposium), Melbourne, 24 May 2021.

5.1 Abstract

Background The rising incidence of cancer and increasing numbers of cancer survivors have resulted in the need to find alternative models of care for cancer follow-up care. The acceptability for follow-up care in general practice is growing, and acceptance increases with shared-care models where oncologists continue to oversee the care. However, a major barrier to this model is the effective exchange of information in real-time between oncologists and general practitioners. Improved communication technology plays an important role in the acceptability and feasibility of shared cancer follow-up care.

Objective The aim of this study is to evaluate the feasibility and acceptability of a shared cancer follow-up model of care between patients, general practitioners and radiation oncologists. Methods: This is a mixed methods, multisite implementation study exploring shared follow-up care for breast, colorectal, and prostate cancer patients treated with curative radiotherapy in New South Wales, Australia. This study uses web-based technology to support general practitioners in performing some aspects of routine radiotherapy follow-up care, while being overseen by a radiation oncologist in real-time. The study has two phases: Phase 1 is designed to establish the level of agreement between general practitioners and radiation oncologists and Phase 2 is designed to implement shared follow-up care into practice and to evaluate this implementation.

Results Recruitment of radiation oncologists, patients, and general practitioners commenced in December 2020 and will continue until February 2021. Data collection will occur during 2021, and data will be ready for analysis by the end of 2021.

Conclusion Few studies have investigated the role of health technologies in supporting communication deficiencies for shared cancer follow-up care. The implementation and evaluation of models of care need to be conducted using a person-centred approach that is responsive to patients' preferences and needs. Should the findings of the study be acceptable and feasible to radiation oncologists, general practitioners, and patients, it can be quickly implemented and expanded to other tumour groups or to medical oncology and hematology.

5.2 Introduction

The increasing incidence of cancer, coupled with improved survivorship, has resulted in higher demand for cancer follow-up care (56,261,262). This has led to the sustainability of oncologist-led cancer follow-up care in the secondary health setting being questioned (236,237) and to a call for alternative models of cancer follow-up care (60,263). There is a growing body of literature on the benefits of shared cancer follow-up models between general practitioners and oncologists (120); however, this is yet to be integrated into routine practice.

Randomized controlled trials have shown that cancer follow-up care delivered by a general practitioner in the primary health care setting produces no difference in the rate of recurrence or quality of life compared to cancer follow-up with an oncologist (51,118,119). General practitioners are willing to take a greater role in cancer follow-up care (202) provided they are supported by the oncologist (62,63,204,215) and the oncologist maintains overall responsibility (264).

Despite an acceptance by patients for their general practitioner to be involved in their follow-up care, barriers to shared care exist. The barriers are role clarification (97,265,266) and effective two-way communication (198,200,211,212,267). There is a need for a robust information-sharing system that allows both the general practitioner and the overseeing oncologist to be involved in the follow-up care. Real-time and open access to patient information is crucial to coordinate the care of cancer survivors appropriately (176,268,269).

At present, cancer patients maintain follow-up with their oncologists in the secondary health care setting, and routine communication is transferred from the oncologist to the general practitioner via letter or secure email. In the case where a general practitioner has undertaken a cancer-specific follow-up, it is uncommon for the general practitioner to communicate their findings to the oncologist. This study will trial a web-based technology to breach the communication divide between the general practitioner and the oncologist so that they can work together collaboratively, should patients choose a shared-care model.

To our knowledge, there is currently no system that supports the involvement of general practitioners in shared cancer follow-up care where the radiation oncologist can oversee the care. This study trials a web-based system that allows general practitioners to undertake routine aspects of cancer follow-up care, while sharing the data with oncologists at the hospital in real-time so that they can continue to monitor, oversee, and maintain responsibility for the patient.

This research aims to evaluate the feasibility and acceptability of a shared cancer follow-up model of care between patients, general practitioners and radiation oncologists. The objectives of this study are to implement a model of care using a web-based system that transfers clinical information between the general practitioner and radiation oncologist in real-time, to determine the level of agreement between general practitioners and oncologists completing a standardized follow-up assessment, and to establish the feasibility and acceptability of this model of care.

5.3 Methods

This research is a mixed methods, multisite implementation study for breast, colorectal, and prostate cancer patients who have undertaken curative radiotherapy treatment. Mixed methods investigations involve integrating quantitative and qualitative data collection and analysis into a single study (270) and can strengthen the credibility of evidence and evaluation (143).

The study will implement the shared cancer follow-up model of care into practice at baseline (Phase 1) and at 6 months post recruitment (Phase 2) (see Figure 8). During Phase 1, there will be a standard clinical review by the radiation oncologist as per the patient's routine follow-up schedule, plus an additional follow-up review by the general practitioner using the same standardized follow-up assessment. This first phase will determine the level of agreement between general practitioners and radiation oncologists when completing the same radiotherapy follow-up clinical assessment on the patient. This first phase is essential, as it informs the educational and training requirements for general practitioners. By demonstrating the level of agreement, it reassures both the general practitioner and radiation oncologist that the general practitioner can reliably conduct a cancer-specific follow-up review.

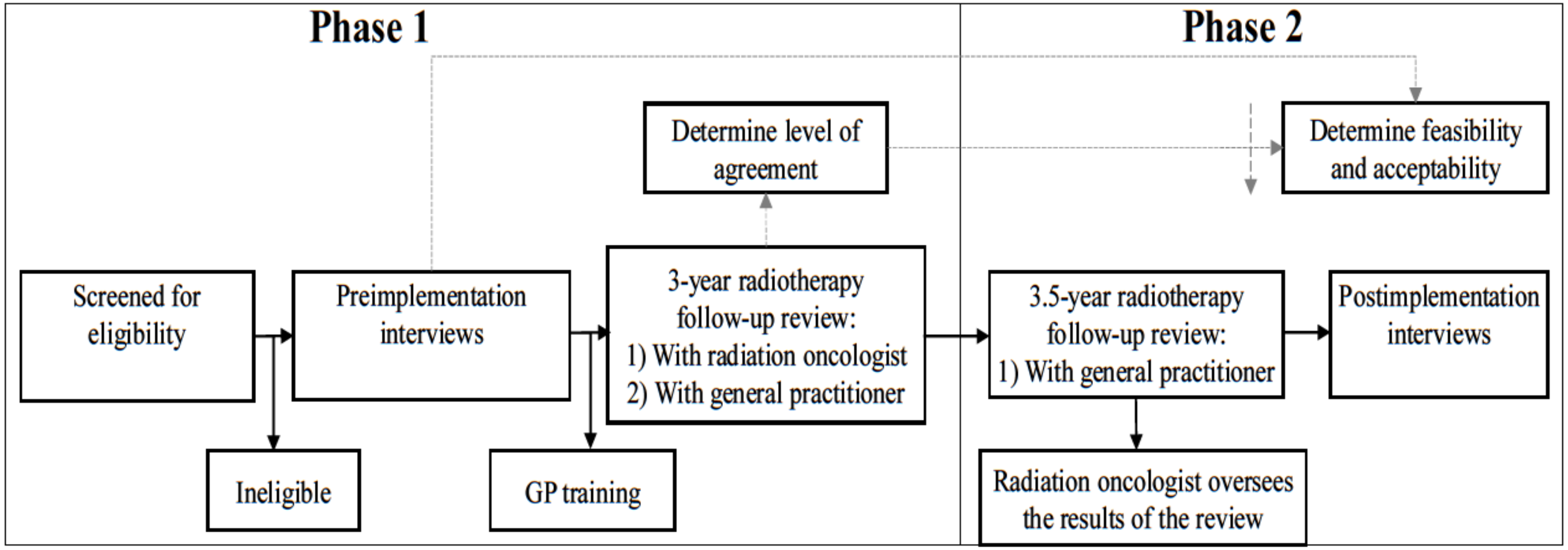


Figure 8. Flow diagram of study phases

The second phase of the study is the implementation of the shared cancer follow-up model of care into practice. The patient will visit their general practitioner at 3.5 years follow-up for a radiation oncology–specific follow-up appointment. The results will be transferred to the hospital, and the patient's radiation oncologist will be alerted by an automatic quality checklist to review the outcomes of the review in real-time on the hospital's oncology information system. The system has a rapid referral built into it in the case of adverse events or should the general practitioner suspect cancer recurrence.

Study Setting The research will be conducted within the Illawarra Shoalhaven Local Health District (ISLHD) region in New South Wales, Australia. The ISLHD provides public health services to over 400,000 people and cancer services to almost 9000 people annually (ie, medical oncology, hematology, and radiation oncology). Radiation oncology outpatient services are provided at Wollongong Hospital (ie, tertiary hospital and regional care) and the Shoalhaven District Memorial Hospital (ie, secondary hospital and rural care).

The ISLHD radiation oncology service consults and treats over 1400 patients with radiotherapy and conducts over 5000 follow-up consultations annually. The service has experienced a 20% increase in follow-up consultations over a 5-year period (2015-2019), and treatment activity is projected to increase by 18% by 2031. A substantial proportion of radiotherapy treatment at each site is attributed to breast, colorectal, and prostate cancer. The study will take place at the two hospital radiation oncology outpatient clinics and in the referring general practices. The relationship between general practice and local health districts in Australia is increasingly pivotal to the health system. General practice in Australia is typically comprised of small businesses with an average of three to five general practitioners, and a universal medical insurance scheme (ie, Medicare) covers all or part of a person’s cost to visit a general practitioner (271).

Local Follow-Up Guidelines

While there are many statements regarding “standard follow-up practices,” postradiotherapy follow-up for patients varies greatly depending on the disease type, the oncologist's preference, and the patient's preference. At the ISLHD, a visit 6 weeks after radiotherapy is routine for most cases to review the settling of acute side effects. The pattern of remaining follow-up sessions for all cancers will include a period of every 3 months for the first year and every 6 months for the second year, followed by yearly reviews and then, finally, discharge from follow-up. For many cancers, a 5-year period of follow-up is common.

At the ISLHD, an acceptable practice for breast cancer patients’ postradiotherapy follow-up care would be a follow-up at 6 weeks, then every 3 months for 2 years, then every 6 months to 5 years, and then yearly to 10 years. An acceptable practice for colorectal cancer patients would be follow-ups every 6 months for the first year and then yearly to 5 years. An acceptable practice for prostate cancer patients would be follow-ups every 6 months or yearly to 5 years. However, the actual frequency depends on the individual patient's health, stage, and treatment and their preference for whom to see; in addition, there is currently no early discharge, transfer of care, or shared care for radiation oncology follow-up care to general practitioners.

Health Technology

The free and open source software framework PROsaiq (Didymo Pty Ltd) will be used (227). PROsaiq is based around a web server that extracts assessments from inside the oncology information system and encodes the assessment data into XForms (ie, an XML format used for collecting inputs from web forms), which is then presented as a webpage in a web browser. When the clinical assessment is completed on a smart device (ie, phone, computer, or tablet), the clinical assessment is returned to the web server and converted into a Health Level Seven (HL7) message; HL7 is an accepted international communication standard for clinical systems, such as those comprising laboratory information. The HL7 message is presented to the oncology information system MOSAIQ (Elekta AB), where it is imported to become part of the patient's oncological record.

Australia is equipped with reliable internet capability, and the webpage link will be made available to the general practitioner by integrating it into a current local system that they utilize. The general practitioner will complete the patient follow-up clinical assessments using PROsaiq, and the radiation oncologist will receive an automated alert in real-time to review the results at the hospital. PROsaiq has been trialed for the collection of cancer patient–reported quality-of-life outcomes from patients and has demonstrated its operational feasibility (272).

Eligibility Criteria

To be eligible for the study, patients must (1) have a previous diagnosis of colorectal, breast, or prostate cancer; (2) have completed curative-intent radiotherapy treatment and are due for their 3-year review; (3) be over 18 years of age; (4) be able to understand and speak English; and (5) have a general practitioner willing to participate. Patients who do not meet these criteria will be excluded, as will patients who have suspected or confirmed recurrence of cancer. Patients 3 years posttreatment have been selected, as it was deemed a safe time period by the oncologists for a feasibility study, and the patients will have experienced the standard oncologist-led follow-up model. Participants can withdraw at any stage up until data analysis.

Sample Size

The sample will consist of 20 triads comprising the patient, their radiation oncologist, and their general practitioner, for a total of 35 to 45 participants. A total of 10 patients will be from the Wollongong Cancer Centre (ie, regional) and 10 will be from the Shoalhaven Cancer Centre (ie, rural). Sample size guidelines for qualitative interviews suggest that a range between 20 and 30 interviews is adequate for each group to reach data saturation (273). The sample size for the quantitative level of agreement data requires a minimum of 5 samples; however, to increase the confidence interval, a higher sample is required (274).

Recruitment

The radiation oncologists will review their follow-up clinic lists from both sites and screen for initial inclusion criteria. The researcher will invite each patient to participate via a postal letter on behalf of the radiation oncologist. Once each patient consents to participate, their general practitioner will be invited. General practitioners will be eligible for continuing professional development points for participating. If the general practitioners do not consent to participate, the patient will not be eligible.

Implementation

The foundation of this shared cancer follow-up model of care is that clinician communication exchange is two-way and in real-time, while the radiation oncologist continues to oversee the follow-up care. The model includes real-time transfer of results, internal system alerts, and rapid referral to address any issues that may arise. During this study, patients maintain their current specialist standard follow-up care, with all relevant specialists, and will continue follow-up care with their radiation oncologist upon completion of the study. General practitioners will complete a standardized online radiation oncology course developed by the Cancer Institute New South Wales (275). The course developed for health professionals addresses the principles of radiation therapy, patient assessment grading systems of side effects, and supportive care management.

General practitioners will receive one-on-one training by a radiation oncologist that includes localized radiotherapy-specific follow-up care, a review of the recruited patient's treatment background, and a demonstration of the clinical follow-up assessment that the general practitioner will use in the patient's follow-up review.

Data Collection

The PROsaiq software will be used to administer clinical assessments. The assessments were compiled internally at the ISLHD for follow-up of radiotherapy patients. These clinical assessments review physical items on a scale from 0 to 4 for items specific to radiotherapy follow-up care, such as pain, fatigue, physical performance, bowel issues, urinary issues, and appetite (see Table 13). The included scales were sourced from the Radiation Therapy Oncology Group scales (276) and the Common Terminology Criteria for Adverse Events, version 3.0 (277).

Table 13. Radiation oncology follow-up standardised clinical assessment

Tumour	**Clinical assessments**
Breast	Fatigue, ECOG (Eastern Cooperative Oncology Group) Performance Status, appetite, weight loss, chest and breast pain, telangiectasia, lymphedema-related fibrosis, and disease state (ie, local, regional, or distant)
Colorectal	Fatigue, ECOG Performance Status, appetite, weight loss, proctitis, pelvic pain, vomiting, and diarrhea
Prostate	Fatigue, ECOG Performance Status, erectile dysfunction, dysuria, and rectal hemorrhage

Quantitative Data

The quantitative data will be collected from Phase 1. The radiation oncologist will enter the clinical assessment directly into the oncology information system, while the general practitioners will enter the clinical assessment on the webpage link that will be provided to the general practitioner. Both sets of data from these clinical assessments will be stored in the hospital oncology information system.

Qualitative Data

At pre- and postimplementation, participants (ie, patients, general practitioners, and radiation oncologists) will participate in semi structured interviews following a topic guide about radiotherapy follow-up care and their experience of shared care. Demographic data will be collected for all participants (ie, age, sex, level of education, and working years). The interviews will be audio-recorded and transcribed verbatim in preparation for thematic analysis in NVivo (QSR International).

Data Analyses

Quantitative Data

The clinical assessment data will be extracted from the oncology information system; the Cohen κ value and percent agreement for each variable from Table 13 will determine the level of agreement between general practitioners and radiation oncologists. The agreement will assess the concordance between two measurements of each variable with the expectation that there will be near-perfect agreement on each item (>0.81). The results of the analysis and level of agreement will be presented to the general practitioners and radiation oncologists to guide any additional education and training.

Qualitative Data

Thematic analysis is a commonly used analytical approach for qualitative data in implementation studies (278). This involves mapping the transcribed data and emergent themes onto a priori domains. The themes will be compared across the regional and rural sites (ie, Wollongong and Shoalhaven) and triangulated between radiation oncologists, patients, and general practitioners.

Ethics Approval and Trial Registration

Ethics approval was received on May 12, 2020, from the Joint University of Wollongong and the ISLHD Human Research Ethics Committee (2020/ETH00301). The trial was registered with the Australian New Zealand Clinical Trials Registry on October 20, 2020 (ACTRN12620001083987).

5.4 Results

Recruitment of radiation oncologists, patients, and general practitioners commenced in December 2020 and will continue until February 2021. Data collection will occur during 2021, and data will be ready for analysis by the end of 2021.

5.5 Discussion

The important skill set and experience that oncologists have is undisputed. However, there appear to be limited alternate models of cancer follow-up care that address the principles of equity in access, connecting health services, and where the cancer survivor can make an informed decision about their cancer follow-up care. Cancer survivors are more likely to accept shared cancer follow-up care with a general practitioner if their care is overseen by their oncologist (215). However, effective two-way communication between oncologists and general practitioners is lacking. Improved communication is the strongest enabler to routine shared cancer follow-up care and is an area that is still being established (122,200,279,280).

Few studies have investigated the role of health technologies in supporting communication deficiencies for shared cancer follow-up care (281). There have been no explicit recommendations of what type of health technology to use or how to use it. Health technology has been embraced for the collection of patient-reported outcomes of cancer patients during follow-up care, which utilizes the internet to complete online assessments that connect to the hospitals' patient medical files (226). To our knowledge, using this type of technology between general practitioners and the oncologists is the first of its kind.

The body of literature on the benefits of general practitioner–led and shared cancer follow-up models of care is growing. Although shared follow-up care may not be desired or appropriate for everyone, Australia's oncologist-led model currently leaves limited patient choice as to when, where, and by whom their follow-up care is delivered. A well-informed patient can actively participate in the decision-making process about their care based on their personal circumstances, beliefs, and priorities.

Oncologists, general practitioners, and patients are supportive of a model of shared care]; however, any model developed needs to address the two-way communication barrier and be evaluated for acceptability. The outcomes of this study may lead to a longitudinal implementation to measure patient satisfaction, cost-benefit analysis, health economic analysis, management of rapid referrals, and long-term outcomes of patients.

Limitations

Possible limitations of this research are the number of participants needed to determine the level of agreement; the research team will monitor this. Another limitation identified is that the general practitioners and radiation oncologists recruited may assess the same oncological patients from a different viewpoint due to differences in training. The researcher will assist in the coordination of appointments and try to minimize the impact on the patients and health professionals.

CHAPTER 6: Patient self-reported follow-up for radiation oncology patients during COVID-19: Feasibility and patient-clinician agreement

Chapter overview

This chapter was an additional study that was opportunistically included. During the COVID-19 pandemic, restrictions limited face-to-face follow-up care with both radiation oncologists and general practitioners. It highlighted a need to explore alternate models of follow-up care if both oncologist-led and shared care were not available.

This remote monitoring study aimed to address Objective 3 of this thesis: To test the model and determine the concordance in clinical data between patients and oncologists completing the follow-up clinical assessment in the radiation oncology setting.

Findings from this study were published in the Journal of Radiation Oncology Information and presented at the Australian Public Health Conference.

Citations:

Sandell T, Miller A, Schütze H, Ivers R, Vijayakumar V, Dinh L. Patient self-reported follow-up for radiation oncology patients during COVID-19: Feasibility and patient-clinician agreement, JROI, 2023

Sandell T, Miller A, Schütze H, Ivers R, Vijayakumar V and Dinh L. Radiation oncology patient self-reported follow-up during the COVID-19 pandemic, Australian Public Health Conference, Supporting and Re-energising Public Health in a Disrupted Word, 23-24 September 2021, Canberra (virtual presentation).

6.1 Abstract

Introduction The COVID-19 global pandemic required health services to be innovative and quickly adapt their health service delivery, including adopting health technology in cancer clinical practice. COVID-19 restrictions forced our health service to introduce follow-up consultations for many patients via telehealth. At the same time, we explored an alternative follow-up model of care in preparation for unknown future restrictions and changes to health resources. We adapted an existing Patient Reported Outcome messaging service that linked to the patient's medical record. Clear and meaningful interpretation of patient-reported outcome scores is fundamental to their use to determine if they could become a means of follow-up care when service delivery is impeded. Therefore, this study aimed to evaluate the feasibility of a patient self-reported follow-up model of care for radiation oncology that was opportunistically introduced during COVID.

Methods This was a cross-sectional clinical practice study set in Wollongong, Australia. Patients on radiation oncology follow-up care were sent an unannounced text message with a weblink to a survey to self-report their health before their radiation oncology telehealth appointment. Radiation oncologists completed the same set of questions during or within a day of the telehealth follow-up consultation. Descriptive statistics were analysed to evaluate the uptake of self-reporting. Percent agreement and Cohen's Kappa were used to determine patient-clinician agreement.

Results A moderate response rate of 62% was achieved from the 142 patients. Percent agreement between the patient reported and the clinician-reported for weight change, appetite, physical performance, side effects was acceptable (>75%). However, percent agreement was moderate for pain and sleep. For most items, Cohen's Kappa indicated moderate agreement, with pain, side effects, and recurrence being fair. Patients were more likely to report themselves worse than the clinician for all items, except for side effects.

Conclusion Based on the findings of this study, a standalone patient-reported follow-up model of care is not feasible due to the lower than ideal response rate and fair to moderate patient-clinician agreement. However, we show the importance of capturing the patient perspective for radiation oncology follow-up care as complementary information for clinicians prior to telehealth consultations. Patient-reported information could triage phone consultation from a standard to a long consultation or triage patients requiring physical consultation and immediate attention. With further research, patients self-reporting before their telehealth consultation holds promise for future models of follow-up care, particularly for rural and remote patients and during pandemics and other disasters where clinic attendance is not possible.

6.2 Introduction

Patients who complete active cancer treatment require ongoing follow-up care to manage ongoing and late side effects, monitor recurrence and provide psychosocial care (19–21). When the novel SARS-CoV-2 2019 virus caused the COVID-19 pandemic, health services were forced to rapidly change how they delivered cancer follow-up care. There was a need to minimise cancer patients' exposure to the virus, as they were twice as likely to die from the first variant of COVID-19 than the general population (282). The American Medical Association encouraged the use of telehealth and technology (283), and Cancer Australia recommended that hospitals minimise outpatient visits and find alternative methods to deliver care (284).

In Australia, telehealth substituted face-to-face follow-up consultations and provided a means to continue care and maintain the safety of both patients and healthcare workers during the pandemic (285). When faced with restrictions, a regional hospital in Australia saw the COVID-19 pandemic as an opportunity to adopt new healthcare innovations, harness existing online health technologies, and explore alternative follow-up models of care as recommended by Cancer Australia (284). An alternative follow-up model of care considered was the use of patients' self-reporting, also known as Patient Reported Outcomes (PROs) (286).

PROs are defined as a measurement based on any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else (287). PROs can be measured in absolute terms, such as a pain rating scale of zero to 10, or changes in reported nausea (288). The collection of PROs in cancer care has become an important and frequent clinical practice activity to understand the impact of the disease on the patient and develop appropriate support and screening measures (226,289,290). However, whilst there has been a proliferation of validated PRO tools used in cancer care (277,291–293), there is no gold standard for measuring PROs in radiation oncology follow-up care (294,295).

As per the definition above, a PRO is without amendment or interpretation by the clinician. However, when the clinician interprets the PRO, it is often not well understood because of insufficient data or lack of experience or clinical understanding (296). Additionally, some clinicians are sceptical of the role PROs play and whether the information reported represents their patient's current situation (297). Patient-reported responses are subject to social and environmental conditions (297), individual motivation, interpretation of the questions, expectations and personality (298), and clinicians should not rely on PROs data to fully represent a patient's experience or condition (297). Clear and meaningful interpretation of patient-reported outcome scores is fundamental to their use (296).

In recent years, the ability to electronically collect, report and use PRO data in cancer care has become increasingly important (299); however, inadequate health technology and poor integration of PROs with hospital electronic medical records are barriers to its integration (300). The internet has been increasingly leveraged to enable and enhance supportive care services for cancer survivors, using websites, support groups and a broad range of mobile applications to collect patient-reported outcomes (301,302). Web-based technology has allowed patients to self-report their health, screen patients and reduce hospital admissions (226). In addition, there is growing recognition that combining health technology with good measurement properties and shorter instruments could be more user-friendly and facilitate better translation of research into clinical practice (303).

Despite the barriers to interpreting and collecting PROs, there are many advantages to using PROs during COVID-19 including: monitoring the clinical trend of symptoms and side effects; prevention of the occurrence of severe adverse events; efficient screening of patients who need further phone assistance or direct medical intervention; prompt management of medical needs; positive psychological impact on patients; and increased patient satisfaction with health care services (286).

Understanding the discordance of the PRO information is essential to help interpret the data and support clinical care remotely during a pandemic or in other circumstances where access to care is impeded, such as living in rural or remote areas. Given the change and limited access to radiation oncology follow-up consultations due to hospital restrictions during COVID-19, this study aimed to evaluate the feasibility of a rapidly deployed patient self-reported follow-up model of care for radiation oncology. The objectives were to a) develop a set of patient-reported questions specific to radiation oncology follow-up consultations, b) evaluate patients' ability to self-report their current health status via an unannounced text message, c) determine the level of agreement between patient self-report and clinician assessment.

6.3 Methods

This study was a cross-sectional clinical practice study conducted at the Wollongong hospital, Australia. Radiation oncology was selected as the service was familiar with and had implemented the web-based health technology to collect patient-reported outcomes to screen patients commencing treatment. Ethics approval from the Joint University of Wollongong and Illawarra Shoalhaven Local Health District’s Health and Medical Human Research Ethics committee (2020/ETH01427).

Sample

This study used a convenience sample. Patients were eligible if they were scheduled for a radiation oncology follow-up telehealth consultation between June and September 2020 in the Oncology Information System (OIS - MOSAIQ®). The end date coincided with the announced cessation of the Australian Government's funding for telehealth consultations, even though this was subsequently extended. The sample size target was a minimum of 32 sets of patient-clinician data (304). Patients were not recruited or provided any training, reflecting real-time clinical practice.

Web-based technology

Web-based technologies are important as they allow patients to complete a survey online in their own time and have them subsequently transferred into the patient's oncological medical record. The information technology infrastructure (PROsaiq®) (227) consists of a webserver that uses the surveys existing within the OIS to produce a webpage in Xform format with a specific Uniform Resource Locator (URL) that can be shared. The webform contains placeholders for patient identifiers and survey assessment items. When the form is submitted, the webserver alters the returned survey from a JavaScript Object Notation (JSON) format into HL7 format and imports it into the OIS through the usual HL7 gateway. The submitted answers are stored and appear as if the survey had been completed entirely within the OIS.

The PROsaiq platform was specifically designed to obtain PRO data from patients during their cancer journey. The system has been trialled for collecting quality of life-based patient-reported outcomes and deemed feasible in terms of use (226,272). For this study, the system was piloted for one month to monitor the condition of data being returned; no changes were required to the assessment or process. The PROsaiq platform acts only as a server of empty forms and a converter of returned forms; it does not store patient data, and deliberately cleans RAM after completing data conversion and transfer.

Tool development

At the time of writing, the hospital cancer centre used validated tools to collect PROs to screen radiotherapy patients commencing treatment and review patients on active treatment (Distress Thermometer, Problem Checklist, Edmonton Symptoms Assessment scale, Common Terminology Criteria for Adverse Events). As no specific tool that addressed radiation oncology follow-up consultations was available, a patient questionnaire that reflected standard questions addressed and recorded in follow-up consultations was developed after extensive consultation with radiation oncologists across two cancer centres. In addition to this, a document review of a sample of 20 follow-up consultation letters from radiation oncologists to general practitioners was performed to ascertain the most frequently documented items during a follow-up consultation. The questions were developed to be broad and relevant to all tumours, with plans to individualise based on tumour groups, pending the results of this study.

The final clinical assessment included performance level, sleep, appetite, weight, pain, side effects and recurrence (see Table 14). When the patients selected the weblink from the text message, it took them to the survey. Patients were asked the specific questions shown in Table 14, for example, "Are you eating well?". In contrast, the clinician was only prompted by a single word for that assessment area, for example, 'Appetite'. The reporting scales were the same for both the patient and the radiation oncologist.

Table 14. Clinician and patient assessment questions

Clinician Prompt	Patient Question	Scale (both clinician and patient)
NA	Please enter your name Please enter your Medical Record Number (it is in the text message and your appointment care). Please enter your date of birth	-
ECOG	How well are you moving about?	0. I am fully active, able to carry on all pre-disease performance without restriction 1. I am restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work. 2. I am ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours 3. I am capable of only limited selfcare; confined to bed or chair more than 50% of waking hours 4. I am completely disabled; cannot carry on any selfcare; totally confined to bed or chair
Appetite	Are you eating well?	0. My appetite is normal for me 1. My appetite is decreased but I am able to eat 2. I am hungry, but I experience difficulty with eating 3. My appetite is poor; I have no interest in eating 4. I am unable to eat
Weight change	Has your weight been stable?	0. No 1. Yes
Pain	Have you had any treatment related pain in the last 24 hours?	0. No pain 1. Between no and mild pain 2. Mild pain 3. Between mild and moderate pain 4. Moderate pain 5. Between moderate and severe pain 6. Severe pain 7. Between severe and very severe pain 8. Very severe pain 9. Between very severe and worst possible pain 10. Worst possible pain

Clinician Prompt	Patient Question	Scale (both clinician and patient)
Sleep	Apart from going to the toilet, are you sleeping well?	0. I am able to sleep through the night without awakening 1. I awaken less than 2 times per night 2. I awaken more than 2 times per night 3. I am unable to sleep throughout the night
Side-effects	Do you have any treatment related side-effects?	0. No, I have no treatment related side-effects present 1. Yes, I have treatment related side effects present
Recurrence	Are you worried your cancer has returned?	0. No, I do not think my cancer has returned 1. Yes, I do think that my cancer has returned
NA	If you have a message for your doctor or the team, please write here:	*Free text*

Data collection

Patients: A list of radiation oncology patients scheduled for their follow-up telehealth consultation was extracted from the OIS. Using the Telstra TIM messaging system[1] via email, the patient's mobile number was entered, and they were sent the following personalised message with the link to the assessment the day before their scheduled telehealth consultation (see Figure 9).

Hello Jane, Dr x team here. Please complete this survey about your health before your telehealth appointment tomorrow. Your medical record number to enter is:123456. If unable - do not worry. www.health.nsw.gov.au/prosaiq.xxxx

Figure 9. Personalised text message to a patient

The initial text message was sent unannounced, that is, without pre-warning the patient or providing the patient with training. If the patient opened and completed the survey, the data from the completed clinical assessment was sent from the patient's mobile phone into the hospital's OIS via a secure webserver. The PROsaiq system also included a module to monitor rejected incoming assessments to allow for manual

---

[1] Telstra Integrated Messaging (https://tim.telstra.com/)

correction of contained errors, for example, incorrect spelling of the surname, switching of first and last names, or incorrect medical record number. The first author monitored this portal daily.

Radiation oncologists: were provided with a list of patients sent the clinical assessment prior to their clinic to remind them to enter the data at that point in time. During the radiation oncology telehealth follow-up consultation, the clinician-reported data were entered directly into the OIS as standard practice so that the record contained two sets of the same survey (that is, patient and clinician). When clinical needs interfered, some data was entered retrospectively based on the patient's progress notes; how much was entered retrospectively cannot be ascertained. To ensure that the patient's self-report data did not influence the oncologist's assessment, the oncologist was unaware of where the patient's entered data was located.

Data analysis

The response rate and identified errors will evaluate patients' ability to self-report via a text message. A response rate of 60% (305) is deemed an acceptable level for researchers. In addition, analysing the patient-reported and clinician-reported data provides evidence to understand if the information reported can be used to support follow-up care when patients are unable to access 'usual care' (i.e. face to face consultations, pre/post-pandemic).

To minimise errors associated with manual data transfer, the patient self-reported data and the clinician-reported data were extracted separately from the OIS, copied and pasted into the same Microsoft Excel spreadsheet for analysis. The patient and clinician data were matched using the patient's medical record number, and de-identified. Typically, percent agreement and kappa should be calculated if there are four or fewer discrete ratings (306). Therefore, percent agreement and Cohen's Kappa were used to analyse the patient-clinician agreement. Percent of agreement is the simplest measure of inter-rater agreement, with values >75% demonstrating an acceptable level of agreement (306). Cohen's Kappa is a more rigorous measure of the level of agreement, as it is a measure of agreement in excess of chance and interpreted as: <0.00 as poor, 0.00-0.20 slight, 0.21-0.40 fair, 0.41-0.60 moderate, 0.61-0.80 substantial, and 0.81-0.99 as almost perfect agreement (306). If chance agreement is high, then the percentage of absolute agreement will overstate how much agreement occurred (306).

6.4 Results

A total of 167 patients were extracted from the OIS. Fifteen percent (n=25) did not have a mobile phone number and were therefore ineligible. The average age of the excluded patients without a mobile number recorded was 84 years (range 77 to 91 years); the average age of patients with a mobile number recorded was 71 years (range 24 to 92 years).

Of the 142 eligible patients, the response rate was 62% (n=88). There was no significant difference in age for patients who could self-report via text message (average age 70 years) compared to those who did not send back (average age 71). Twenty-two females were sent text messages, compared to 120 males. This difference in male and female samples resulted from the radiation oncologists that primarily treated prostate cancer having scheduled clinics on the days selected for this research, which was unknown to the research team when the sampling strategy was created and performed.

Despite the lower number of females, their response to self-reporting was slightly higher (68%, n=16) than males (60%, n=67). There were seven errors where the patient either entered a letter in their surname incorrectly or the wrong number for their medical record number; this was manually corrected. In addition, there were five instances where there was no data from the clinician due to late cancellation, no show or clinician unavailability; this resulted in a study population of 83 patient-clinician matched datasets. Patient characteristics, shown in Table 15, present that the sample comprised more prostate cancer and head and neck cancer patients, and 70% of the sample was aged between 60 and 79.

Table 15. Patient self-report characteristics

	Head/ Neck		**Lung**		**Pelvis**		**Prostate**	**Breast**	
Age group	M		M	F	M	F	M	F	Total
40-49	3								**3**
50-59	11						2		**13**
60-69	7		4	3		3	9	2	**28**
70-79	4	1	1				21	2	**29**
80-89	1	2	1		1	1	3		**9**
>90							1		**1**
Total	**29**		**9**		**5**		**36**	**4**	**83**

Figure 10 and Table 16 presents that of the 83 patient-clinician matched datasets, there was acceptable percent agreement for most items: performance status (ECOG), appetite, weight, side effects and recurrence; with pain and sleep below the 75% threshold for acceptability. The Cohen's Kappa accounted for chance, with many items resulting in moderate agreement: ECOG, appetite, weight and side effects. Similar to the percent agreement results, sleep and pain were below an acceptable level of agreement with Kappa being fair. Despite having a high percent agreement (83%), the item for recurrence had the lowest Kappa of 0.230, and this result was not significant.

For all variables, excluding side effects, the patient self-reported their condition as poorer than the clinician-reported (see Appendix E). Sleep had the largest variance of reporting, with 37 patients reporting their sleep as being poorer than what the clinician reported. Pain was also scored as being worse by the patient on 24 occasions (15 out of the 24 occasions where the clinician rated the patients' pain lower, the variance was by one point). For the treatment-related side-effects variable, four patients reported that they had side effects when the clinician reported nil. Conversely, there were 12 occasions when the patient reported nil side effects, and the clinician reported that side effects were present.

Table 16. Patient-clinician agreement

	Percent agreement	Kappa (p)
Physical performance (ECOG)	90%	0.508 (<.001)
Appetite	85%	0.473 (<.001)
Weight change	85%	0.458 (<.001)
Sleep	52%	0.303 (<.001)
Pain	64%	0.303 (<.001)
Side effects	76%	0.460 (<.001)
Cancer recurrence	83%	0.230 (<.012)

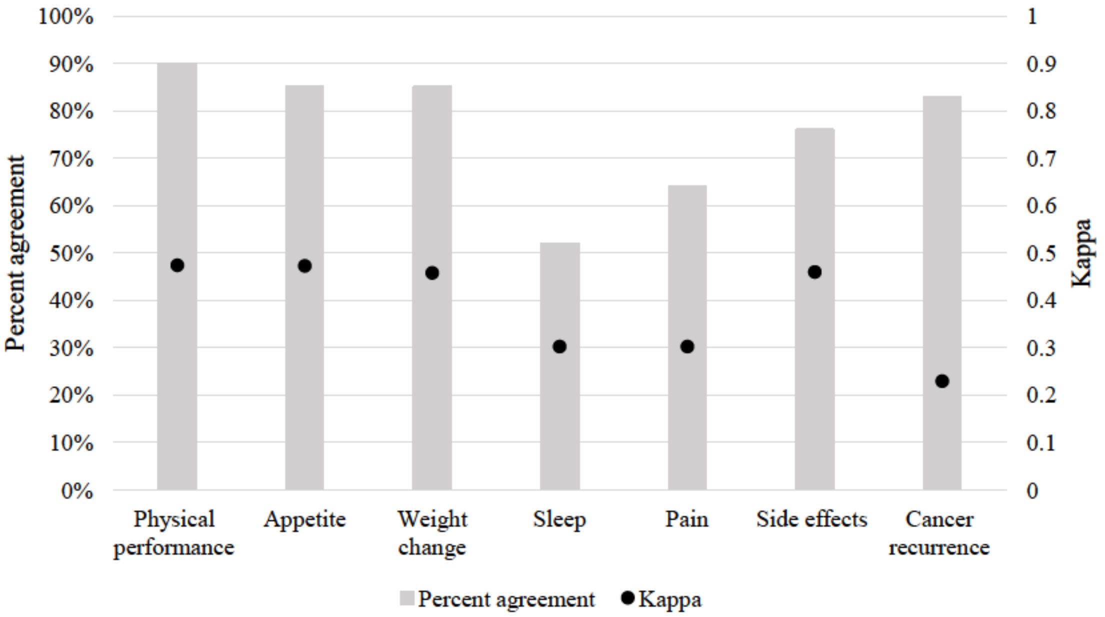


Figure 10. Level of patient-clinician agreement

6.5 Discussion

This study rapidly implemented innovative health technology for cancer follow-up patients invoked by the COVID-19 restrictions. The feasibility of using text messages for cancer patients to self-report during their follow-up period is good, and the patient-clinician level of agreement is fair to moderate. Our results are consistent with other studies, where patients were more likely to score themselves as being more impacted than clinicians' ratings for disease severity, physical performance, pain and quality of life (307–309). Although this study found a fair to moderate patient-clinician agreement, the questions were broad and not specific to individual tumours. However, a study that was individualised to breast cancer treated with radiotherapy also found low to poor patient-clinician concordance (for example, breast hardness, shrinkage, and veins) (310).

The response rate of 62% was above the target goal of 60% for researchers (305). However, our response rate is lower than two other studies that asked patients to self-report their health (311,312). The noticeable was that the other two study's participants were recruited and willing to be involved. In contrast, our study provided no notice, recruitment or training to the patients due to COVID-19 and the rapid changes to health service delivery, reflecting real-time clinical practice.

While the overall agreement between patient-clinicians was measured as 'Fair' to ' Moderate', the value of each assessment is not equally important or valuable. The discordance between patients and clinicians is known to be substantial for pain scales (313) since the patient evaluation is based on perception. In contrast, the clinician's assessment includes patient language, sleeping, activity levels and pain relief use. Some of the variance in scores, specifically for pain, could be attributed to the time frame between when the patient self-reported and when the clinician entered the data during the consultation; this time frame was usually 24 hours in advance, with some minor variation due to changes in consultation time. The assessments of performance status, appetite and weight change are based on more discrete and substantive parameters. These findings are similar to a systematic review that sought to find the association of clinician-reported common toxicity scales (such as those used in this study) against patient-reported outcomes of the same toxicity items, which found there was poor to moderate association (314).

Some of the lack of agreement in sleep is understandable and demonstrates the need for slower implementation. The patient assessment asked the question, “Apart from going to the toilet, are you sleeping well?”, while the OIS assessment for the clinician simply stated the word “Sleep”. Given that most patients had a prostate cancer diagnosis with a reasonable frequency of prostatism symptoms in this group, this difference in wording is likely to produce a variance in answers between patient and clinician. The analysis of level of agreement should therefore downplay the influence of pain and sleep. The fair correlation of cancer recurrence belies its importance in the dialogue between patient and clinician, identifying and addressing the patient's real concerns. While these assessments are very broad, their use by the patient to identify real clinical concerns can allow the clinician to focus on these issues.

Clinicians were more likely to score the patient as having treatment-related side effects when the patient reported that they had no side effects. There is no qualitative data to understand further why the clinicians were more likely to report that the patients had treatment-related side effects. However, it is hypothesised that during the telehealth consultation, the clinician asked additional questions about the patient's health and well-being specific to their cancer type (breast, colorectal, prostate, lung, etc.) where there are other toxicities to monitor, such as skin irritation, fatigue, dysuria, cosmesis, telangiectasia, proctitis and so on. Given that the number of questions was kept to a minimum to prevent survey fatigue, there is scope to individualise the questions to the different cancer types to ascertain individualised patient information.

While the text message to the patient was manually prepared in this setting, the automatic sequencing, preparation and sending of these messages is imminently achievable within the existing PROsaiq system and would allow for more frequent and variable contact.

Limitations

The moderate response rate shows that surveys delivered by text message are acceptable for many patients; however, the study did not explore the reasons for the 38% of patients that did not respond. Possible causes for not responding are that patients do not own a smart device, the text size was too small for the phone survey, or patients may have had difficulty reading and interpreting the questions from a health literacy level. Some patients may not have been able to enter their medical record number that was provided in the text message into the survey. Since this study, PROsaiq now has been enhanced with a module that generates a URL link with a hashed identifier specific for the patient in question so that the patient does not need to add identifying information that might need manual review.

It is acknowledged that the reporting timeframe may be a factor to consider, as the pain that a patient reports 24 hours before the telehealth appointment can change quickly. However, reporting in advance would allow the patient to be triaged, and support put in place before the consultation. Additionally, responses may not be directly related to their cancer follow-up or radiation oncology toxicities, especially if the patient had concurrent treatment or other comorbidities.

Strengths

A text message-based survey administered via weblink may offer a convenient and reliable method of measuring patient-reported outcomes, particularly for weight change, appetite, physical function and side effects, and allow clinicians to triage radiation oncology patients to earlier telehealth or face-to-face appointments for clinical review.

Future implications

To better assist clinicians in supporting their patients long-term and remotely, future research should systematically correlate clinician-reported and patient-reported data and qualitatively review patient preference for clinical interaction use of text messages. Once the discordance is known, the data from the patient ratings can be interpreted with more knowledge to assist the patient better. It would be beneficial to analyse results on other demographic data, such as gender. In addition, expansion to tumour-specific items is suggested, such as breast, prostate, and colorectal, as clinical questions would be more specific and potentially reduce the disparity of patient-clinician report of side effects.

6.6 Conclusion

Oncologists needed to balance the logistics of the healthcare service and patient care during COVID-19. This study showed that rapid implementation of this existing technology (PROsaiq) has benefited in catering for rapidly changing needs in follow-up cancer care. The lower than ideal response rate and fair to moderate patient-clinician agreement found in this study means that the results of this study alone cannot say that a standalone patient self-reported follow-up model of care is feasible. However, we recognise the importance of capturing the patient perspective for radiation oncology follow-up care as complementary information for clinicians prior to telehealth consultations.

Outside of the COVID-19 global pandemic, patients' self-reporting for their follow-up care can provide useful information to clinicians. Instead, this information could efficiently screen patients who need further phone assistance or direct medical intervention**.** Patients' self-reporting before their telehealth consultation holds promise for future models of follow-up care, particularly for rural and remote patients, and during pandemics and other disasters where clinic attendance is not possible.

CHAPTER 7: Concordance between general practitioners and radiation oncologists for cancer follow-up care

Chapter overview

This chapter addresses Objective 5 of this thesis: To test the model and determine the concordance in clinical data between GPs and oncologists completing the follow-up clinical assessment in the radiation oncology setting.

Findings from this study were published in the International Journal of Environmental Research and Public Health (IJERPH). The IJERPH is Q1 journal and has an impact factor of 4.6.

Citations:

Sandell T, Miller A, Schütze H. Concordance between general practitioners and radiation oncologists for cancer follow-up care, International Journal of Environmental Research and Public Health, January 2023

7.1 Abstract

Background Patients treated with radiotherapy require follow-up care to detect and treat acute and late side effects, and to monitor for recurrence. The increasing demand for follow-up care poses a challenge for specialists and general practitioners. There is a perception that general practitioners do not have the specialised knowledge of treatment side effects and how to manage these. Knowing the concordance between general practitioner and oncologist clinical assessments can improve confidence in healthcare professionals. This study aimed to measure the level of agreement between general practitioners and radiation oncologists using a standardised clinical assessment.

Methods A cross-sectional clinical practice study; sample aim of 20 breast, prostate or colorectal patients, three years post-radiotherapy treatment; their general practitioner and radiation oncologist.

Results There was acceptable percent agreement (>75%) and a moderate to almost perfect agreement (Fleiss kappa) for all variables between the 15 general practitioner-radiation oncologist dyads.

Conclusion The general practitioner and radiation oncologist concordance of a clinical follow-up assessment for radiation oncology patients is an important finding. These results can reassure both general practitioners and oncologists that general practitioners can provide cancer follow-up care. However, further studies are warranted to confirm the findings and improve reassurance for health professionals.

7.2 Introduction

Patients treated with radiotherapy require follow-up care to detect and treat acute, consequential and late side effects specific to radiotherapy, and monitor for recurrence (315). Acute side effects generally occur during treatment, persist up to a few weeks after treatment, and usually involve intermitotic cells (skin and mucosa). Consequential side effects occur when acute complications persist for longer durations and cause persistent damage (316), whereas late side effects emerge months to years after radiotherapy treatment and usually involve postmitotic cells (liver, kidney, heart, muscle and bone) (315). The most common follow-up model of care to manage these side effects is the specialist-led model, where the radiation oncologist oversees the care, usually in a hospital setting. However, improved screening, earlier detection and increased incidence of cancer have led to an increased demand for cancer-related services (56) and, subsequently, follow-up care (317). This increase in the demand for follow-up care poses a challenge to specialists and general practitioners to provide optimal follow-up care (258).

It has been recommended that general practitioners take a greater role in cancer follow-up care (60,318,319) in the form of shared care. Shared care is a collaborative process through which different professional groups work together to improve health care quality (320), in this case, the patient’s general practitioner and oncologist. The evidence for the benefits of shared cancer follow-up models of care is growing (51,120,185,187), with randomised controlled trials finding no difference in recurrence or quality of life when a general practitioner is involved in cancer follow-up care compared to an oncologist (95,119,188,189). Yet, there are still barriers to implementing shared cancer follow-up care into practice.

A systematic review examined the factors that influence the translation of shared cancer care into practice (321) and found that general practitioners were willing to take a greater role in cancer follow-up care, however, general practitioners sought specific follow-up clinical management guidelines to support them, which were based on best practice and preferably written by oncologists. The follow-up assessments could be in the form of a printable checklist or validated instruments and would reassure general practitioners that they are addressing aspects critical for the particular patients’ care (121,200,206,220). However, some oncologists felt that general practitioners did not have the specialised knowledge of specific treatment side effects and how to manage the side effects (97,213,215), thus posing a barrier in the move to shared cancer follow-up care.

Establishing concordance between health professionals is important as models of care adapt to the ever-changing demands of optimal patient management. However, there is limited research on the concordance (or discordance) of general practitioners and specialists in healthcare. It is important to understand the concordance to improve general practitioner confidence in providing follow-up care and reduce oncologists' hesitancy to transfer some aspects of care for low-risk patients. Therefore, this study aimed to create a standardised follow-up clinical assessment for general practitioners and radiation oncologists to use on patients previously treated with radiotherapy and measure the level of agreement between general practitioners and radiation oncologists. To our knowledge, this is the first study of its kind.

7.3 Methods

This was a cross-sectional clinical practice study at the Illawarra Cancer Care Centre (regional) and the Shoalhaven Cancer Care Centre (rural), Australia. The radiation oncology services within these centres were familiar with a web-based health technology and had an existing system that could be integrated into the primary care setting. Ethics approval was received from the Joint University of Wollongong and the Illawarra Shoalhaven Local Health District Human Research Ethics Committee (2020/ETH00301). A detailed protocol is available (3); the trial was registered with the Australian New Zealand Clinical Trials Registry on 20 October 2020, ACTRN12620001083987.

Sample and Recruitment

Patients were eligible if they were scheduled for a radiation oncology follow-up consultation in 2021 and were three years post-radiotherapy treatment for breast, colorectal or prostate cancer. We purposely selected three years post-radiotherapy as it was expected that patients would have fewer toxicity issues. Radiation oncologists selected patients from their follow-up clinic list that they believed would suit a shared cancer follow-up model of care based on clinical considerations, including treatment type, prescription, and cancer staging.

The sample was taken from the overarching study with a recruitment aim of 20 patients. Patients were sent a participant information sheet informing them about the study aims, processes and inviting them to participate. Once patients consented in writing, their general practitioner was invited to participate.

General Practitioner Training

All general practitioners were visited by a radiation oncologist who provided a demonstration of how to access and complete the follow-up clinical assessment. In addition to this, the research team designed a training program that was approved for continuing professional development points. The training program included information on radiation oncology side effects and management, with a video demonstration on conducting a clinical assessment.

Web-Based Technology

The hospital's PROsaiq® platform (227) was used to administer clinical assessments between oncologists and general practice via HealthPathways (described further below). PROsaiq consists of a webserver that uses the clinical assessments existing within the Oncology Information System (OIS), to produce a webpage in Xform format with a specific Uniform Resource Locator (URL) that can be shared. The webform contains placeholders for patient identifiers and survey assessment items. When the form is submitted, the webserver alters the returned survey from a JavaScript Object Notation (JSON) format into HL7 format and imports it into the OIS through the usual HL7 gateway. The submitted answers are stored and appear as if the survey had been completed entirely within the OIS. The PROsaiq system also included a module to monitor rejected incoming assessments to allow for manual correction of contained errors, for example, incorrect spelling of the surname, switching of first and last names, or incorrect medical record number. The first author monitored this portal.

The system was trialed for collecting quality of life-based patient-reported outcomes and deemed feasible in terms of use (226,272). The PROsaiq platform acts only as a server of empty forms and a converter of returned forms, not storing any patient data and deliberately cleaning RAM after the completion of conversion and transfer.

Tool Development

At the time of writing, the cancer centres had an internal Dashboard system using PROsaiq that linked directly to the OIS for follow-up consultations. This allowed for the follow-up process to be streamlined internally. The assessments were compiled internally at the Illawarra Shoalhaven Local Health District for follow-up of radiotherapy patients and were based on current practice. These clinical assessments review physical items on a scale from 0 to 3 or 4 (see Table 17) for items specific to radiotherapy follow-up care, such as pain, fatigue, physical performance, bowel issues, urinary issues, and appetite. The included scales were sourced from the Radiation Therapy Oncology Group scales (276) and the Common Terminology Criteria for Adverse Events, version 3.0 (226,272). Table 18 displays the items that apply for breast, prostate and colorectal follow-up care.

Table 17. Clinical assessment items and grading scale

Clinical Assessment Item	Grade
Appetite	0. Normal 1. Decreased, able to eat 2. Hunger, but experiences difficulty with eating 3. Poor, no interest in eating 4. Unable to eat
Chest and breast pain CTCAE 5.0	0. None 1. Mild pain 2. Moderate pain; limiting instrumental activities of daily living (ADL) 3. Severe pain; limiting self care ADL
Diarrhea CTCAE 5.0	0. None 1. Increase of <4 stools per day over baseline; mild increase in ostomy output compared to baseline 2. increase of 4–6 stools per day over baseline; moderate increase in ostomy output compared to baseline; limiting instrumental ADL 3. increase of >=7 stools per day over baseline; hospitalization indicated; severe increase in ostomy output compared to baseline; limiting self care ADL
Dysuria CTCAE 5.0	0. None 1. mild symptoms requiring no intervention 2. symptoms relieved with therapy 3. symptoms not relieved despite therapy
Physical performance ECOG	0. Fully active, able to carry on all pre-disease performance without restriction 1. Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work 2. Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours 3. Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours 4. Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
Erectile dysfunction CTCAE 5.0	0. None 1. Decrease in erectile function, intervention not needed 2. Decrease in erectile function, erectile intervention indicated 3. Decrease in erectile function, erectile intervention not helpful
Fatigue CTCAE 5.0	0. None 1. Fatigue relieved by rest 2. Fatigue not relieved by rest; limiting instrumental ADL 3. Fatigue not relieved by rest, limiting self care ADL
Lymphedema-related fibrosis CTCAE 3.0	0. None 1. minimal to moderate redundant soft tissue that was unresponsive to elevation or compression and that was also firm or spongy 2. Marked increase in density and firmness, with or without tethering 3. Very marked density and firmness with tethering affecting ≥40% of the edematous area
Pelvic pain CTCAE 5.0	0. None 1. Mild pain 2. Moderate pain; limiting instrumental ADL 3. Severe pain; limiting self care ADL
Proctitis CTCAE 5.0	0. None 1. Rectal discomfort, intervention not indicated 2. Symptomatic (e.g., rectal discomfort, passing blood or mucus); medical intervention indicated; limiting instrumental ADL 3. Severe symptoms; fecal urgency or stool incontinence; limiting self care ADL 4. Life-threatening consequences; urgent intervention indicated

Clinical Assessment Item		Grade
Rectal hemorrhage CTCAE 5.0	0.	None
	1.	Mild symptoms; intervention not indicated
	2.	Moderate symptoms; intervention indicated
	3.	Transfusion indicated; invasive intervention indicated; hospitalization
	4.	Life-threatening consequences; urgent intervention indicated
Telangiectasia RTOG	0.	None
	1.	Slight atrophy, pigmentation change, some hair loss
	2.	Patchy atrophy, moderate telangiectasia, total hair loss
	3.	Marked atrophy, gross telangiectasia
	4.	Ulceration
Vomiting CTC	0.	None
	1.	1 episode in 24 h
	2.	2–5 episodes in 24 h
	3.	$\geq$6 episodes in 24 h over pretreatment; or need for IV fluids
	4.	requiring parenteral nutrition; or physiologic consequences requiring intensive care
Weight loss (RTOG)	0.	<5.0%5.0–9.9%, intervention not indicated
	1.	10.0–19.9%, nutritional support indicated
	2.	>=20.0%, tube feeding or TPN indicated

Table 18. Radiation oncology follow-up standardised clinical assessment

Tumour Type	Clinical Assessment
Breast	Fatigue, ECOG (Eastern Cooperative Oncology Group) Performance Status, appetite, weight loss, chest and breast pain, telangiectasia, lymphedema-related fibrosis, and disease state (i.e., local, regional, or distant)
Colorectal	Fatigue, ECOG Performance Status, appetite, weight loss, proctitis, pelvic pain, vomiting, and diarrhea
Prostate	Fatigue, ECOG Performance Status, erectile dysfunction, dysuria, and rectal hemorrhage

Data Collection

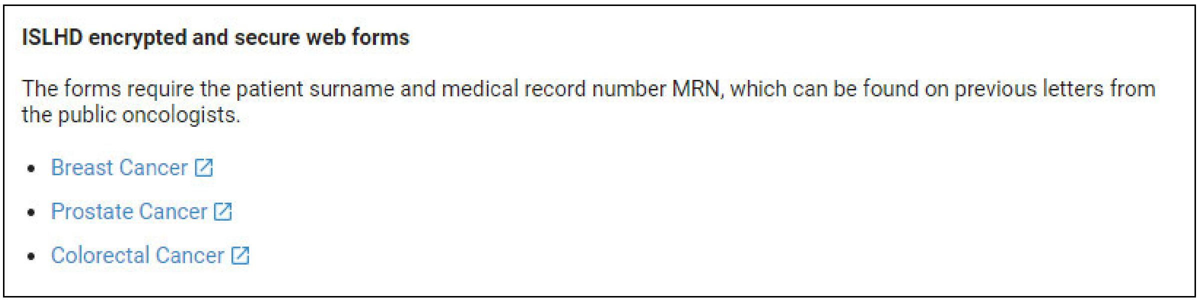
Radiation oncologist data

Patients attended their standard scheduled radiation oncology follow-up appointment with their radiation oncologist. The radiation oncologists were provided with a list of patients before their clinic to remind them to enter the data at that point in time, instead of retrospectively. The radiation oncologist entered the clinical assessment data directly into Oncology Information System (OIS: MOSAIQ®) as part of their standard consultation practice.

General practitioner data

The patient was requested to visit their general practitioner the day before, the day of, or the day after their radiation oncologist follow-up appointment. This was to try and reflect contemporaneous results for the clinical assessments. The general practitioner accessed the clinical assessment via HealthPathways. HealthPathways is a web-based information portal being implemented in New Zealand, Australia, and the United Kingdom to help general practitioners make assessment, management, and specialist request decisions. Each 'pathway' is an agreement between the primary and specialist services, it is developed by specialists or hospital staff and is reviewed and approved by general practitioners.

To access the assessment, the general practitioner would first select the relevant cancer type based on the patient (see Figure 11), enter the patient's name and medical record, and complete the clinical assessment.



ISLHD encrypted and secure web forms

The forms require the patient surname and medical record number MRN, which can be found on previous letters from the public oncologists.

- Breast Cancer
- Prostate Cancer
- Colorectal Cancer

Figure 11. Example of HealthPathways interface and accessing the clinical assessment

Data Analysis

The general practitioner and radiation oncologist data were extracted separately from the OIS, copied and pasted into the same Microsoft Excel spreadsheet for analysis. The data were matched using the patient's medical record number, and de-identified. Percent agreement and Fleiss' Kappa was used to determine the level of agreement of the clinical items outlined in Table 18. A 75–90% per cent agreement demonstrates an acceptable level of agreement (322). Fleiss kappa accounts for chance and is used when the raters are different (four radiation oncologists were the non-unique raters). Fleiss kappa also shows the level of agreement within the variable for each category. Level of agreement is measured from 0 to 1 (slight agreement is <0.20; fair agreement 0.21–0.40; is moderate 0.41–0.60; substantial 0.61–80; and 0.81–1.00 is almost perfect agreement) (323).

7.4 Results

Results were returned on 15 general practitioner-radiation oncologist dyads of data for analysis from the recruited sample of 19 (79%). For participant demographics, see Table 19. Seven dyads were from the Shoalhaven (rural) and eight dyads from the Illawarra (regional); seven were breast cancer patients, seven were prostate patients, and one was a colorectal patient.

Table 19. Participant characteristics

	General Practitioner	**Radiation Oncologist**	**Total**
Sex			
Male	9		
Female	6		
Total	**15**	**4 ***	**19**
Age			
30–39	3	1	**4**
40–49	7	2	**9**
50–59	2	1	**3**
60+	3		**3**
Training			
Australia	6	4	**10**
Overseas	9		**9**
Years practising			
<10 years	3	2	**5**
11–19 years	7	1	**8**
>20 years	5	1	**6**
Most recent oncology training			
2–5 years	3	4	**7**
6–10 years	1		**1**
>10 years	7		**7**
No training	4		**4**

* Due to the potential to identify participants' sex has not been itemised.

The percent agreement between general practitioners and radiation oncologists was above an acceptable level >75% for every variable. The Fleiss kappa ranged from moderate agreement to almost perfect agreement for the variables, see Table 20, and sub analysis by demographic variable was therefore not required.

The clinical items with 100% percent agreement and almost perfect agreement (Fleiss Kappa) were Lymphoedema (all seven patients scored grade 0), recurrence (all seven patients scored grade 0), erectile dysfunction (all seven patients scored grade 3), proctitis and rectal hemorrhage. Fatigue and physical performance had an overall percent level of agreement of 87% and substantial Fleiss Kappa agreement (0.695, 0.0659). General practitioners reported seven patients as experiencing some level of fatigue, and radiation oncologists scored four patients with fatigue. For physical performance, two patients were scored as having some form of physical restriction by the general practitioner, compared to five patients being scored with physical restriction by the radiation oncologist. Appetite and unintended weight change agreement was moderate.

Table 20. Results of level of agreement between general practitioners and radiation oncologists

Tumour	Variable	N	Percent Agreement	Fleiss Multi Rater Kappa	Significance
All	fatigue	15	87%	0.695	0.003
	ECOG	15	87%	0.659	0.011
Breast and colorectal	Appetite	8	88%	0.590	0.095
	Unintended weight change	8	88%	0.590	0.095
Breast	Chest pain	7	100%	1.00	0.008
	Telangiectasia	7	86%	0.712	0.011
	Lymphoedema	7	100%	1.00	0.008
	Recurrence (local, regional, distant)	7	100%	1.00	0.008
Prostate	Erectile dysfunction	7	100%	1.00	0.008
	Proctitis	7	100%	1.00	0.008
	Rectal	7	100%	1.00	0.008
Prostate and colorectal	Dysuria	8	88%	0.590	0.095
Colorectal	Pelvic pain	1	100%	-	-
	Vomiting	1	100%	-	-
	Diarrhea	1	100%	-	-
	Proctitis	1	100%	-	-

7.5 Discussion

There is limited research in understanding the concordance in knowledge, care patterns, and care outcomes between general practitioners and specialists for many health conditions. This knowledge of concordance (or discordance) is important when evaluating the feasibility of new models of care to manage both the clinical load and patients' needs and preferences. For example, a study on the concordance of cardiac right bundle branch block diagnosis between cardiologists and general practitioners had substantial agreement, indicating general practitioners had scope to be more involved (324). However, a study on the diagnosis of skin conditions between general practitioners and dermatologists had moderate agreement, indicating more training was needed if the model was to change (325).

Our study aimed to address two of the barriers to shared cancer follow-up care: the provision of clinical follow-up guidelines; and the perception that general practitioners may lack cancer specific skills and knowledge for shared cancer follow-up care. Our study has demonstrated a moderate to almost perfect agreement between the general practitioner and radiation oncologist completing a prescribed follow-up clinical assessment. The difference in reporting fatigue may be due to the radiation oncologist recording fatigue attributable to radiotherapy treatment from pre-treatment levels, compared to the general practitioner recording general tiredness level. Overall the results indicate general practitioners can adequately assess some aspects of cancer patients during follow-up for radiotherapy side effects and disease recurrence based on a prescribed clinical assessment.

The provision of a follow-up clinical assessment designed by the radiation oncologist is a key component of this research. Studies have suggested the need for specific and localised clinical follow-up guidelines or assessments (121,200). There are a myriad of programs and software utilised across general practice clinics, and therefore the provision of clinical assessments needs to be easily accessible by general practitioners. Using specific follow-up guidelines that oncologists prepare should reassure both the general practitioner and the radiation oncologist that the general practitioner is addressing critical aspects of the patient's care (200,220). Given the moderate to almost perfect agreement we found, these results will be useful to bridge that gap. However, we did not evaluate if using the clinical assessment reassured general practitioners and improved their confidence.

One potential reason that oncologists feel uncertain about general practitioners providing shared follow-up care is that general practitioners rarely contact oncologists unless there is a problem. However, there is an absence in literature regarding general practitioners communicating with oncologists when changes in a patient's overall condition, co-morbidities or concern for recurrence (326). Shared cancer follow-up care requires improved communication channels between general practitioners and oncologists in real-time (215). Our study successfully implemented a system that was easily accessible to general practitioners and allowed them to transfer the consultation results back to the radiation oncologist for review in real-time. Thus the radiation oncologist was not only able to maintain involvement in the patient's care but could oversee the care. Although there is good concordance between the general practitioner and radiation oncologist, and the radiation oncologist could review the results from the shared care consultation in real-time, we do not know if this has improved the radiation oncologists' acceptance and the likelihood of engaging in shared care models.

Limitations

This was the first study to our knowledge to evaluate the concordance between general practitioners' and radiation oncologists' clinical assessment in cancer follow-up care. A strength of the study was the use of a predefined protocol to minimise subjective clinical review. The limited sample size, which was partly due to the COVID-19 global pandemic and reduced face-to-face consultations, is acknowledged, and the results should be reviewed with caution. In addition, patients were three years post-treatment as it was expected that they would have fewer toxicity issues (as confirmed by our results), and these results cannot be generalised to patients on active treatment or earlier post-treatment. The reporting timeframe may be a factor to consider, as the level of pain or fatigue that a patient reports may be different in the timeframe between appointments of the radiation oncologist and general practitioner.

Future Implications

Future research should consider larger sample sizes, moving the post-treatment follow-up review to earlier in the follow-up phase, and expanding the assessments available for other cancers. Future research should also explore whether the provision of the clinical assessments resulted in improved general practitioner and radiation oncologist reassurance, and confidence that general practitioners can be involved in shared cancer follow-up model of care, and whether good concordance improves acceptance.

7.6 Conclusion

This study supports general practitioners taking a greater role in cancer follow-up care. Collaborative care between general practitioners and oncologists should be further explored. However, it is recognised that there are challenges to translating available evidence into systems to allow health professionals to work both independently and collaboratively to best meet the needs of patients. Systems for shared cancer follow-up care need to be integrated into both health settings and further development and analysis of specific clinical follow-up assessments. Further research with a larger sample, earlier in the post-treatment phase and qualitative analysis is warranted.

CHAPTER 8: Acceptability of a shared cancer follow-up model of care between general practitioners and radiation oncologists: A qualitative evaluation

Chapter overview

This chapter presents the results from the pre- and post-intervention interviews. This study addresses Objective 6 of this thesis: To evaluate the acceptability of the model to patients, GPs and ROs.

Findings from this study were submitted to a Q1 journal and under review at the time of thesis submission. (This is not the final published version. The final version has been accepted for publication in Health Expectations August 2023).

See Appendix F for a copy of the semi-structured interview guide.

8.1 Abstract

Introduction Facilitators to implement shared cancer follow-up care into clinical practice include mechanisms to allow the oncologist to continue overseeing the care of their patient, two-way information sharing and clear follow-up protocols for general practitioners (GP). This paper aimed to evaluate patients, GPs and radiation oncologists (RO) acceptance of a shared care intervention.

Methods Semi-structured interviews with patients that were three-year post-radiotherapy treatment for breast, colorectal or prostate cancer, their RO, and their GP. Inductive and deductive thematical analysis was employed.

Results Thirty-two participants were interviewed (19 patients, nine GPs and four ROs). Pre-intervention, there was support for GPs to play a greater role in cancer follow-up care, however, patients were concerned about the GPs cancer-specific skills. Patients, GPs and ROs were concerned about increasing the GPs workload. Post-intervention, participants were satisfied that the GPs had the specific skills and that the impact on GP workload was comparable to writing a referral. However, GPs expressed concern about remuneration. GPs and ROs felt the model provided patient choice and was suitable for low-risk, stable patients around two to three years post-treatment. Patients emphasised that they trusted their RO to advise them on the most appropriate follow-up model suited to their individual situation. The overall acceptance for shared care depended on successful health technology to connect the GP and RO. There were no differences in patient acceptance between rural, regional and cancer types. ROs presented differences in acceptance for the different cancer types, with breast cancer strongly supported.

Conclusion Patients, GPs and ROs felt this shared cancer follow-up model of care was acceptable, but only if the RO remained directly involved and the health technology worked. There is a need to review funding and advocate for health technology advances to support integration.

8.2 Introduction

Once cancer patients complete active treatment, they require long-term follow-up care to monitor for treatment-related side effects and recurrence and provide psychosocial support (19–21). The oncologist-led model is the most common and accepted follow-up model of care for cancer survivors in Australia and internationally (79–88). In this model, the oncologist manages patient care and side effects into the survivorship phase, often in a public or private hospital setting (327), and parallel to the care provided by the patient's general practitioner (GP). Although GPs are usually the first point of contact during a cancer diagnosis, GPs play a small or no role in cancer follow-up care and focus on other facets of the patient's health and well-being.

The demand for cancer follow-up care continues to increase globally (56). Subsequently, there is a need to explore and implement alternative models of cancer follow-up care to address sustainability. While the oncologist-led model suits many patients, it may not always meet patients' physical and psychosocial needs (236,237). For some patients, a shared care model might be more appropriate, tailored to their tumour, treatments, locality (metropolitan, regional or rural), access to specialists, and their specific physical and emotional needs and preferences (67). A shared cancer follow-up model of care is distinct from the sole transfer or discharge of care from one provider to another. A shared cancer follow-up model of care harnesses the expertise of various health professionals (113) and involves the explicit sharing of information and coordination of follow-up care (64), usually between a GP and a specialist (for example, surgeon, medical oncologist, haematologist, or radiation oncologist (RO)). For shared care to be truly shared, the GP and the oncologist have to be involved in each episode of care.

Although shared cancer follow-up care is safe in terms of quality of life and cancer recurrence (95,119,188,189), barriers remain to implementing it into clinical practice (321). There is a need for specific follow-up guidelines for GPs (321) and direct communication channels between the GP and the oncologist (215,219) to allow the oncologist to oversee their patient's care. Despite several shared care trials (49,225), no mechanism has been utilised to facilitate the oncologist to remotely oversee care in real-time. Secure health technology solutions to support shared cancer care remain unavailable (224). To address the above issues, we developed a shared cancer follow-up model of care between GPs and ROs (see Figure 12). As part of the intervention, patients attended two cancer follow-up appointments with their general practitioner six months apart. This study aimed to evaluate the acceptability for this shared cancer follow-up model of care among patients, GPs and ROs.

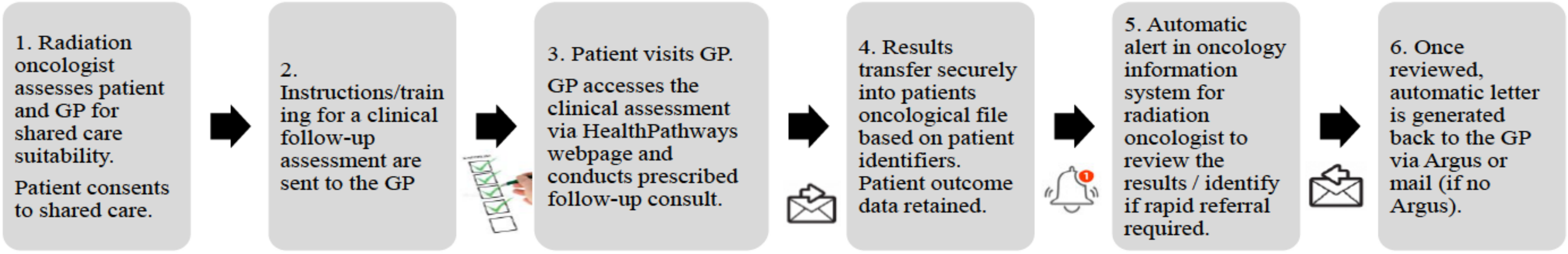


Figure 12. The radiation oncology shared follow-up model of care process

8.3 Methods

Study design and setting

The study design was qualitative, with a critical realism lens. This intervention is part of a larger study described elsewhere (3). The study was conducted at two hospital cancer centres, one regional, Illawarra Cancer Care Centre, and one rural, Shoalhaven Cancer Care Centre, in New South Wales, Australia.

Australia's universal healthcare system, Medicare, provides free services in public hospitals and substantial coverage for other medical services for those who are eligible (citizens, permanent residents, reciprocal agreement visitors). Medicare provides rebates to patients for general practice consultations, however, may not always cover the full fee. Patients in this study did not have to pay at either the hospital cancer centre or their GP.

Participants and recruitment

ROs selected eligible patients from their follow-up clinic list, that were: scheduled for a radiation oncology follow-up consultation in 2021; three years post-radiotherapy treatment; breast, colorectal or prostate cancer; and suited to a shared cancer follow-up model of care based on clinical considerations, including treatment type, prescription, and cancer staging. Patients were sent a Participant Information Sheet outlining the purpose and process of the study and informed that participation was voluntary. Once a patient consented, their GP was invited to participate. All consent was received in writing. The target sample was 20 patients, their RO and GP.

Data collection

Semi-structured interviews were conducted pre- and post-intervention. Interviews were initially conducted face-to-face at a private setting in a mutually agreed location and then changed to telephone due to COVID-19 restrictions. Pre-intervention, participants were asked about their views on the purpose of radiation oncology follow-up care; they were then presented with the shared care model (see Figure 12) and asked their thoughts on the model. Post-intervention, participants were asked about their experience of the shared care model. Interviews were audio-recorded with consent.

Data analysis

Interviews were transcribed verbatim with identifiable data removed and then imported into NVivo version 12 (328) for analysis. Two researchers (TS and HS) coded one-third of the interviews together to create and refine the coding framework. Using a critical realism lens, both inductive and deductive coding was employed, using the Theoretical Framework of Acceptability (TFA) (described further below) as a scaffold for the latter. Following the development of the coding framework, TS coded the remaining interviews, which HS reviewed. Any discrepancies were discussed and resolved by consensus.

A number of steps were taken to increase the rigour. To ensure credibility of the data analysis, researcher triangulation was employed (329) as described above. Once data saturation was thought to have been reached, interviewing continued further to ensure that no new themes arose and that the varied views had been captured (329). Participants were not asked to validate the interpretations of their interviews (a process known as member checking or participant validation) (329), out of respect for the amount of time that they had already afforded the study and taking and because doing so for the pre-intervention interviews could have influenced the intervention. The COREQ-32 checklist was used for reporting the findings.

The TFA is a framework that facilitates the evaluation of health intervention acceptability based on the perceived and lived experience of the health intervention (126). The framework accounts for personal, organisational and other contextual factors that could influence the health intervention and acceptance. The TFA consists of seven constructs to determine overall acceptability (see Table 21).

Table 21. Theoretical Framework of Acceptability constructs (126)

TFA Constructs	Definition
Affective Attitude	How an individual feels about the intervention.
Burden	The perceived amount of effort that is required to participate in the intervention.
Ethicality	The extent to which the intervention has good fit with an individual's value system.
Intervention Coherence	The extent to which the participant understands the intervention and how it works.
Opportunity Costs	The extent to which benefits, profits, or values must be given up to engage in the intervention.
Perceived Effectiveness	The extent to which the intervention is perceived to be likely to achieve its purpose.
Self-efficacy	The participant's confidence that they can perform the behaviour(s) required to participate in the intervention.

Ethics Approval and Trial Registration

Ethics approval was received from the Joint University of Wollongong and Illawarra Shoalhaven Local Health District Human Research Ethics Committee (2020/ETH00301). The trial was registered with the Australian New Zealand Clinical Trials Registry.

8.4 Results

Thirty-two of the 42 participants from the overarching study were recruited for this portion of the study. This included 19 patients, four ROs, and nine GPs. Participant demographics are shown in Table 22 and Table 23. All patients and ROs contacted for interview participated; GP reasons for not participating were due to time constraints. Sixty-four (32 pre and 28 post-intervention) interviews were conducted between February 2021 and February 2022. Average interview length was 16 minutes (range 7-28 minutes).

Table 22. Qualitative study patient demographics

	Regional-Illawarra Cancer Centre		**Rural-Shoalhaven Cancer Centre**		**Total**
	F	M	F	M	
Cancer					
Breast	4		6		**10**
Colorectal				1	**1**
Prostate		8			**8**
Total	**12**		**7**		**19**
Age					
50-59	1		1		**2**
60-69	2	5	3		**10**
70-79	1	1	2		**4**
80-89		2		1	**3**

Table 23. Qualitative study provider demographics

	General practitioner	**Radiation oncologist**	**Total**
Sex			
Male	5		
Female	4		
Total	**9**	**4***	**13**
Age			
30-39	4	1	**5**
40-49	3	2	**5**
50-59		1	**1**
60+	2		**2**
Total	**9**	**4**	**13**
Training			
Australia	4	4	**8**
Overseas	5		**5**
Total	**9**	**4**	**13**
Years practising			
<10 years			
11-20 years	3	2	**5**
>20 years	4	1	**5**
Total	2	1	**3**
	9	**4**	**13**
Most recent oncology training			
<10 years			
10-20 years	3	4	**7**
>20 years	2		**2**
No training	2		**2**
Total	2		**2**
	9	**4**	**13**

* Due to the potential to identify participants' sex has not been itemised.

Thematic analysis

Five major themes were identified: Purpose of follow-up care and views on the current oncologist-led model; intervention coherence and affective attitude; burden and opportunity costs; ethicality and patient suitability; and self-efficacy and perceived effectiveness. These are discussed below.

Purpose of follow-up care and views on the current oncologist-led model of care

This theme relates to participants' views on the purpose of follow-up care and their view of the current oncologist-led model of care.

Participants felt the primary purpose of radiation oncology follow-up care was to manage side effects, monitor for recurrence and to provide reassurance. In addition, ROs highlighted the importance of collecting clinical outcome data to report to the cancer registry and used for research:

> Of course, the last point about collecting clinical data and quality, the data somehow has to be kept in the cancer center so that we can do quality projects and find out about the long-term outcomes. *Pre-intervention interview, RO #2*

Patients, GPs and ROs were positive about the oncologist-led model, highlighting the benefit of easy access to multidisciplinary health professionals, imaging and other equipment:

> … if any other specialty need to be involved or anything needs to be done procedure wise or anything, of course it's readily available. You can kind of do it probably in a better coordinated way because you're connected to the department. *Pre-intervention interview, GP #5*

However, it was acknowledged that there was the possibility of duplication of care, and the oncologist-led model may not suit everyone. While some patients felt more confident seeing a specialist for their follow-up care, others, particularly those who were stable or lived far from the centre, felt it was inconvenient to go to the hospital just to be reassured that everything was okay.

Most patients believed their GP could play a role in their follow-up care as they knew their long-term health status and provided holistic care. However, few GPs stated that they help manage side effects, with most GPs stating they had a limited role in cancer follow-up care, with referrals being their primary responsibility:

> Usually when they come to see me it about another health issue, and not specifically about the cancer, unless it is about a referral. *Pre-intervention interview, GP #9*

Pre-intervention, some patients assumed there was open communication and that information was shared between their GP and RO. The patients were unaware that the Australian Government's

MyHealth Record initiative did not give all health practitioners, including their doctors, access to their medical records.

Intervention coherence and affective attitude

Intervention coherence and affective attitude related to participants understanding of what the intervention involved and how they felt about the intervention.

Patients, GPs and ROs recognised that shared care allowed ROs to focus on new patients, those on active treatment, and those with acute symptoms:

> I'm taking up quite a bit of time. I know it's only 15 minutes or something, but there's thousands of us, and I'll be quite happy to not use their precious time because they've got lots of other far sicker people that they're dealing with. *Pre-intervention interview, Patient #7, breast*

ROs had a good understanding of the evidence to support GPs being involved in shared care and saw it as an opportunity to change their models of care without diminishing the quality of care. Although ROs were supportive, they acknowledged that it was important to ensure that the GP was comfortable and felt adequately supported:

> I suppose the only thing would be making sure that the GP on their end is comfortable with that and making sure that they feel that they're supported enough to take on this role. *Post-intervention interview RO #4*

Although there was good support for the GP to play a greater role in cancer follow-up care, some patients in the pre-intervention interviews questioned their GP's cancer-specific skills. However, both GPs and ROs felt confident in the GP's ability to participate in this shared care model:

> They'll be assessing for side effects, which usually is very minimal, and the side effects haven't really changed that much in the last 20 years [for breast cancer]….therefore I think using primary care physician to help with the follow-up, I think it's a good idea. *Pre-intervention interview, RO #2*

The relationships and continuity of care that existed between patients and their doctors also influenced how participants felt about this shared care model. Patients with a good and longstanding relationship with their GP trusted them and felt positive about the model:

> Just the fact he's been with us for 30 years means that he sort of actually knows how we think, he knows what we've been through… so I trust [my GP] emphatically. *Pre-intervention interview, Patient #8, prostate*

Some patients acknowledged the need to train registrars and balance the demands of hospital resources, however, patients who had little continuity of care with their RO felt more positively about this shared care model:

> …there's a certain detachment. I only ever saw [RO] once... I haven't see the same person twice... But going in each time and getting someone different is a bit daunting whereas having [my GP] is not. *Pre-intervention interview, Patient #6, breast*

The one patient that preferred the oncologist-led model acknowledged their preference was based on the relationship with their RO:

> I guess if I wasn't so happy with [my RO], it may lead me more towards the GP stuff, but because it is so well organised and run in there, I actually don't mind going in there. *Post-intervention interview, Patient #19, prostate*

Burden and opportunity costs

This theme relates to the amount of effort and any sacrifices required to participate in this shared care model.

Pre-intervention, there were mixed views about the extra time demands this shared care model would place on GPs. Patients did not want to add extra work to their GP, GPs were uncertain how much it would impact their workload, and ROs acknowledged this model could be a time burden for GPs:

> I would love it. I think that it's sorely needed but it potentially might be a source of an added burden to their [the GP] already existing schedule, which is full. *Pre-intervention interview, RO #1*

Post-intervention, GPs felt the consultation was similar to a standard clinical review for other chronic health conditions such as diabetes or cardiovascular care. Some GPs stated it took longer than a standard appointment and noted that they spend different amounts of time with patients based on their medical needs. However, most GPs stated that there was no notable time burden, and some likened the time as being similar to writing a referral:

> It's no big deal. It's actually probably easier than writing a referral. *Post-intervention interview, GP #4*

Although the model did not notably increase workload, there were concerns that future work may increase depending on the complexity and number of patients:

> If it is just for prostate cancer or for a stable patient, I guess it wouldn't be too sort of time consuming. But if it then started to include breast cancer patients, I think that would probably end up taking a bit more time. *Post-intervention interview, GP #8*

ROs felt that this model did not increase their time burden as they remotely monitored the patient's clinical assessment. One RO highlighted how the automatically generated letter back to the GP upon their review saved their time and additional administrative staff time. However, ROs felt it was too soon to identify if the model would make a difference in the long term:

> There hasn't been too many patients, but from the few that have gone to their GPs, I feel good about it. I think it worked well. It is not enough to make a dent in my clinic schedule yet though. *Post-intervention interview, RO #3*

Participants felt that the model alleviated some burdens on patients, especially physical access to care. Patients appreciated greater flexibility with rescheduling appointments and not waiting months for a new appointment. Patients appreciated not having to travel the distance to the hospital for their follow-up appointment when their GP was closer:

> … to be able to go to the local [my GP] is only 10 minutes away… Whereas, the [RO], obviously, a day trip, which I don't mind… It's not a killer of a thing, but there are times when you don't have the time. *Post-intervention interview, Patient #1, breast*

Patient's who were not required to make a copayment to visit their GPs that bulk billed (that is no copayment was required), felt that outside of this intervention cost was not a burden to this model. However, patients who were required to make a copayment to visit their GP, identified cost as a barrier in the future:

> [The GP is] actually charging $30… And I've got to go and see him monthly now because of [other health issues]. So I've got to see him at least once a month now and then adding that extra. *Post-intervention interview, Patient #12, breast*

Some GPs highlighted that in order for the model to work, there would need to be appropriate government funding to remunerate it on a time-based consultation:

> There would need to be an [Medicare] item code for this. Even though I'm able to do it there needs to be better support if I'm to actually do this. *Post-intervention interview, GP #1*

Ethicality and patient suitability

Ethicality explored the participant's view of this shared care model regarding its appropriateness with their personal and professional value system, including patient suitability for shared care.

GPs and ROs acknowledged that this shared care model might not suit every patient and recognised that some patients might want to continue with the oncologist-led model if they were anxious or preferred the RO:

> I have some patients that enjoy going to the specialist, just to have to big power say they are doing ok. *Pre-intervention interview, GP #9*

Although GPs and ROs saw the model as providing a choice to the patient, patients trusted their RO, and wanted their RO to advise them on the most appropriate follow-up model suited to their individual situation:

> Trust is the major feature. Distance and cost is secondary. *Pre-intervention interview, Patient #14, prostate*
>
> It's whatever the professionals think is best. Because they have my best interests at heart. *Pre- intervention interview, Patient #6, breast*

GPs and ROs recognised that patients needed to be carefully selected based on their post-treatment stage. Transitioning away from the oncologist-led model to shared care would be best two to three years post-treatment in stable patients:

> Especially in the initial first two years, it's really important to get the hospital fully involved and making sure everything is good. But it is the future years, when we're moving on beyond the two-year mark, then that is the time when the patients really don't want to go to the hospital. They want that sort of care to be available at the GP. *Post-intervention interview, GP #3*

However, ROs had varied views on which cancers were suitable for this model of care. The implementation of funded telehealth during the COVID-19 pandemic influenced some ROs views on prostate cancer. Some ROs felt that telehealth follow-up for prostate patients was appropriate as it removed some access issues for patients. All ROs thought breast cancer patients would be suitable for this shared care model based on improved treatments, known side effects and the need for a physical examination and review of the skin:

> Telehealth has its advantages. But shared care, well if the patient is still physically seen by the GP, to assess their skin, that is important. *Post-intervention interview, RO #2*

Although GPs' and ROs' views aligned on having stable patients in this shared care model, some GPs and ROs highlighted concerns about liability and who maintained overall responsibility for the patient:

> Who takes the responsibility?…. So if something was to happen, it's not really my responsibility because the information that I have is limited… So I think that there is a remote monitoring, but I think ultimately, and I'm just saying that if something were to go wrong, the GP missed a recurrence, it's still the GP's responsibility, or his responsibility to have raised a concern. *Post-intervention interview, RO #2*

Self-efficacy and perceived effectiveness

This theme related to whether the participants felt that they could carry out what was required of them to participate in shared care, and their views on the effectiveness of this shared care intervention.

Post-intervention, ROs maintained their positive view and reported that their patients appreciated their GP being more involved in their care, and that it allowed them to know more about their follow-up care. Many patients highlighted that the follow-up review with their GP was the same as if they had seen their RO:

> She gave me a physical examination sitting up and lying down and everything was basically exactly the same as what happens when I've gone in the past to the cancer center. *Post-intervention interview, Patient #7, breast*

Post-intervention, all GPs felt confident in performing the follow-up review, and one highlighted that their confidence in had improved:

> I was really apprehensive to start with, but it was really good. I mean, it went very well and I could do it. *Post-intervention interview, GP #3*

Providing a clinical assessment protocol for the GP was important in allowing the GP to know specifically what information the RO wanted. Being able to access it from a frequently used GP website (HealthPathways) was viewed positively. The use of the protocol was also identified as a self-learning tool for GPs:

> Having a framework that says this, this, and this is really good because it makes sure we don't miss anything. And then, obviously for your viewpoint, that gives you consistency in the feedback that you are getting. So yeah, I've found that all very, very good. *Post-intervention interview GP #4*

Patients, GPs and ROs felt confident the patient would be referred quickly back to the RO if any recurrence was suspected via the rapid referral option. Although the rapid referral option in the clinical assessment protocol was not used within this study, participants likened the intervention mechanism to a safety net:

> It's the convenience to the patient and also the safety net. *Post-intervention interview, GP #5*

An important factor in the acceptance of this model depended on the electronic communication system working properly so that the GP could access the clinical assessment protocol and that the transfer of information to the RO worked in real-time:

> The electronic media system is certainly making this... When it works, these sort of situations are very streamlined. But, of course, when they don't work, though, totally wretched. *Post-intervention interview, Patient #1, breast*

While some GPs had electronic recall scheduling systems for their patients, not all did, and this was viewed as essential for a shared care model:

> I think main thing is the time and also the recall system. We have a robust recall but for different reasons, but not for this cancer follow-up... so that’s not included in our software. *Pre-interview, GP #1*

The fact that the RO maintained involvement was important for patients’ acceptance. Patients wanted the RO to stay involved. Some patients also felt it was important to know if their RO had reviewed the clinical assessment results:

> I guess I don’t know if [my RO] saw anything. Well I guess just me needing to know that [my RO] is actually still involved. *Post-intervention interview, Patient #3, breast*

The ROs felt comfortable with the transfer of information from the GP to the hospital system. They also thought the clinical information received was consistent with what they observed from their clinical practice. However, there remain further requirements to improve overall acceptance:

> It's a good concept. I still think there might need to be some more work to individualise the clinical assessments, I know they reflect our consultations, but sometimes we might get patients that need that unique item reviewed. *Post-intervention interview, RO #3*

GPs and ROs acknowledged there was a need to manage patient expectations and that if the patient expects their follow-up care to be with the RO they may be disappointed if their follow-up care is with the GP. ROs recognised they played an important role in advocating the shared care model to their patients. Patients and GPs viewed the shared care model positively. ROs saw this model as important to continue to provide safe follow-up care to suitable patients in general practice, whilst improving access for newly diagnosed patients and those with recurrence:

> So I'm satisfied that it's feasible and practical…I think now that I've moved from being one who's supportive to one who feels that it's absolutely necessary in order for us to maintain services for newer patients who come through because, otherwise, we'll be overwhelmed. *Post-intervention interview, RO#1*

8.5 Discussion

Concerns about the sustainability of the current oncologist-led model for cancer follow-up care have led to the need to explore alternative models of care (49,225). Despite studies showing acceptance for shared cancer follow-up care (330,331), barriers remain to implementing the model into clinical practice (211,223,321). A unique feature of the intervention evaluated in this study was the direct use of health technology to bridge the communication gap between GPs and ROs and specific protocols to support shared cancer follow-up care.

A documented barrier to shared cancer follow-up care is that patients and oncologists perceived that GPs lacked the cancer-specific skills required (204,207,211). Similarly, our study found that patients had the same concerns pre-intervention. However, post-intervention, patients felt confident that their GPs had the required skills and found it comparable to an RO follow-up assessment. The ROs in our study did not have concerns about the GPs ability to perform follow-up using the prescribed clinical assessment protocol.

Clear protocols are thought to foster acceptance for shared cancer care (121,199,215). We provided a specific clinical assessment protocol for GPs to follow. GPs appreciated knowing what information the RO needed for follow-up care, felt it acted as a self-learning tool, and felt the protocol was easy to follow and to integrate into their work. ROs saw that the GPs' assessment results were similar to their assessment results, increasing their acceptability of the model. However, ROs saw an opportunity to further individualise patients' clinical assessments, noting that patients have had different treatments with varying side effects and toxicities to monitor.

Another concern about adopting shared care was the additional burdens the model would place on GPs (202,332–334). Although this was an initial concern from the participants, our results showed that GPs found the time taken to assess the patient in this model to be no more burdensome than writing a referral. However, GPs had reservations about what types of cancers and how many patients would be expected to transition from the oncologist-led model to the shared care model in the future and how that would impact their workload.

GPs and ROs felt that transitioning from the oncologist-led model to the shared care model would be best for low-risk and stable patients, consistent with a recent Australian qualitative study (335). Additionally, GPs and ROs thought the transition would be appropriate for patients two to three years post-treatment. Some ROs felt that the recent changes to telehealth funding due to the COVID-19 pandemic made telehealth follow-up for prostate patients preferable to this shared care model. However, ROs saw the benefit of this shared care model for breast patients, as they required a physical examination and review of their skin.

GPs and ROs saw the benefits for this shared care model for patients in rural areas. Interestingly, shared care has been suggested as a way to improve access for patients in rural areas (336); while this may be true, access was not emphasised as a benefit by rural patients in this study to any greater extent than for regional patients. Nevertheless, the adoption of a shared care model is about patient choice.

GPs and ROs felt that it was the patient's choice to participate in shared care. Patient choice aligns with person-centred care principles (184). However, patients emphasised that they trust their RO to advise them on the most appropriate follow-up model suited to their individual situation. This trust is the foundation of the doctor-patient relationship, and patients who have that trust are more likely to adhere to the plan recommended to them (337). GPs also looked to the RO for support and guidance to foster the adoption of a shared care model. It has been reported that relationships were poor between GPs and oncologists (213), and the ROs in this study recognised that they have an opportunity to increase their role in supporting GPs in the transition to a shared care model.

This shared care model relied heavily on health technology in both the GP and RO settings. The use of health technology to better connect the GP and RO acted as a safety net for participants in this shared care model. GPs and patients valued rapid access to oncologist assessment for new symptoms, or for suspected recurrence. Providing the clinical assessment online via HealthPathways and transferring the clinical information directly into the hospital's medical record system allowed the RO to oversee care, and fostered acceptance for this shared model. For ROs, the retention and access to patient outcome data were integral to acceptance, which is seldom discussed in other studies (196). ROs within this study were very clear that any model moving forward needed to integrate with the hospital's system so that they could continue to use the clinical outcome data of their patients for their medical reviews, reporting requirements to state or national bodies, and use in research. Additionally, existing electronic medical record systems routinely used in general practice use recalls systems, and while they may not exist for cancer follow-up, they can be customised to allow recall.

Although this study has attempted to overcome some barriers to adopting shared care, this study has highlighted an additional barrier, remuneration to the GP and cost to the patient. An Australian study found that a shared cancer follow-up model is cheaper than usual care (49). Promoting the cost-effectiveness of shared care is important for advocating changes to models of care and funding at a federal level. However, consideration is also required to understand the cost impact of shared care on patients. In this study's setting, there are no patient copayments for RO consultations in the public hospital system, and although Medicare can cover GP consultation fees, many patients may be charged a copayment (6). Although patients made no copayment to their GP for this study, this was highlighted as a barrier by patients who have GPs that charge copayments. Consequently, adopting a shared cancer follow-up model may impose additional costs on patients to visit their GP.

There is a need to review the funding model and its implications for the patient, GP and RO. There is a need to determine an appropriate Medicare item that addresses the GP's remuneration needs on a time-based consultation and minimise the need to charge patients a copayment. Additionally, in Australia, hospitals are funded based on their activity; therefore, by reducing the RO's hospital activity, the model could potentially reduce the funding provided to the facility and to the ROs for research and development purposes. However, considering that ROs will still be directly involved in remotely monitoring the patient's medical record, this activity should be captured and remunerated.

Strengths and Limitations

This study has several strengths. Firstly, a strength of this study is its varied sample of participants, thus its ability to examine different perspectives of this shared cancer follow-up model of care. This meant that their views of follow-up cancer care and shared care were tangible and considered the interpersonal dynamics of the empirical, actual and real relationships. Secondly, the use of health technology as the mechanism to support a streamlined shared care model was integral to the success of this model of care. Finally, frameworks are often underutilised in health implementation studies (338); using the TFA contributes to the field as a whole and the topic.

This study has some limitations. Firstly, interviews changed from face-to-face to telephone interviews due to the COVID-19 travel restrictions during data collection. While some consider face-to-face interviews as the gold standard (339), current research has not found variations in data quality (340,341). Secondly, this study was in a rural and regional Australian setting with publicly funded ROs, and the results may not apply to metropolitan, private or international settings.

8.6 Conclusion

This shared cancer follow-up model of care is acceptable to the patients, GPs and ROs. Central to the acceptance was the health technology used within the intervention: the clinical assessment protocol accessible via a website and the system that transferred the results securely from the GP to the RO in real-time, allowing the RO to maintain involvement, oversee care and collect outcome data. The mechanisms acted as a safety net for patients, GPs and the RO. For a shared cancer follow-up model of care to be adopted into clinical practice, the model needs to be endorsed and supported by ROs. There is a need to review funding and advocate for health technology advances to support integration.

CHAPTER 9: Discussion and Conclusion

Chapter overview

This chapter starts by providing an overview of the quantitative and qualitative studies and how they align with the thesis objectives. This is followed by synthesising the quantitative and qualitative studies to answer the overarching thesis aim. The research contributions to shared cancer follow-up care are then presented, followed by the strengths and limitations. Finally, implications for practice and opportunities for future research are presented.

9.1 Discussion and synthesis of findings

The overarching aim of this thesis was to develop and implement a novel shared cancer follow-up model of care and evaluate the acceptability and feasibility to patients, general practitioners (GP) and radiation oncologists (RO).

As presented in the Methodology and Methods Chapter (Chapter 2), within the critical realism lens, understanding events and mechanisms in the real and actual domains (as per the Iceberg Metaphor in section 2.1, Figure 5), are gained through inference from outcomes observed or detected in the empirical stratum. The events observed within this thesis at an empirical level used different quantitative and qualitative data types, and an overview is presented below.

9.1.1 Overview of empirical findings

Objective 1: To identify the barriers and facilitators for shared cancer follow-up care between GPs and oncologists. This objective was addressed by performing a systematic review presented in Chapter 3.

The narrative systematic review included a mix of quantitative and qualitative papers (n=38). Five main themes emerged: 1. The need for timely, relevant and reciprocal clinical information sharing between oncologists and GPs; 2. Responsibility of care should be shared with the oncologist overseeing care; 3. GP's skills and knowledge to provide cancer follow-up care; 4. Clinical management guidelines and rapid referral are needed to support GPs to provide shared follow-up care; 5. Continuity of care and satisfaction of care are vital for shared care. This paper contributed to the body of evidence by identifying the need for reciprocal, two-way communication and establishing a mechanism for the oncologist to maintain overall responsibility for overseeing follow-up care.

Objective 2: To determine the level of acceptance for shared cancer follow-up care in the ISLHD cancer patients. A quantitative cross-sectional study was designed to address this objective and presented in Chapter 4.

Of the 414 surveys returned, the acceptance for radiation oncology shared cancer follow-up care was high (80%). Patients who were more likely to accept shared follow-up care were treated with only radiotherapy or preferred follow-up care for fewer than three years. The Theoretical Framework of Acceptability domains of high ‘Intervention Coherence', 'Affective Attitude' and 'Self-Efficacy' were significant predictive factors in accepting shared follow-up care. Patients' acceptance for shared cancer follow-up care needs to be considered alongside other clinical and organisational factors.

Objective 3: To develop a shared cancer follow-up model of care. This was achieved by developing a protocol, presented in Chapter 6.

The model of care involved using a clinical assessment protocol that the GP accessed via a website (HealthPathways) and sent securely in real-time (via PROsaiq) to the RO to review (in MOSAIQ). Once the RO had reviewed the clinical assessment, this triggered an automatically generated letter, which was sent electronically back to the GP (via Argus) informing them that the RO had reviewed the assessment, and also included a copy of the results and specified the next proposed follow-up date.

Objective 3a: To test the model by determining the concordance in clinical data between patients and oncologists completing the follow-up clinical assessment in the radiation oncology setting. A quantitative cross-sectional study was designed to address this objective and was presented in Chapter 5.

This study was included opportunistically when the COVID-19 pandemic impaired cancer follow-up care and highlighted the need to explore alternative models of care when neither the oncologist-led nor a shared care model was available face-to-face for patients. Additionally, the PROsaiq software planned for the shared care intervention was tested within this study.

“Unannounced text messages with a weblink were sent to patients on follow-up care to self-report their health before their radiation oncology telehealth appointment. ROs completed the same set of questions. The purpose was to determine the concordance in clinical data between patients and oncologists. A moderate response rate of 62% was achieved from the 142 patients. Percent agreement between the patient-reported and the clinician-reported for weight change, appetite, physical performance, and side effects was acceptable (>75%). However, the percent agreement was moderate for pain and sleep. Cohen's Kappa indicated moderate agreement for most items, with pain, side effects, and recurrence being fair. Patients were more likely to report themselves worse than the clinician for all items except side effects” (342) p.1.

“Due to the lower-than-ideal ideal response rate and fair to moderate patient-clinician agreement found in this study, means that the results of this study alone cannot say that a standalone patient self-reported follow-up model of care is feasible. However, we recognise the importance of capturing the patient perspective for radiation oncology follow-up care as complementary information for clinicians prior to telehealth consultations. Patients self-reporting before their telehealth consultation holds promise for future models of follow-up care, particularly for rural and remote patients, and during pandemics and other disasters where clinic attendance is not possible” (342 p.10).

Objective 3b was to test the model and determine the concordance in clinical data between GPs and oncologists completing the follow-up clinical assessment in the radiation oncology setting. A quantitative cross-sectional study was designed to address this objective and was presented in Chapter 7.

Concordance was assessed between 15 GP–RO dyads, and an acceptable percent agreement (>75%) and a moderate to almost perfect agreement (Fleiss kappa) were found for all variables (pain, fatigue, physical performance, telangiectasia, proctitis, etcetera). Previous research had highlighted the need for specific and localised clinical follow-up guidelines or assessments for shared cancer follow-up care (121,200), and the provision of a follow-up clinical assessment was a key component of this thesis. The GP-RO concordance of a clinical follow-up assessment for radiation oncology patients was an important finding and forms part of the feasibility of shared cancer care.

Objective 3c: To evaluate the acceptability of the model to patients, GPs and ROs. A repeat cross-sectional qualitative study was designed to address this objective and was presented in Chapter 8. The intervention involved the patients attending two cancer follow-up consultations with their GP six months apart and the RO overseeing the care, as described in the protocol in Chapter 6.

Thirty-two participants (19 patients, nine GPs and four ROs) were interviewed pre- and post-intervention. A documented barrier to shared cancer follow-up care was that patients and oncologists perceived that GPs lacked the cancer-specific skills required (204,207,211). Similarly, the study found that patients had the same concerns pre-intervention. However, post-intervention, patients felt confident that their GP had the required skills and found it comparable to a radiation oncology follow-up assessment. Previous research has suggested that clear protocols for GPs would help foster acceptance of shared cancer care (121,199,215). This study confirmed this. GPs appreciated the clinical assessment protocol as it allowed them to know what information the RO needed for follow-up care and was easy to follow and integrate into their work. GPs also felt the clinical assessment acted as a self-learning tool.

Participants were initially concerned that a shared cancer follow-up model of care would increase the GP's workload. GPs reported that they found the follow-up review comparable to writing a referral. However, GPs were concerned about the impact on their future workload depending on how many cancer patients and different cancer types they had and being adequately remunerated for their additional time and potential legal liability. GPs and ROs felt the model provided patient choice and was suitable for low-risk, stable patients around two to three years post-treatment. ROs presented differences in acceptance for the different cancer types, with breast cancer strongly supported.

Patients trusted that their RO would advise them on the most appropriate follow-up model suited to their individual situation. The overall acceptance for this shared care model depended on successful health technology to connect the GP and the RO. There were no differences in patient acceptance between rural, regional and cancer types.

The final stage of evaluating the model was to synthesise the findings, which are discussed below.

9.1.2 Synthesis of findings

Critical realism encourages a holistic exploration of phenomena using multiple research methods (343). Therefore, synthesising qualitative and quantitative results to determine what is real from a critical realist paradigm is integral to addressing this thesis' overall aim. By synthesising the nature of the human agents (patients, GPs and ROs), how the agents influence structures and how structures influence human agents are used to determine the overall acceptability and feasibility. The mechanisms referred to below are the clinical assessment, HealthPathways, PROsaiq, MOSAIQ and Argus (see section 2.1, Table 4).

Human Agency

The systematic review highlighted that cancer survivors want their GP to be involved in their follow-up care, GPs want to play a greater role in cancer follow-up care, and oncologists want to remain involved and oversee the care (321). However, several barriers still existed to translating shared follow-up care into practice, including a mechanism that allowed two-way communication between GPs and oncologists, so that GPs could be supported, and oncologists could still oversee the care (9). This thesis addressed these barriers by providing a clinical assessment protocol and implementing two-way communication in real-time between the GP and RO, allowing both the GP and RO to be involved in each episode of care. These novel mechanisms allowed true shared care between GPs and ROs instead of transferring aspects of care to GPs.

The clinical assessment protocol was important in several ways. First, it provided GPs with the tools to know exactly what the RO wanted them to review. They saw they could perform the tasks, increasing their confidence and self-efficacy. The clinical assessment protocol reassured both GPs and ROs that GPs had the requisite skillset to perform cancer follow-up assessments. The moderate to almost perfect concordance between GPs and ROs in the clinical assessment was central to this acceptance. Furthermore, because patients saw their GP doing what their oncologist usually did in an appointment, they were also reassured that their GPs had the requisite cancer-specific skills.

The mechanism to transfer the GPs assessment to the RO and allow the RO to review the results in real-time, allowed the oncologist to oversee care and maintain responsibility for their patients. This provided additional reassurance to GPs, ROs and patients, and increased acceptability. Patients saw that their RO was involved in this model, thereby endorsing that it was an appropriate model for their care, which was important to their acceptance *(Medical hierarchy and trust is further discussed in Social Structures)*. The transfer of information still allowed ROs to collect and retain long-term clinical outcome data, further increasing their acceptance.

The inbuilt rapid referral in the assessment for a suspected cancer recurrence reassured GPs and ROs and aligned with recent literature (332,344). However, it should be noted that a rapid referral trigger is not considered a referral for billing purposes. An alternate solution must be found to satisfy billing conditions and is discussed below in *Implications, recommendations and conclusion.*

Referring back to the critical realism iceberg metaphor, the clinical assessment protocol and two-way communication mechanism achieved several improvements observable on the empirical plane. Collectively, these allowed all the agents to work collaboratively in a true shared care model, with both GPs and oncologists active in the same episode of care. However, ROs acknowledged that the clinical assessment protocol was not a one-size-fits-all tool; therefore, there is scope to individualise the assessments based on patients' circumstances; this is discussed in the *Implications, recommendations and conclusion.*

Social Structure

Critical realists argue that even though the social structure is unobservable, it is real as it affects changes to observable human behaviour (345). Human agency is not above social structures, and in the context of this thesis, without the implementation of health technology to support shared care, the mechanisms would not be activated, and they would not influence the outcome. Social structures and mechanisms act in either a constraining or enabling mode (346). The social structures identified within this thesis include legislation changes to how healthcare was delivered due to the COVID-19 pandemic, telehealth, healthcare funding, trust in the medical hierarchy, and legal liabilities. These actual events are not necessarily synonymous with the participant's empirical experiences but reveal some structural and social contexts.

“Social structure is the ever-present condition (material cause) and the continually reproduced outcome of human agency” (137 p.169). An extreme example of how human agency altered the social structure of how healthcare operated was the COVID-19 pandemic. The COVID-19 pandemic triggered government leaders to change how they delivered healthcare services. The American Medical Association encouraged the use of telehealth and health technology (283), and Cancer Australia recommended that hospitals minimise outpatient visits and find alternative methods to deliver care in order to protect vulnerable cancer patients (284). This prompted two changes that influenced this thesis.

First, the COVID-19 pandemic caused changes to the structure of cancer follow-up care in that neither the oncologist-led nor the shared care model was available to all patients due to restrictions on face-to-face medical consultations. This highlighted the need for and presented the opportunity to explore alternative follow-up models of care. The hospitals involved in this research supported the use of patient self-reported data as an option for follow-up care. However, due to the lower-than-ideal response rate and fair to moderate patient-clinician agreement reported in Chapter 5, the findings could not be used to support a standalone patient-reported follow-up model of care. Although patient self-reporting may be beneficial for monitoring patient outcomes and side effects, it loses the agent-to-agent relationship and does little to provide the psychological reassurance patients need.

Secondly, the telehealth structures introduced during the COVID-19 pandemic negatively impacted acceptance for shared care for prostate cancer patients. The availability of telehealth consultations with oncologists meant that access to the RO was improved for some patients. This is demonstrated in the qualitative paper (Chapter 8), where a patient with prostate cancer stated that their telehealth consultation with their RO was easier for them than going to see their GP. Additionally, two ROs stated that they preferred patients with prostate cancer to remain in the oncologist-led telehealth model as opposed to the shared care model. This was because no physical examination was required for prostate cancer patients' long-term follow-up, but rather only monitoring of blood results for prostate-specific antigen, and this could be done by telehealth. However, because breast cancer patients required a physical examination, the shared care model, where the GP performed the physical examination and then transferred the results to the oncologist, was preferable.

The current healthcare funding model is a potential barrier for patients to participate in shared cancer care. Patients eligible for Medicare are not charged to see publicly funded ROs, medical oncologists and oncology surgeons. The oncologists in this thesis were publicly funded, and patients were not charged to see their RO. However, the majority of oncology surgeons review patients in the private system, which often requires a copayment from patients. Patients in this study were also not charged a copayment when they saw their GP, however, more and more GPs are charging patients copayments (9). Therefore, whilst this model of shared care promotes follow-up access by reducing travel distances, it also means that some patients may incur additional healthcare expenses in the form of GP copayments. In addition to GP and private oncologist consultation fees, patients might incur additional costs such as imaging and pathology costs, if they do not access these services through public hospitals.

There is no Medicare rebate to support GPs undertaking shared cancer follow-up care. Furthermore, funding for ROs in a shared care model also needs to be considered because reviewing patients remotely is not a reportable activity, meaning that the hospital is not remunerated for the time spent reviewing shared care patients. An economic analysis of projected activity for shared care, new consultations, GP consultations and National Weighted Unit Activity is suggested in the *Implications, recommendations and conclusion.*

The cancer hospital clinics were often described as busy places, with more parking issues and longer appointment waiting times compared to GP clinics. Although improved access was viewed as a benefit and formed a part of patient acceptance of shared care, it was not the primary factor. Some patients expressed that the benefit of accessing trusted expert care and advice from their oncologist outweighed the cost of travel, and the endorsement of shared care by the oncologist was critical to most patients' acceptance. The patient's need for endorsement from the oncologist is intertwined with the social context of the current oncologist-led (specialist-led) medical model and trust. Cancer patients' trust in their oncologist differs from that of their GP (347). When a person is diagnosed with cancer, trust in an oncologist becomes essential to grasp complex information and make medical decisions (348,349). The foundation of the doctor-patient relationship is trust, and patients who have that trust are more likely to adhere to the treatment plan recommended to them (337). In the intervention, the ROs supported and advocated for shared care; hence, their patients were also supportive. Interestingly, the agent-agent relationship between the patient and the GP forms part of the acceptance but does not determine it. Acceptance was, instead, strongly influenced by the agent-structure relationship – that is, patients' trust in the oncologists' advice.

Some GPs and ROs highlighted their concern about legal liability in the shared care model. There is little research on shared care models in the Australian context regarding legal parameters. In this model, while the RO retains overall responsibility for the care and has legal responsibilities, the GP will also have a legal obligation to the patient to exercise reasonable medical care. Although GPs know the legal responsibilities, hesitancy to participate in a shared care model like this may be a barrier for some GPs.

9.2 Research contributions

This thesis explored shared cancer care from a critical realism perspective to understand the interplay of the agents and the structures that produce them. This paradigm explained *why*, *how,* and *under what circumstances* the intervention was or was not acceptable and feasible to the agents (patients, GPs and oncologists).

This thesis contributes original research providing solutions that address some of the barriers to implementing shared cancer follow-up care into clinical practice. The research in this thesis has made a significant contribution to the field of shared cancer care with five published or in-press manuscripts (see Chapters 3, 4, 5, 6 and 7) in high-impact journals (BMJ Open, Journal of Medical Internet Research, BMC Primary Care, Journal of Radiation Oncology Informatics, and the International Journal of Environmental Research and Public Health), and another manuscript (Chapter 8) submitted to a Q1 journal. Studies from this thesis have been presented at three international and national conferences and at local ISLHD and Research Groups.

9.3 Strengths and Limitations

The strengths and limitations of each study within this thesis have been discussed in Chapters 3-8. The following section describes those of the thesis more broadly.

Strengths

Research into shared cancer follow-up care has occurred since the late 1990s; however, there have been barriers to implementing the model into practice. This thesis contributes to the gap in existing literature to address some barriers to implementing shared cancer care into practice by providing a clinical assessment protocol for GPs to follow and allowing the RO to check the results in real-time, thereby implementing true shared care. Furthermore, given the international interest in shared cancer follow-up care, the results of this thesis are likely to be of interest to researchers, health professionals and health organisations nationally and internationally.

This thesis included several novel contributions, which were:

- To explore the feasibility of a remote cancer follow-up model of care by determining the concordance between patient self-reporting and RO assessment
- To implement a follow-up clinical assessment protocol for GPs to use for a cancer-specific follow-up consultation
- To find the concordance between GPs and oncologists completing the clinical follow-up review
- To establish and implement health technology to allow the oncologist to oversee care within the hospitals' oncology information system and collect clinical outcome data
- To apply the Theoretical Framework of Acceptability to healthcare interventions quantitatively (previous research has been qualitative).

A strength of this thesis is that it examined the views of patients, GPs and ROs and therefore gathered different perspectives of this shared cancer follow-up model of care. This meant that their views of shared cancer follow-up care considered the interpersonal dynamics of the empirical, actual and real relationships. Using both qualitative and quantitative research methods meant a more rounded view was obtained. The research was supported by extensive clinical and academic knowledge, communication, and collaboration with different health professionals to ensure all perspectives were included.

Limitations

All patients in the recruited sample had regular GPs. According to the population survey, 97% of respondents had a regular GP; however, it is acknowledged that this percentage varies nationally and internationally, and this study has not analysed acceptance for shared cancer care for people who do not have a regular GP.

While this thesis involved the evaluation of participants' viewpoints, they were not involved in the development of the model. Therefore, consideration should be given to incorporating a participant reference group in future studies.

Although this thesis highlights that there may be additional costs to some patients who see a public oncologist to transition to a shared care model, this thesis has not considered oncologists in the private setting nor the additional expenses patients pay during the follow-up phase.

This thesis has not analysed other cancer follow-up models of care, such as hospital-based survivorship clinics, oncology nurse-led clinics, GP-led or telehealth models. While one study in this thesis investigated the feasibility of a novel patient self-report model by measuring concordance between patients' self-report and ROs, further research could be undertaken to see if better response rates alter the outcomes.

9.4 Implications, recommendations and conclusion

This thesis found that a shared cancer follow-up model of care was acceptable to patients, GPs and ROs and feasible in practice. However, several barriers still exist in the Australian context before considering large-scale implementation. It should be noted that "realist researchers do not offer specific advice about action: instead, they provide practitioners with knowledge of structures, their mechanisms and tendencies that practitioners can apply to their specific contexts" (350 p.322). Therefore, readers must consider their specific internal national and external international contexts when deciding on transferability.

Oncologists are the trained professionals for oncology follow-up care and are key to advocating for shared care. However, patients need to have a regular GP who is willing to participate in shared care. The earlier the GP is introduced into a patient's cancer care, the more normalised shared cancer care will become, and this could help increase acceptability for GPs who might not yet be willing to undertake shared care. Engagement between GPs and oncologists could be facilitated through shared care information sessions, or simply engaging the GP earlier in the treatment phase or including the GP in multidisciplinary meetings.

It is important for the oncologist to discuss and present shared care to their patients as an option early in the cancer care continuum. Patients trust their oncologist to guide them to the most appropriate follow-up model of care for their situation. This guidance can be further supported by updating patient information resources to promote and communicate the benefits of shared care, thus empowering patients to play an active role in choosing their follow-up care. These resources can assist in normalising shared care. For example, cancer information resources can explain that when patients start active treatment, their main contact will be their oncologists, but their GP will be kept in the loop. However, once patients finish active treatment and become more stable over time, some may transition to shared follow-up care with the GP becoming the main contact.

Several factors need to be addressed to transition from the oncologist-led model to the shared care model. When patients are transitioned to the shared care model, oncologists must provide documentation to the GP in line with national and international guidelines specifying the expected duration for the shared care model to be in place. In addition, this thesis recommends including information on how to access the clinical assessment protocols and what to do should recurrence be suspected. Although the clinical assessment has the option for a rapid referral, it is important to highlight that emergency referrals can still be made by phone or via the emergency department (for example, in emergency situations such as spinal metastasis causing cauda equina). Furthermore, there needs to be an option where all agents review the continuation of the shared care model or have the ability to cease shared care at any other time. Therefore, this thesis recommends that the clinical assessment protocol be adapted to include adding new items that the GP or oncologist can select: 'Continue shared care', 'Cease shared care and revert to oncologist-led care', and 'Cease shared care and transfer to GP care'.

Whilst the shared care model in this thesis included a rapid referral option, it did not produce a referral in the form required for Medicare billing. Future iterations of the model should incorporate an electronic referral that fulfils the Medicare billing requirements. An alternative solution could be an indefinite referral. While GPs can provide an annual referral, including updated clinical information, in the case of shared care, the provision of an indefinite referral should be considered as the patient transitions from the oncologist-led model to the shared care model.

Although this thesis has successfully implemented and evaluated the two-way transfer of information to create a truly shared care model, further support and investment in health technology are required. Consideration should be given for a dedicated shared care coordinator to help establish roles, explain the clinical assessment protocols, assist with health technology training, and facilitate communication between patients, GPs and oncologists if needed. Additionally, the PROsaiq platform (or any alternative platform) will require ongoing investment to ensure its ongoing stability and the security of data being transferred between the GP and the oncology information system. Furthermore, it is also suggested to embed patient identifiers within the clinical assessment protocols to reduce the burden of entering patient identifiers. Long-term, there is a need for better integration of the results not just being transferred from the GP to hospital systems but one that automatically uploads the clinical assessment data into the GP system. This requires that any platform be compatible with the various GP medical information systems utilised.

GP practices would benefit from increased use of electronic health records and electronic recall systems to facilitate shared care. In the case of shared care, there is a need for the GP practice to have a reliable system to recall patients when they are due for their shared care follow-up appointment. It is recommended that general practices with electronic recall systems modify and create a 'Shared cancer follow-up' appointment and set the timeframe for recall as per the oncologist's consultant letter that prescribes the frequency for follow-up care. In addition, the public oncology service could create a monthly audit to identify patients who may have missed their shared care appointment to act as a safety net.

Advocating for a sustainable funding mechanism to remunerate GPs and oncologists for shared care is necessary. Consideration should be given to establishing a Medicare item code for GPs to use for shared cancer follow-up care. Additionally, there is a need for the activity of the oncologists reviewing the clinical assessment to be captured in the oncology information system to attract a National Weighted Unit Activity. Consideration should be given to ensure that the rebate provided to GPs and oncologists is sufficient to cover their costs so that the cost burden of follow-up care is not transferred to the patient.

Whilst GPs and oncologists are aware of their medico-legal liabilities, clearer information should be provided about shared care to ensure all providers have a clear understanding. Once this information has been established, the shared care coordinator could incorporate sharing said information as part of their role.

Recommendations for future research that will further support the translation of evidence for shared cancer follow-up care into clinical practice include:

- To implement and evaluate this shared cancer intervention on a larger scale in metropolitan, regional and rural areas
- Evaluate this shared care model in medical oncology, surgical and haematology disciplines
- Establish the clinical parameters and circumstances that describe patients eligible for shared care and create adaptable clinical assessments
- To develop a reliable and valid screening tool based on the Theoretical Framework of Acceptability, to support GPs and oncologists in determining patients' acceptance for shared cancer follow-up care
- To conduct economic analyses for shared cancer care exploring:
  - The cost differences between the oncologist-led model and the shared care model, including public and private providers
  - GP and oncologist workforce requirements against the expected number of patients for shared cancer care
- Long term analysis of shared care model clinical outcomes, including cancer recurrence, mortality, morbidity (admissions, presentations to emergency), patient satisfaction and patient-reported outcomes.

The original research from this thesis has contributed to the body of knowledge on the acceptability and feasibility for shared cancer follow-up care. The thesis included a systematic review that identified key barriers and enablers for shared cancer follow-up care, and the development, implementation and evaluation of a novel shared cancer follow-up model of care. This was done through a population survey on cancer patients' acceptance for shared care, two concordance studies (one between patients and ROs, the other between GPs and ROs), and a qualitative study using semi-structured interviews.

This thesis has shown a novel shared cancer follow-up model of care is acceptable to patients, GPs and ROs, and feasible in practice. This acceptability and feasibility rely on the oncologists' endorsement of the model and on the mechanisms that allow the oncologist to oversee the care and act as a safety net. To support implementing this shared cancer follow-up model of care into practice, there is a need to review funding models, have continued support for health technology interfaces, support to ensure GPs have adequate recall systems in place, initial and ongoing support for GPs and oncologists in the form of a shared care coordinator, and support normalising the model into practice for all agents.

References

1. Radecki J, Schonfeld R. The Impacts of COVID-19 on the Research Enterprise. A Landscape Review. New York: Ithaka S+R; 2020 Oct.

2. Stutchbury K. Critical realism: an explanatory framework for small-scale qualitative studies or an ‘unhelpful edifice’? Int J Res Method Educ. 2022;45(2):113–28.

3. Sandell T, Schütze H, Miller A. A Shared Cancer Follow-Up Model of Care Between General Practitioners and Radiation Oncologists for Patients With Breast, Prostate, and Colorectal Cancer: Protocol for a Mixed Methods Implementation Study. JMIR Res Protoc. 2021;10(1):e21752.

4. Australian Institute of Health and Welfare. Health Expenditure - 2022. [Internet]. AIHW: Canberra; 2022 [Accessed 2022 Sep 26]. Available from: https://www.aihw.gov.au/reports/health-welfare-expenditure/health-expenditure2022.

5. Services Australia. Enrolling in Medicare. [Internet]. Services Australia: Canberra [Accessed 2023 Mar 22]. Available from: https://www.servicesaustralia.gov.au/enrolling-medicare?context=60092

6. O’Sullivan B, Kippen R, Hickson H, Wallace G. Mandatory bulk billing policies may have differential rural effects: an exploration of Australian data. RRH. 2022;22(1):7138.

7. Gillespie J. Blue Report - National General Practitioner Listings. Australia: Cleanbill; 2023 Jan.

8. The Royal Australian College of General Practitioners. General Practice: Health of the nation - An annual insight into the state of Australian general practice. Melbourne; 2022.

9. Gillespie J. Blue Report 2023 - Historical Comparison. Australia: Cleanbill; 2023 Mar.

10. Australian Bureau of Statistics. Patient Experiences, 2021-22. [Internet]. ABS: Canberra; 2022 [Accessed 2023 Feb 24]. Available from: https://www.abs.gov.au/statistics/health/health-services/patient-experiences/latest-release. 2022.

11. Australian Government Productivity Commission. Report on Government Services 2022 - Primary and community health. [Internet]. Productivity Commission: Canberra; 2022 [Accessed 2022 Feb 1]. Available from: https://www.pc.gov.au/ongoing/report-on-government-services/2022/health/primary-and-community-health. 2022.

12. European Union. Eurostat - Statistics and data on Europe. [Internet]. European Union: Luxembourg [Accessed 2023 Feb 25]. Available from: https://ec.europa.eu/eurostat/.

13. Willis J, Antono B, Bazemore A, Jetty A, Petterson S, George J, et al. The State of Primary Care in the United States: A Chartbook of Facts and Statistics. Washington, D.C; 2020.

14. Office for National Statistics England. Trends in patient-to-staff numbers at GP practices in England. [Internet]. OPS: London; 2022 [Accessed 2023 Feb 24]. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/trendsinpatienttostaffnumbersatgppracticesinengland/2022.

15. Mullins A, Morris H, Bailey C, Ben-Meir M, Rankin D, Mousa M, et al. Physicians’ and pharmacists’ use of My Health Record in the emergency department: results from a mixed-methods study. Health Inf Sci Syst. 2021;9(1):19.

16. Gradishar W, Anderson B, Abraham J, Aft R, Agnese D, Allison KH, et al. NCCN Clinical Practice Guidelines in Oncology. JNCCN. 2020;18(4):452–78.

17. Hewitt M, Ganz P, Institute of Medicine and National Research Council, American Society of Clinical Oncology. From Cancer Patient to Cancer Survivor: Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine Symposium. Washington, D.C: The National Academies Press; 2006.

18. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology - Survivorship. Pennsylvania: National Comprehensive Cancer Network; 2022. (1).

19. Bernat J, Wittman D, Hawley S, Hamstra D, Helfand A, Haggstrom DA, et al. Symptom burden and information needs in prostate cancer survivors: a case for tailored long-term survivorship care. BJU Int. 2016;118(3):372–8.

20. McCabe M, Partridge A, Grunfeld E, Hudson M. Risk-Based Health Care, the Cancer Survivor, the Oncologist, and the Primary Care Physician. Semin Oncol. 2013;40(6):804–12.

21. Madarnas Y, Joy A, Verma S, Sehdev S, Lam W, Sideris L. Models of care for early-stage breast cancer in Canada. Curr Oncol. 2011;18(Suppl 1):10–9.

22. Buzaglo J, Miller S, Kendall J, Stanton A, Wen KY, Scarpato J, et al. Evaluation of the efficacy and usability of NCI's Facing Forward booklet in the cancer community setting. J Cancer Surviv. 2013;7(1):63–73.

23. Klimmek R, Wenzel J. Adaptation of the Illness Trajectory Theory to Describe the Work of Transitional Cancer Survivorship. Oncol Nurs Forum. 2012;39(6):499–510.

24. McCann L, Illingworth N, Wengström Y, Hubbard G, Kearney N. Transitional experiences of women with breast cancer within the first year following diagnosis. J Clin Nurs. 2010;19(13–14):1969–76.

25. Boland L, Bennett K, Connolly D. Self-management interventions for cancer survivors: a systematic review. Support Care Cancer. 2018;26(5):1585–95.

26. Stein K, Syrjala K, Andrykowski M. Physical and psychological long-term and late effects of cancer. Cancer. 2008;112(11 Suppl):2577–92.

27. Pearce N, Sanson-Fisher R, Campbell HS. Measuring quality of life in cancer survivors: a methodological review of existing scales. Psycho-Oncology. 2008;17(7):629–40.

28. Maass S, Brandenbarg D, Boerman L, Verhaak P, de Bock Geertruida, Berendsen A. Fatigue among Long-Term Breast Cancer Survivors: A Controlled Cross-Sectional Study. Cancers (Basel). 2021;13(6):1301.

29. Jim H, Andrykowski Michael, Munster P, Jacobsen P. Physical symptoms/side effects during breast cancer treatment predict posttreatment distress. Ann Behav Med. 2007;34(2):200–8.

30. Chan R, Crawford-Williams F, Crichton M, Joseph R, Hart N, Milley K, et al. Effectiveness and implementation of models of cancer survivorship care: an overview of systematic reviews. J Cancer Surviv. 2021;1–25.

31. Hoffman K, McCarthy E, Recklitis C, Ng A. Psychological distress in long-term survivors of adult-onset cancer: results from a national survey. Arch Intern Med. 2009;169(14):1274–81.

32. Brandenbarg D, Maass S, Geerse O, Stegmann M, Handberg C, Schroevers M, et al. A systematic review on the prevalence of symptoms of depression, anxiety and distress in long-term cancer survivors: Implications for primary care. Eur J Cancer Care. 2019;28(3):13086.

33. O'Brien R, Rose P, Campbell C, Weller D, Neal R, Wilkinson C, et al. “I wish I'd told them”: a qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. Patient Educ Couns. 2011;84(2):200–7.

34. Husain W. Components of psychosocial health. Health Education. 2021;122(4):387–401.

35. Mullens A, McCaul K, Erickson S, Sandgren A. Coping after cancer: Risk perceptions, worry, and health behaviors among colorectal cancer survivors. Psycho-Oncology. 2004;13(6):367–76.

36. Hewitt M, Bamundo A, Day R, Harvey C. Perspectives on Post-Treatment Cancer Care: Qualitative Research With Survivors, Nurses, and Physicians. Clin Oncol. 2007;25(16):2270–3.

37. Urquhart R, Folkes A, Babineau J, Grunfeld E. Views of breast and colorectal cancer survivors on their routine follow-up care. Clin Oncol. 2012;19(6).

38. Pollack L, Greer G, Rowland J, Miller A, Doneski D, Coughlin SS, et al. Cancer Survivorship: A New Challenge in Comprehensive Cancer Control. Cancer Causes & Control. 2005;16:51–9.

39. Koocher G. Coping with Survivorship in Childhood Cancer: Family Problems. Childhood Cancer. 1984;5:203–11.

40. The Sword of Damocles Image. [Internet] [Accessed 2022 Sep 22]. Available from: https://ackland.emuseum.com/objects/485/the-sword-of-damocles;jsessionid=18853E47BDD5635B4DDDA5FFF41CC979.

41. Aziz N. Cancer survivorship research: State of knowledge, challenges and opportunities. Acta Oncol. 2007;46(4):417–32.

42. Irwin M, Mayne S. Impact of Nutrition and Exercise on Cancer Survival. J Cancer. 2008;14(6):435–41.

43. Gusani N, Schubart J, Wise J, Farace E, Green M, Jiang Y, et al. Cancer Survivorship: A New Challenge for Surgical and Medical Oncologists. J Gen Intern Med. 2009;24(S2):456–8.

44. Pinto B, Papandonatos G, Goldstein M. A randomized trial to promote physical activity among breast cancer patients. Health Psychol. 2013;32(6):616–26.

45. Absolom K, Holch P, Pini S, Hill K, Liu A, Sharpe M, et al. The detection and management of emotional distress in cancer patients: the views of health-care professionals: The detection and management of emotional distress. Psychooncology. 2011;20(6):601–8.

46. National Institute for Clinical Excellence. Guidance on cancer services - Improving supportive and palliative care for adults with cancer - The Manual. London: NHS; 2004.

47. Deckx L, Chow K, Askew D, van Driel M, Mitchell G, van den Akker M. Psychosocial care for cancer survivors: A systematic literature review on the role of general practitioners. Psychooncology. 2021;30(4):444–54.

48. Boekhout A, Maunsell E, Pond G, Julian JA, Coyle D, Levine M, et al. A survivorship care plan for breast cancer survivors: extended results of a randomized clinical trial. J Cancer Surviv. 2015;9(4):683–91.

49. Emery J, Jefford M, King M, Hayne D, Martin A, Doorey J, et al. ProCare Trial: a phase II randomized controlled trial of shared care for follow-up of men with prostate cancer. BJU International. 2017;119(3):381–9.

50. Gall C, Weller D, Esterman A, Pilotto L, McGorm K, Hammett Z, et al. Patient satisfaction and health-related quality of life after treatment for colon cancer. Dis Colon Rectum. 2007;50(6):801–9.

51. Grunfeld E, Levine M, Julian J, Coyle D, Szechtman B, Mirsky D, et al. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. J Clin Oncol. 2006;24(6):848–55.

52. Kvale E, Huang CH, Meneses K, Demark-Wahnefried W, Bae S, Azuero C, et al. Patient-Centered Support in the Survivorship Care Transition: Outcomes From the Patient-Owned Survivorship Care Plan Intervention. J Cancer. 2016;122(20):3232–42.

53. Beumeler L, Waarsenburg E, Booij S, Scheurink A, Hoenders H. Evaluation of a lifestyle intervention program in primary care on physical and mental health and quality of life of cancer survivors: A pilot study. Eur J Integr Med. 2018;23:1–5.

54. Sharpe M, Walker J, Holm Hansen C, Martin P, Symeonides S, Gourley C, et al. Integrated collaborative care for comorbid major depression in patients with cancer (SMaRT Oncology-2): a multicentre randomised controlled effectiveness trial. Lancet. 2014;384(9948):1099–108.

55. Walker J, Hansen C, Martin P, Symeonides S, Gourley C, Wall L, et al. Integrated collaborative care for major depression comorbid with a poor prognosis cancer (SMaRT Oncology-3): a multicentre randomised controlled trial in patients with lung cancer. Lancet Oncol. 2014;15(10):1168–76.

56. Bray F, Ferlay J, Soerjomataram I, Siegel R, Torre L, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2018;68(6):394–424.

57. Australian Institute of Health, Australasian Association of Cancer Registries. Cancer in Australia 2000. Canberra: AIH and AACR; 2003. (Can 23).

58. Roser M, Ritchie H. Our World in Data. [Internet]. England; 2018 [Accessed 2022 Dec 5]. Available from: https://ourworldindata.org/cancer. Our World in Data. 2018.

59. Australian Institute of Health and Welfare. Australian Cancer Database. [Internet]. AIHW: Canberra; 2014 [Accessed 2020 Nov 24]. Available from: https://www.aihw.gov.au/about-our-data/our-data-collections/australian-cancer-database. Australian Institute of Health and Welfare.

60. Institute of Medicine. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. Institute of Medicine. Washington, D.C: National Academies Press; 2013.

61. Nielsen J, Palshof T, Mainz J, Jensen, Olesen F. Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. Qual Saf Health Care. 2003;12(4):263–72.

62. Laporte C, Vaure J, Bottet A, Eschalier B, Raineau C, Pezet D, et al. French women's representations and experiences of the post-treatment management of breast cancer and their perception of the general practitioner's role in follow-up care: A qualitative study. Health Expect. 2017;20(4):788–96.

63. Lang V, Walter S, Fessler J, Koester M, Ruetters D, Huebner J. The role of the general practitioner in cancer care: a survey of the patients' perspective. J Cancer Res Clin Oncol. 2017;143(5):895–904.

64. Rubin G, Berendsen A, Crawford S, Dommett R, Earle C, Emery J, et al. The expanding role of primary care in cancer control. Lancet Oncol. 2015;16(12):1231–72.

65. Clinical Oncology Society of Australia. Model of Survivorship Care - Critical Components of Cancer Survivorship Care in Australia. Sydney: COSA; 2016.

66. Cancer Australia. Principles of Cancer Survivorship. Sydney: Cancer Australia; 2017.

67. Cancer Council Victoria and Department of Health Victoria. Optimal care pathway for people with breast cancer. Cancer Council Victoria, Melbourne; 2021.

68. Runowicz C, Leach C, Henry N, Henry K, Mackey HT, Cowens-Alvarado R, et al. American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline. JCO. 2016;34(6):611–35.

69. Resnick M, Lacchetti C, Bergman J, Hauke R, Hoffman K, Kungel TM, et al. Prostate Cancer Survivorship Care Guideline: American Society of Clinical Oncology Clinical Practice Guideline Endorsement. JCO. 2015;33(9):1078–85.

70. National Institute for Clinical Excellence. Early and locally advanced breast cancer: diagnosis and management. London: NICE; 2018. Report No.: NG101.

71. Cancer Council Victoria and Department of Health Victoria. Optimal care pathway for men with prostate cancer, 2nd edn. Cancer Council Victoria, Melbourne; 2021.

72. McCance T, McCormack B, Dewing J. An exploration of person-centredness in practice. Online J Issues Nurs. 2011;16(2):1.

73. de Silva D. Helping measure person-centred care A review of evidence about commonly used approaches and tools used to help measure person-centred care. Health Foundation, London; 2014.

74. Australian Commission on Safety and Quality in Health Care. Patient-centred care: improving quality and safety through partnerships with patients and consumers. Sydney: Australian Commission on Safety and Quality in Health Care; 2011.

75. Delaney L. Patient-centred care as an approach to improving health care in Australia. Collegian Aust J Nurs Prac. 2018;25(1):119–23.

76. National Health Service. Creating a Patient-led NHS Delivering the NHS Improvement Plan. Department of Health, London. 2005;39.

77. Department of Health and Human Services. Personalized Health Care: Pioneers, Partnerships, Progress. Washington, D.C; 2008 p. 1–302.

78. Department of Health. Models of Care for Cancer. WA Cancer & Palliative Care Network, Department of Health, Western Australia; 2008.

79. Brandenbarg D, Berendsen AJ, de Bock GH. Patients' expectations and preferences regarding cancer follow-up care. Maturitas. 2017;105:58–63.

80. Brennan M, Butow P, Spillane A, Boyle F. Survivorship care after breast cancer: Follow-up practices of Australian health professionals and attitudes to a survivorship care plan: Breast cancer survivorship care survey. J Clin Oncol. 2010;6(2):116–25.

81. Cheung W, Neville B, Cameron D, Cook E, Earle C. Comparisons of Patient and Physician Expectations for Cancer Survivorship Care. J Clin Oncol. 2009;27(15):2489–95.

82. Haggstrom D, Arora N, Helft P, Clayman M, Oakley-Girvan I. Follow-up Care Delivery Among Colorectal Cancer Survivors Most Often Seen by Primary and Subspecialty Care Physicians. J Gen Intern Med. 2009;24(S2):472–9.

83. Kimman M, Dellaert B, Boersma L, Lambin P, Dirksen C. Follow-up after treatment for breast cancer: one strategy fits all? An investigation of patient preferences using a discrete choice experiment. Acta Oncol. 2010;49(3):328–37.

84. Papagrigoriadis S. Patients' views on follow up of colorectal cancer: implications for risk communication and decision making. Postgrad Med J. 2003;79(933):403–7.

85. Leeson S, Stuart N, Sylvestre Y, Hall L, Whitaker R. Gynaecological cancer follow-up: national survey of current practice in the UK. BMJ Open. 2013;3(7):e002859.

86. Mao J, Bowman M, Stricker C, DeMichele A, Jacobs L, Chan D, et al. Delivery of Survivorship Care by Primary Care Physicians: The Perspective of Breast Cancer Patients. J Clin Oncol. 2009;27(6):933–8.

87. Mayer E, Gropper A, Neville B, Partridge A, Cameron D, Winer E, et al. Breast Cancer Survivors' Perceptions of Survivorship Care Options. J Clin Oncol. 2012;30(2):158–63.

88. Miedema B, MacDonald I, Tatemichi S. Cancer follow-up care. Patients' perspectives. Can Fam Physician. 2003;49:890–5.

89. Brandenbarg D, Roorda C, Stadlander M, de Bock G, Berger M, Berendsen A. Patients' views on general practitioners' role during treatment and follow-up of colorectal cancer: a qualitative study. Family Practice. 2017;34(2):234–8.

90. Watson E, O'Brien R, Campbell C, Weller D, Neal R, Wilkinson C, et al. Views of health professionals on the role of primary care in the follow-up of men with prostate cancer. Family Practice. 2011;28(6):647–54.

91. Aubin M, Vézina L, Verreault R, Fillion L, Hudon É, Lehmann F, et al. Patient, Primary Care Physician and Specialist Expectations of Primary Care Physician Involvement in Cancer Care. J Gen Intern Med. 2012;27(1):8–15.

92. Smith J, Sibthorpe B. Divisions of general practice in Australia: how do they measure up in the international context? ANZJPH. 2007;4:15.

93. Piterman L, Koritsas S. Part I. General practitioner-specialist relationship. Intern Med J. 2005;35(7):430–4.

94. Emery J, Shaw K, Williams B, Mazza D, Fallon-Ferguson J, Varlow M, et al. The role of primary care in early detection and follow-up of cancer. Nat Rev Clin Oncol. 2014;11(1):38–48.

95. Grunfeld E, Fitzpatrick R, Mant D, Yudkin P, Adewuyi-Dalton R, Stewart J, et al. Comparison of breast cancer patient satisfaction with follow-up in primary care versus specialist care: results from a randomized controlled trial. Br J Gen Pract. 1999;49(446):705–10.

96. Jefford M, Howell D, Li Q, Lisy K, Maher J, Alfano CM, et al. Improved models of care for cancer survivors. Lancet. 2022;399(10334):1551–60.

97. Potosky A, Han P, Rowland J, Klabunde C, Smith T, Aziz N, et al. Differences Between Primary Care Physicians' and Oncologists' Knowledge, Attitudes and Practices Regarding the Care of Cancer Survivors. J Gen Intern Med. 2011;26(12):1403–10.

98. Virgo K, Lerro C, Klabunde C, Earle C, Ganz P. Barriers to Breast and Colorectal Cancer Survivorship Care: Perceptions of Primary Care Physicians and Medical Oncologists in the United States. J Clin Oncol. 2013;31(18):2322–36.

99. Lewis R, Neal R, Hendry M, France B, Williams NH, Russell D, et al. Patients' and healthcare professionals' views of cancer follow-up: systematic review. Br J Gen Pract. 2009;59(564):533.

100. Murchie P, Norwood P, Pietrucin-Materek M, Porteous T, Hannaford P, Ryan M. Determining cancer survivors' preferences to inform new models of follow-up care. Br J Cancer. 2016;115(12):1495–503.

101. Koinberg I, Fridlund B, Engholm G, Holmberg L. Nurse-led follow-up on demand or by a physician after breast cancer surgery: a randomised study. Eur J Oncol Nurs. 2004;8(2):109–20.

102. Saltbæk L, Karlsen R, Bidstrup P, Høeg BL, Zoffmann V, Horsbøl T, et al. MyHealth: specialist nurse-led follow-up in breast cancer. A randomized controlled trial – development and feasibility. Acta Oncol. 2019;1–8.

103. McFarlane K, Dixon L, Wakeman C, Robertson G, Eglinton T, Frizelle F. The process and outcomes of a nurse-led colorectal cancer follow-up clinic: A nurse-led colorectal cancer follow-up clinic. Colorectal Dis. 2012;14(5):e245–9.

104. Cox K, Wilson E, Heath L, Collier J, Jones L, Johnston I. Preferences for Follow-up After Treatment for Lung Cancer: Assessing the Nurse-led Option. Cancer Nursing. 2006;29(3):176–87.

105. Moore S, Corner J, Haviland J, Wells M, Salmon E, Normand C, et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. BMJ. 2002;325:7.

106. Bessen T, Chen G, Street J, Eliott J, Karnon J, Keefe D, et al. What sort of follow-up services would Australian breast cancer survivors prefer if we could no longer offer long-term specialist-based care? A discrete choice experiment. Br J Cancer. 2014;110(4):859–67.

107. Jiwa M, Halkett G, Deas K, Meng X. Women with breast cancers' preferences for surveillance follow-up. Collegian. 2011;18(2):81–6.

108. National Health Service England. Technology Enabled Care Services (TECS). [Internet]. NHS: London [Accessed 2022 Aug 11]. Available from: https://www.england nhs.uk/tecs/.

109. Catalyst N. What Is Telehealth? Telehealth: The delivery of health care, health education, and health information services via remote technologies. [Internet]. Massachusetts; 2018 [Accessed 2022 Aug 11]. Available from: https://catalyst nejm.org/doi/full/10.1056/CAT.18.0268. NEJM catalyst innovations in care delivery.

110. Zon R, Kennedy E, Adelson K, Blau S, Dickson N, Gill D, et al. Telehealth in Oncology: ASCO Standards and Practice Recommendations. JCO Oncol Pract. 2021;17(9):546–64.

111. Leonardsen A, Helgesen A, Stensvold A, Magnussen J, Grøndahl V. Cancer patients' perspectives on remote monitoring at home during the COVID-19 pandemic- a qualitative study in Norway. BMC Health Serv Res. 2022;22(1):453.

112. Chazan G, Franchini F, Alexander M, Banerjee S, Mileshkin L, Blinman P, et al. Impact of COVID-19 on cancer service delivery: results from an international survey of oncology clinicians. ESMO Open. 2020;5(6):e001090.

113. Cohen H. A Model for the Shared Care of Elderly Patients with Cancer. JAGS. 2009;57:s300–2.

114. Lucas C, Charlton K, Brown L, Brock E, Cummins L. Review of patient satisfaction with services provided by general practitioners in an antenatal shared care program. Aust Fam Physician. 2015;44(5):317–21.

115. Drummond N, Abdalla M, Buckingham JK, Beattie J a. G, Lindsay T, Osman L, et al. Integrated care for asthma: a clinical, social, and economic evaluation. BMJ. 1994;308(6928):559–64.

116. Smith S, O'Leary M, Bury G, Shannon W, Tynan A, Staines A, et al. A qualitative investigation of the views and health beliefs of patients with Type 2 diabetes following the introduction of a diabetes shared care service. Diabet Med. 2003;20(10):853–7.

117. Sebern M, Woda A. Shared Care Dyadic Intervention: Outcome Patterns for Heart Failure Care Partners. West J Nurs Res. 2012;34(3):289–316.

118. Grunfeld E, Julian J, Pond G, Maunsell E, Coyle D, Folkes A, et al. Evaluating Survivorship Care Plans: Results of a Randomized, Clinical Trial of Patients With Breast Cancer. J Clin Oncol. 2011;29(36):4755–62.

119. Johnson C, Saunders C, Phillips M, Emery J, Nowak AK, Overheu K, et al. Randomized Controlled Trial of Shared Care for Patients With Cancer Involving General Practitioners and Cancer Specialists. J Oncol Pract. 2015;11(5):349–55.

120. Grunfeld E. Cancer survivorship: a challenge for primary care physicians. Br J Gen Pract. 2005;55(519):741–2.

121. Anvik T, Holtedahl K, Mikalsen H. "When patients have cancer, they stop seeing me" -- the role of the general practitioner in early follow-up of patients with cancer -- a qualitative study. Fam Pract. 2006;7:1–9.

122. Aubin M, Vezina L, Verreault R, Fillion L, Hudon E, Lehmann F, et al. Family Physician Involvement in Cancer Care Follow-up: The Experience of a Cohort of Patients With Lung Cancer. Ann Fam Med. 2010;8(6):526–32.

123. Brennan M, Butow P, Marven M, Spillane A, Boyle F. Survivorship care after breast cancer treatment – Experiences and preferences of Australian women. The Breast. 2011;20(3):271–7.

124. Forster D, Newton M, McLachlan H, Willis K. Exploring implementation and sustainability of models of care: can theory help? BMC Public Health. 2011;11(5):S8.

125. Polit D, Tatano Beck C. Generating and Assessing Evidence for Nursing Practice. 10th ed. Philadelphia: Wolters Kluwer Health; 2017.

126. Sekhon M, Cartwright M, Francis J. Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. BMC Health Serv Res. 2017;17(1).

127. Guba E, Lincoln Y. Competing paradigms in qualitative research. In: Handbook of qualitative research. Thousand Oaks, CA, US: Sage Publications, Inc; 1994. p. 105–17.

128. Syed J, Mingers J, Murray P. Beyond Rigour and Relevance: A Critical Realist Approach to Business Education. Manag Learn. 2010;(1).

129. Bishop J, Scott, Goldsby M. A Construct Validity Study of Commitment and Perceived Support Variables: A Multifoci Approach across Different Team Environments. GOM. 2005;30(2).

130. Bhaskar R. On the Possibility of Social Scientific Knowledge and the Limits of Naturalism -. J Theory Soc Behaviour. 1978;8.

131. Bhaskar R. On the Ontological Status of Ideas. J Theory Soc Behaviour. 1997;27(3):39–147.

132. Brönnimann A. How to phrase critical realist interview questions in applied social science research. Journal of Critical Realism. 2022;21(1):1–24.

133. Fletcher A. Applying critical realism in qualitative research: methodology meets method. Int J Soc Res Methodol. 2016;20(2):181.

134. Sturgiss E, Clark A. Using critical realism in primary care research: an overview of methods. Fam Pract. 2020;37(1):143–5.

135. Clark A. What are the components of complex interventions in healthcare? Theorizing approaches to parts, powers and the whole intervention. Soc Sci Med. 2013;93:185–93.

136. Harwood L, Clark A. Understanding health decisions using critical realism: home-dialysis decision-making during chronic kidney disease. Nursing Inquiry. 2012;19(1):29–38.

137. Bhaskar R. A realist theory of science. London ; New York: Routledge Taylor & Francis Group; 2008. 284 p.

138. McEvoy P, Richards D. Critical realism: a way forward for evaluation research in nursing? J Adv Nurs. 2003;43(4):411–20.

139. Sobh R, Perry C. Research design and data analysis in realism research. Eur J Mark. 2006;40(11/12):1194–209.

140. Niiniluoto I. Chapter 4 - Realism in Epistemology. In: Critical Scientific Realism. Oxford Academic; 2002.

141. Lemercier C, Zalc C, Goldhammer A. Quantitative Methods in the Humanities: An Introduction. Charlottesville, United States: University of Virginia Press; 2019.

142. Suter W. Qualitative Data, Analysis, and Design, Chapter 12. In: Introduction to Educational Research: A critical thinking approach. 2nd ed. California, USA: Sage Publications; 2011. p. 342–84.

143. Patton M. Qualitative Research and Evaluation Methods. 4th ed. Thousand Oaks: Sage Publications; 2015.

144. Okoli C. Critical Realist Considerations for Literature Reviews. SSRN. 2015;

145. Wasti S, Simkhada P, Teijlingen, Sathian, Banerjee I. The Growing Importance of Mixed-Methods Research in Health. Nepal J Epidemiol. 2022;12(1):1175–8.

146. Ranganathan P, Aggarwal R. Study designs: Part 1 – An overview and classification. Perspect Clin Res. 2018;9(4):184–6.

147. Ranganathan P, Aggarwal R. Study designs: Part 7 – Systematic reviews. Perspect Clin Res. 2020;11(2):97–100.

148. Moher D, Stewart L, Shekelle P. Implementing PRISMA-P: recommendations for prospective authors. Systematic Reviews. 2016;5(1):15.

149. PRISMA Checklist 2020 - 27-item checklist. [Internet]. [Accessed 2022 Oct 24]. Available from: https://prisma-statement.org/PRISMAStatement/Checklist.aspx.

150. Danermark, Ekström, Karlsson J. Explaining Society | Critical Realism in the Social Sciences | Berth D. 2nd edn. London: Routledge; 2019. 242 p.

151. Setia MS. Methodology Series Module 3: Cross-sectional Studies. Indian J Dermatol. 2016;61(3):261–4.

152. American Society for Quality. What is a Data Collection Survey? [Internet]. ASQ: Milwaukee; 2022 [Accessed 2023 Mar 13]. Available from: https://asq.org/quality-resources/survey.

153. Covell C, Sidani S, Ritchie J. Does the sequence of data collection influence participants' responses to closed and open-ended questions? A methodological study. Int J Nurs Stud. 2012;49(6):664–71.

154. Doyle-Lindrud S. The evolution of the electronic health record. Clin J Oncol Nurs. 2015;19(2):153–4.

155. Dash S, Shakyawar S, Sharma M, Kaushik S. Big data in healthcare: management, analysis and future prospects. J Big Data. 2019;6(1):54.

156. Smith C, Elger T. Critical Realism and Interviewing Subjects. In: Edwards PK, O'Mahoney J, Vincent S, editors. Studying Organizations Using Critical Realism: A Practical Guide. Oxford University Press; 2014.

157. Archer M. Realist Social Theory: The Morphogenetic Approach. Cambridge University Press; 1995. 370 p.

158. Mingers J. A Critique of Statistical Modelling from a Critical Realist Perspective. ECIS 2003 Proceedings. 2003;81.

159. Yeung H. Critical realism and realist research in human geography: a method or a philosophy in search of a method? Prog Hum Geogr. 1997;21:51–74.

160. Maxwell J. A Realist Approach for Qualitative Research. 1st ed. Sage Publications Inc; 2012.

161. Blair E. A reflexive exploration of two qualitative data coding techniques. JMM. 2015;6:14–29.

162. Chinn C, Brewer W. Models of Data: A Theory of How People Evaluate Data. Cogn Instr. 2001;19(3).

163. Denzin N. The Research Act: A Theoretical Introduction to Sociological Methods. Transaction Publishers; 2017. 384 p.

164. Flick U. Triangulation Revisited: Strategy of Validation or Alternative? J Theory Soc Behav. 1992;22(2).

165. Gilbert N. Researching social life. Thousand Oaks, CA, US: Sage Publications, Inc; 1993. 366 p.

166. Mathison S. Why Triangulate? Vol. 17. American Educational Research Association; 1988.

167. McEvoy P, Richards D. A critical realist rationale for using a combination of quantitative and qualitative methods. J Res Nurs. 2006;11(1):66–78.

168. Bechara J, Van den ven A. Triangulating Philosophies of Science to Understand Complex Organizational and Managerial Problems. Phil Org Theory. 2011;32:22.

169. Collier A. Critical realism: an introduction to Roy Bhaskar's philosophy. London ; Verso; 1994. 276 p.

170. Ryan G, Rutty J. Philosophy and quality? TAPUPASM as an approach to rigour in critical realist research. Nurse Res. 2019;27(1):33–40.

171. Pawson R. Types and Quality of Knowledge in Social Care. London: Social Care Institute for Excellence; 2003. 83 p.

172. Porter S. Validity, trustworthiness and rigour: reasserting realism in qualitative research. J Adv Nurs. 2007;60(1):79–86.

173. The National Health and Medical Research Council, Australian Research Council and Universities Australia, Commonwealth of Australia. National Statement on Ethical Conduct in Human Research. 2018;116.

174. Illawarra Shoalhaven Local Health District. Information for researchers [Internet]. Wollongong: ISLHD; 2013 [Accessed 2023 Mar 24]. Available from: https://documents.uow.edu.au/content/groups/public/@web/@raid/documents/doc/uow157677.pdf

175. Pieper I, Thomson C. The value of respect in human research ethics: a conceptual analysis and a practical guide. Monash Bioeth Rev. 2014;32(3–4):232–53.

176. Barnes E, Chow E, Danjoux C, Tsao M. Collaboration between primary care physicians and radiation oncologists. Ann Palliat Med. 2017;6(1):81–6.

177. Gosain R, Miller K. Symptoms and symptom management in long-term cancer survivors. Cancer. 2013;19(5):405–9.

178. Lewis R, Neal R, Williams N, France B, Hendry M, Russell D, et al. Follow-up of cancer in primary care versus secondary care: systematic review. Br J Gen Pract. 2009;59(564):e234-247.

179. Brennan M, Jefford M. General Practitioner-based Models of Post-treatment Follow Up. Cancer Forum. 2009;(3):180.

180. Hickman M, Drummond N, Grimshaw J. A taxonomy of shared care for chronic disease. J Public Health Med. 1994;16(4):447–54.

181. Wait S, Han D, Muthu V, Oliver K, Chrostowski S, Florindi F, et al. Towards sustainable cancer care: Reducing inefficiencies, improving outcomes—A policy report from the All.Can initiative. J Cancer Policy. 2017;13:47–64.

182. Pezaro C, Jefford M. Early stage bowel cancer – follow up and survivorship. Aust Fam Physician. 2009;205–8.

183. Grunfeld E, Mant D, Vessey M, Yudkin P. Evaluating primary care follow-up of breast cancer: Methods and preliminary results of three studies. Ann Oncol. 1995;6(suppl 2):S47–52.

184. Picker. Principles of person centred care. [Internet]. Picker: Oxford [Accessed 2018 Nov 24]. Available from: https://www.picker.org/about-us/picker-principles-of-person-centred-care/. Picker. 2015.

185. Lund AS, Lund L, Jønler M, Graversen P, Bro F, Borre M. Shared care in prostate cancer: a three-year follow-up. Scand J Urol. 2016;50(5):346–51.

186. Rychetnik L, Morton RL, McCaffery K, Thompson JF, Menzies SW, Irwig L. Shared care in the follow-up of early-stage melanoma: a qualitative study of Australian melanoma clinicians' perspectives and models of care. BMC Health Ser Res. 2012;12(1):468–76.

187. Bro F, Lund L, Morten J, Peter G, Michael B. "To be followed up in general practice" - developing and implementing a shared care model for prostate cancer. Int J Integr Care. 2017;17(3):71–2.

188. Ghezzi P, Magnanini S, Rinaldini M, Berardi F, Biagio GD, Testare F, et al. Impact of Follow-up Testing on Survival and Health-Related Quality of Life in Breast Cancer Patients: A Multicenter Randomized Controlled Trial. JAMA. 1994;271(20):1587–92.

189. Grunfeld E, Mant D, Yudkin P, Adewuyi-Dalton R, Cole D, Stewart J, et al. Routine follow up of breast cancer in primary care: randomised trial. BMJ. 1996;313(7058):665–9.

190. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ. 2009;339(1):2535.

191. Brandt Eriksen M, Faber Frandsen T. The impact of patient, intervention, comparison, outcome (PICO) as a search strategy tool on literature search quality: a systematic review. J Med Libr Assoc. 2018;106(4):420–31.

192. Joanna Briggs Institute. Checklist for systematic reviews and research syntheses. [Internet]. JBI: Adelaide; 2017 [Accessed 2021 Feb 11]. Available from: https://jbi.global/critical-appraisal-tools.

193. Braun V, Clarke V. Using thematic analysis in psychology. Qual Psychol. 2006;3(2):77–101.

194. Berkowitz C, Allen D, Tenhover J, Zullig L, Ragsdale J, Fischer JE, et al. Knowledge and preferences of primary care providers in delivering head and neck cancer survivorship care. J Cancer Educ. 2018;33(6):1323–7.

195. Cheung W, Aziz N, Noone AM, Rowland J, Potosky AL, Ayanian J, et al. Physician preferences and attitudes regarding different models of cancer survivorship care: a comparison of primary care providers and oncologists. J Cancer Surviv. 2013;7(3):343–54.

196. Coschi C, Bainbridge D, Sussman J. Understanding the Attitudes and Beliefs of Oncologists Regarding the Transitioning and Sharing of Survivorship Care. Current Oncol. 2021;28(6):5452–65.

197. Crabtree B, Miller W, Howard J, Rubinstein EB, Tsui J, Hudson S, et al. Cancer Survivorship Care Roles for Primary Care Physicians. Ann Fam Med. 2020;18(3):202–9.

198. Dahlhaus A, Vanneman N, Guethlin C, Behrend J, Siebenhofer A. German general practitioners' views on their involvement and role in cancer care: a qualitative study. Family Practice. 2014;31(2):209–14.

199. Del Giudice M, Grunfeld E, Harvey B, Piliotis E, Verma S. Primary Care Physicians' Views of Routine Follow-Up Care of Cancer Survivors. J Clin Oncol. 2009;27(20):3338–45.

200. DiCicco-Bloom B, Cunningham R. The experience of information sharing among primary care clinicians with cancer survivors and their oncologists. J Cancer Surviv. 2013;7(1):124–30.

201. Doose M, McGee-Avila J, Stroup Antoinette, Ferrante J, Xu B, Herman N, et al. Shared Care During Breast and Colorectal Cancer Treatment: Is It Associated With Patient-Reported Care Quality? J Healthcare Qual. 2019;1.

202. Fidjeland H, Brekke M, Vistad I. General practitioners' attitudes toward follow-up after cancer treatment: A cross-sectional questionnaire study. Scand J Prim Health Care. 2015;33(4):223–32.

203. Fok R, Low L, Quah HMJ, Vasanwala F, Low S, Soh L, et al. Roles and recommendations from primary care physicians towards managing low-risk breast cancer survivors in a shared-care model with specialists in Singapore—a qualitative study. Fam Pract. 2020;37(4):547–53.

204. Hall S, Samuel L, Murchie P. Toward shared care for people with cancer: developing the model with patients and GPs. Fam Pract. 2011;28(5):554–64.

205. Hanks H, Harris M, Veitch C. Managing Colorectal Cancer: The General Practitioner's Roles. Aust J Prim Health. 2008;14(3):78–84.

206. Haq R, Heus L, Baker NA, Dastur D, Leung F, Leung E, et al. Designing a multifaceted survivorship care plan to meet the information and communication needs of breast cancer patients and their family physicians: results of a qualitative pilot study. BMC Med Inform Decis Mak. 2013;13(1).

207. Hudson S, Miller S, Hemler J, Ferrante J, Lyle J, Oeffinger K, et al. Adult Cancer Survivors Discuss Follow-up in Primary Care: "Not What I Want, But Maybe What I Need." Ann Fam Med. 2012;10(5):418–27.

208. Hudson S, Ohman-Strickland PA, Bator A, O'Malley D, Gundersen D, Lee H, et al. Breast and prostate cancer survivors' experiences of patient-centered cancer follow-up care from primary care physicians and oncologists. J Cancer Surviv. 2016;10(5):906–14.

209. Klabunde C, Han P, Earle C, Smith T, Ayanian J, Lee R, et al. Physician Roles in the Cancer-Related Follow-Up Care of Cancer Survivors. Fam Med. 2013;45(7):463–74.

210. Klabunde C, Haggstrom D, Kahn K, Gray SW, Kim B, Liu B, et al. Oncologists' perspectives on post-cancer treatment communication and care coordination with primary care physicians. Eur J Cancer Care. 2017;26(4).

211. Lawn S, Fallon-Ferguson J, Koczwara B. Shared care involving cancer specialists and primary care providers - What do cancer survivors want? Health Expect. 2017;20(5):1081–7.

212. Lizama N, Johnson C, Ghosh M, Garg N, Emery J, Saunders C. Keeping primary care “in the loop”: General practitioners want better communication with specialists and hospitals when caring for people diagnosed with cancer. Asis Pac J Clin Oncol. 2015;11(2):152–9.

213. Puglisi F, Agostinetto E, Gerratana L, Bozza C, Cancian M, Iannelli E, et al. Caring for cancer survivors: perspectives of oncologists, general practitioners and patients in Italy. Future Oncol. 2017;13(3):233–48.

214. Roorda C, Berendsen A, Haverkamp M, van der Meer K, de Bock G. Discharge of breast cancer patients to primary care at the end of hospital follow-up: A cross-sectional survey. Eur J Cancer. 2013;49(8):1836–44.

215. Schütze H, Chin M, Weller D, Harris M. Patient, general practitioner and oncologist views regarding long-term cancer shared care. Fam Pract. 2018;35(3):323–9.

216. Sisler J, Khawaja M, Taylor-Brown J, Nugent Z, Bell D, Czaykowski P, et al. Continuity of care of colorectal cancer survivors at the end of treatment: The oncology-primary care interface. Journal of Cancer Survivorship. 2012;6(4):468–75.

217. Tan L, Gallego G, Nguyen T, Bokey L, Reath J. Perceptions of shared care among survivors of colorectal cancer from non-English-speaking and English-speaking backgrounds: a qualitative study. Fam Pract. 2018;19(1).

218. Taylor S, Johnson H, Peat S, Booker J, Yorke J. Exploring the experiences of patients, general practitioners and oncologists of prostate cancer follow-up: A qualitative interview study. Eur J Oncol Nurs. 2020;48.

219. Vuong K, Uebel K, Agaliotis M, Jun S, Taggart J, Suchy S, et al. Assessing suitability for long-term colorectal cancer shared care: a scenario-based qualitative study. Fam Pract. 2020;21(1):1–8.

220. Walter F, Usher-Smith J, Yadlapalli S, Watson E. Caring for people living with, and beyond, cancer: an online survey of GPs in England. Br J Gen Pract. 2015;65(640):761–8.

221. White V, Der Vartanian C, Tansley F, Ugalde A. Understanding women’s perspectives and information needs about shared follow-up care for early breast cancer: a qualitative study. Fam Pract. 2021;38(6):786–92.

222. Weaver K, Aziz N, Arora N, Forsythe L, Hamilton AS, Oakley-Girvan I, et al. Follow-Up Care Experiences and Perceived Quality of Care Among Long-Term Survivors of Breast, Prostate, Colorectal, and Gynecologic Cancers. J Oncol Pract. 2014;10(4):231–9.

223. Lisy K, Kent J, Piper A, Jefford M. Facilitators and barriers to shared primary and specialist cancer care: a systematic review. Support Care Cancer. 2021;29(1):85–96.

224. Taggart J, Chin M, Liauw W, Goldstein D, Dolezal A, Plahn J, et al. Challenges and solutions to sharing a cancer follow-up e-care plan between a cancer service and general practice. Public Health Res Pract. 2021;1–7.

225. Jefford M, Emery J, Grunfeld E, Martin A, Rodger P, Murray AM, et al. SCORE: Shared care of Colorectal cancer survivors: protocol for a randomised controlled trial. Trials. 2017;18(1).

226. Girgis A, Durcinoska I, Levesque JV, Gerges M, Sandell T, Arnold A, et al. eHealth System for Collecting and Utilizing Patient Reported Outcome Measures for Personalized Treatment and Care (PROMPT-Care) Among Cancer Patients: Mixed Methods Approach to Evaluate Feasibility and Acceptability. J Med Internet Res. 2017;19(10):330.

227. Schuler T, Miller A. PROsaiq: a smart device-based and EMR-integrated system for Patient-Reported Outcome measurement in routine cancer care. J Radiat Oncol. 2014;6(1):23111–31.

228. Karas P, Rankin N, Stone E. Medicolegal Considerations in Multidisciplinary Cancer Care. JTO Clin Res Rep. 2020;1(4).

229. Murchie P, Nicolson M, Hannaford P, Raja E, Lee A, Campbell N. Patient satisfaction with GP-led melanoma follow-up: a randomised controlled trial. Br J Cancer. 2010;102(10):1447–55.

230. Murchie P, Delaney E, Campbell N, Hannaford P. GP-led melanoma follow-up: views and feelings of patient recipients. Support Care Cancer. 2010;18(2):225–33.

231. Zhao Y, Brettle A, Qiu L. The Effectiveness of Shared Care in Cancer Survivors—A Systematic Review. Int J Integr Care. 2018;18(4):1–17.

232. Weber D. Medical Hegemony. Int J Complement Altern Med. 2016;3(2).

233. Ferrer R, Klein W. Risk perceptions and health behavior. Curr Opin Psychol. 2015;5:85–9.

234. Wattchow D, Weller D, Esterman A, Pilotto LS, McGorm K, Hammett Z, et al. General practice vs surgical-based follow-up for patients with colon cancer: randomised controlled trial. Br J Cancer. 2006;94(8):1116–21.

235. Chan R, Emery J, Cuff K, Teleni L, Simonsen C, Turner J, et al. Implementing a nurse-enabled, integrated, shared-care model involving specialists and general practitioners in breast cancer post-treatment follow-up: a study protocol for a phase II randomised controlled trial (the EMINENT trial). Trials. 2020;21(1):855.

236. Berendsen A, Roorda C, Jansen L, de Bock G. Patients' beliefs about the aims of breast cancer follow-up: A qualitative study. Maturitas. 2016;91:140–4.

237. Roorda C, de Bock G, Scholing C, van der Meer K, Berger M, de Fouw M, et al. Patients' preferences for post-treatment breast cancer follow-up in primary care vs. secondary care: a qualitative study. Health Expect. 2015;18(6):2192–201.

238. Brennan M, Butow P, Spillane A, Marven M, Boyle F. Follow up after breast cancer - views of Australian women. Aust Fam Physician. 2011;40(5):311–6.

239. Vanhuyse M, Bedard P, Sheiner J, Fitzgerald B, Clemons M. Transfer of Follow-up Care to Family Physicians for Early-stage Breast Cancer. Clin Oncol. 2007;19(3):172–6.

240. Grunfeld E, Gray A, Mant D, Yudkin P, Adewuyi-Dalton R, Coyle D, et al. Follow up of breast cancer in primary care vs specialist care: results of an economic evaluation. Br J Cancer. 1999;79(7–8):1227–33.

241. Koczwara B, White K, Emery J, Mitchell G, Mazza D, Yates P, et al. Principles Statement: Shared Care. PC4 Cancer Research in Primary Care, Victoria, Australia; 2016.

242. Johnson C, Lizama N, Garg N, Ghosh M, Emery J, Saunders C. Australian general practitioners' preferences for managing the care of people diagnosed with cancer. Asia Pac J Clin Oncol. 2014;10(2):90–8.

243. Greenfield D, Absolom K, Eiser C, Walters S, Michel G, Hancock B, et al. Follow-up care for cancer survivors: the views of clinicians. Br J Cancer. 2009;101(4):568–74.

244. Australian Institute of Health and Welfare. Cancer in Australia 2021 [Internet]. Canberra: AIHW; 2021 [Accessed 2022 Mar 23]. (Cancer series no. 133. Cat. no. CAN 144.). Available from: https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2021/summary

245. de Bruin A, Picavet H, Nossikov A, editors. Health interview surveys: towards international harmonization of methods and instruments. Copenhagen: World Health Organization, Regional Office for Europe; 1996. 161 p.

246. Kwan JYY, Croke J, Panzarella T, Ubhi K, Fyles A, Koch A, et al. Personalizing post-treatment cancer care: a cross-sectional survey of the needs and preferences of well survivors of breast cancer. Curr Oncol. 2019;26(2).

247. Young J, Durcinoska I, DeLoyde K, Solomon M. Patterns of follow up and survivorship care for people with colorectal cancer in new South Wales, Australia: a population-based survey. BMC Cancer. 2018;18.

248. Kost R, Correa da Rosa J. Impact of survey length and compensation on validity, reliability, and sample characteristics for Ultrashort-, Short-, and Long-Research Participant Perception Surveys. J Clin Transl Sci. 2018;2(1):31–7.

249. Clinical Excellence Commission. NSW Health Literacy Framework - 2019-2024. Sydney: Clinical Excellence Commission; 2019.

250. Salkind N. Encyclopedia of Research Design. Vol. 3. Kansas: Sage Publications; 2010.

251. Clark L, Watson D. Constructing validity: Basic issues in objective scale development. Psychological Assessment. 1995;7(3):309–19.

252. Henson R. Understanding internal consistency reliability estimates: A conceptual primer on coefficient alpha. Meas Eval Couns Dev. 2001;34(3):177.

253. Odom L, Morrow, Jr. J. What’s this r? A Correlational Approach to Explaining Validity, Reliability and Objectivity Coefficients. Meas Phys Educ Exerc Sci. 2006;10(2):137–45.

254. Oktavia R, Irwandi, Rajibussalim, Mentari M, Mulia I. Assessing the validity and reliability of questionnaires on the implementation of Indonesian curriculum K-13 in STEM education. J Phys Conf Ser. 2018;1088.

255. IBM Corp. Released 2021. IBM SPSS Statistics for Windows, Version 29.0. Armonk, NY: IBM Corp.

256. Baena-Cañada J, Ramírez-Daffós P, Cortés-Carmona C, Rosado-Varela P, Nieto-Vera J, Benítez-Rodríguez E. Follow-up of long-term survivors of breast cancer in primary care versus specialist attention. Fam Pract. 2013;30(5):525–32.

257. Bandura A. Health promotion from the perspective of social cognitive theory. Psychol Health. 1998;13(4):623–49.

258. McCabe M, Bhatia S, Oeffinger KC, Reaman GH, Tyne C, Wollins DS, et al. American Society of Clinical Oncology Statement: Achieving High-Quality Cancer Survivorship Care. J Clin Oncol. 2013;31(5):631–40.

259. Aubin M, Vézina L, Verreault R, Fillion L, Hudon É, Lehmann F, et al. Family physician involvement in cancer care and lung cancer patient emotional distress and quality of life. Support Care Cancer. 2011;19(11):1719.

260. Van Haitsma K, Abbott K, Arbogast A, Bangerter L, Heid AR, Behrens L, et al. A Preference-Based Model of Care: An Integrative Theoretical Model of the Role of Preferences in Person-Centered Care. Bowers B, editor. Gerontologist. 2020;60(3):376–84.

261. Adam R, Watson E. The role of primary care in supporting patients living with and beyond cancer: Curr Opin Support Palliat Care. 2018;12:261–7.

262. Torre L, Bray F, Siegel R, Ferlay J, Lortet-Tieulent J, Jemal A. Global cancer statistics, 2012. CA Cancer J Clin. 2015;65(2):87–108.

263. Cancer Australia. Cancer Australia Strategic Plan 2014–2019,. Surry Hills, NSW: Cancer Australia; 2014.

264. Cheung W. Sharing clinical responsibility in personalized management of colorectal cancer. Oncology Exchange. 2014;13(1):11–2.

265. Nyarko E, Metz J, Nguyen GT, Archer M, Jacobs L, Mao J. Cancer survivors’ perspectives on delivery of survivorship care by primary care physicians: an internet-based survey. Fam Pract. 2015;16(1).

266. Sisler J, Chaput G, Sussman J, Ozokwelu E. Follow-up after treatment for breast cancer: Practical guide to survivorship care for family physicians. Can Fam Physician. 2016;62(10):805–11.

267. Franco K, Shuk E, Philip E, Blanch-Hartigan D, Parker P, Matasar M, et al. Communication between oncologists and lymphoma survivors during follow-up consultations: A qualitative analysis. J Psychosoc Oncol. 2017;35(5):513–30.

268. Braun T, Hagen N, Smith C, Summers N. Oncologists and family physicians. Using a standardized letter to improve communication. Can Fam Physician. 2003;49:882–6.

269. O'Brien M, Grunfeld E, Sussman J, Porter G, Hammond Mobilio M. Views of family physicians about survivorship care plans to provide breast cancer follow-up care: exploration of results from a randomized controlled trial. Curr Oncol. 2015;22(4):252.

270. Creswell J, Plano Clark V, Guttman M, Hanson W. Advanced mixed methods research designs. In: Tashakkori A, Teddlie C, eds. Handbook on Mixed Methods in the Behavioral and Social Sciences. Thousand Oaks, California: Sage Publications; 2003.

271. Britt H, Miller G, Bayram C, Henderson J, Valenti L, Harrison C et. al. A decade of Australian general practice activity 2006-07 to 2015-16. Sydney University Press; 2016.

272. Girgis A, Durcinoska I, Arnold A, Kaadan N, Miller A, Descallar J, et al. Phase III non-randomized controlled trial of PROMPT-Care, an eHealth intervention utilizing patient reported outcomes in routine clinical care: Impact on emergency department presentations. J Clin Oncol. 2019;37(15):6510–6510.

273. Creswell J. Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks: Sage Publications; 1998.

274. McHugh M. Interrater reliability: the kappa statistic. Biochem Med. 2012;22(3):276–82.

275. Cancer Institute NSW. Radiation oncology - eviQ Education. [Internet} CINSW: Sydney; 2018 [Accessed 202 Oct 27]. Available from: https://education.eviq.org.au/courses/radiation-oncology/radiation-oncology.

276. Cox J, Stetz J, Pajak T. Toxicity criteria of the Radiation Therapy Oncology Group (RTOG) and the European organization for research and treatment of cancer (EORTC). Int J Radiat Oncol Biol Phys. 1995;31(5):1341–6.

277. Trotti A, Colevas A, Setser A, Rusch V, Jaques D, Budach V, et al. CTCAE v3.0: development of a comprehensive grading system for the adverse effects of cancer treatment. Semin Radiat Oncol. 2003;13(3):176–81.

278. Nowell L, Norris J, White D, Moules N. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. International Journal of Qualitative Methods. 2017 Dec;16(1):160940691773384.

279. Sakorafas G, Tsi A. Follow-up after Primary Treatment for Breast Cancer. Acta Oncologica. 2000 Jan;39(8):935–40.

280. Allam O, Gray A, Bailey H, Morrey D. Primary care oncology: addressing the challenges. J Innov Health Inform. 2006 Sep 1;14(3):167–73.

281. Dickinson R, Hall S, Sinclair J, Bond C, Murchie P. Using technology to deliver cancer follow-up: a systematic review. BMC Cancer. 2014 Dec;14(1).

282. Wu Z, McGoogan J. Characteristics of and Important Lessons From the Coronavirus Disease 2019 (COVID-19) Outbreak in China: Summary of a Report of 72 314 Cases From the Chinese Center for Disease Control and Prevention. JAMA. 2020;323(13):1239–42.

283. American Medical Association. AMA Telehealth quick guide. [Internet]. AMA: Chicago; 2021 [Accessed 2021 Jun 22]. Available from: https://www.ama-assn.org/practice-management/digital/ama-telehealth-quick-guide. AMA quick guide to telemedicine in practice.

284. Cancer Australia. Cancer care in the time of COVID-19: A conceptual framework for the management of cancer during a pandemic. Surry Hills NSW Australia: Cancer Australia; 2020 p. 49.

285. Monaghesh E, Hajizadeh A. The role of telehealth during COVID-19 outbreak: a systematic review based on current evidence. BMC Pub Health. 2020;20(1):1193.

286. Marandino L, Necchi A, Aglietta M, Di Maio M. COVID-19 Emergency and the Need to Speed Up the Adoption of Electronic Patient-Reported Outcomes in Cancer Clinical Practice. J Oncol Pract. 2020;OP.20.00237.

287. U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research, U.S. Department of Health and Human Services FDA Center for Biologics Evaluation and Research, U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. Health Qual Life Outcomes. 2006;4(1):79.

288. Weldring T, Smith S. Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). Health Serv Insights. 2013;6:61–8.

289. Gotay C, Kawamoto C, Bottomley A, Efficace F. The prognostic significance of patient-reported outcomes in cancer clinical trials. J Clin Oncol. 2008;26(8):1355–63.

290. Arnold B, Halkett G, Dhillon H, Girgis A. Do radiation therapists feel able to routinely screen for symptoms and distress in people with cancer: barriers impacting practice. J Med Radiat Sci. 2021;68:465.

291. Brucker P, Yost K, Cashy J, Webster K, Cella D. General Population and Cancer Patient Norms for the Functional Assessment of Cancer Therapy-General (FACT-G). Eval Health Prof. 2005;28(2):192–211.

292. Fayers P, European Organization for Research on Treatment of Cancer SG on Q of L. EORTC QLQ-C30 scoring manual. Brussels; 2001.

293. Ware J, Sherbourne C. The MOS 36-item short-form health survey (SF-36) Conceptual framework and item selection. Med Care. 1992;30(6):473–83.

294. Graff J, Coombs J, Burnett D. Quality of life, symptoms, and patient reported outcomes in radiotherapy- is there a global measure for radiotherapy studies. Int J Radiat Oncol Biol Phys. 2002;54(2):310–1.

295. Faithfull S, Lemanska A, Chen T. Patient-reported Outcome Measures in Radiotherapy: Clinical Advances and Research Opportunities in Measurement for Survivorship. Clin Oncol. 2015;27(11):679–85.

296. Cappelleri J, Bushmakin A. Interpretation of patient-reported outcomes. Stat Methods Med Res. 2014;23(5):460–83.

297. Lohr K, Zebrack B. Using patient-reported outcomes in clinical practice: challenges and opportunities. Qual Life Res. 2009;18(1):99–107.

298. Gotay C. Trial-related quality of life: using quality-of-life assessment to distinguish among cancer therapies. J Natl Cancer Inst Monogr. 1996;(20):1–6.

299. Nordan L, Blanchfield L, Niazi S, Sattar J, Coakes CE, Uitti R, et al. Implementing electronic patient-reported outcomes measurements: challenges and success factors. BMJ Qual Saf. 2018;27(10):852.

300. Nguyen H, Butow P, Dhillon H, Sundaresan P. A review of the barriers to using Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) in routine cancer care. J Med Radiat Sci. 2021;68(2):186–95.

301. Pugh G, Hough R, Gravestock H, Jackson S, Fisher A. The Health Behavior Information Needs and Preferences of Teenage and Young Adult Cancer Survivors. J Adolesc Young Adult Oncol. 2017;6(2):318–26.

302. Richter D, Koehler M, Friedrich M, Hilgendorf I, Mehnert A, Weißflog G. Psychosocial interventions for adolescents and young adult cancer patients: A systematic review and meta-analysis. Crit Rev Oncol/Hematol. 2015;95(3):370–86.

303. Edwards P, Roberts I, Clarke M, DiGuiseppi C, Pratap S, Wentz R, et al. Increasing response rates to postal questionnaires: systematic review. BMJ. 2002;324(7347):1183.

304. Liao J. Sample size calculation for an agreement study. Pharm Stat. 2010;9(2):125–32.

305. Fincham J. Response Rates and Responsiveness for Surveys, Standards, and the Journal. Am J Pharm Educ. 2008;72(2).

306. Graham M. Measuring and Promoting Inter-rater Agreement of Teacher and Principal Performance Ratings. Centre for Educator Compensation Reform; 2012 p. 33.

307. Berkanovic E, Hurwicz M, Lachenbruch P. Concordant and discrepant views of patients' physical functioning. Arthritis & Rheumatism. 1995;8(2):94–101.

308. Moore-Reed S, Kibler W, Bush H, Uhl T. Level of patient–physician agreement in assessment of change following conservative rehabilitation for shoulder pain. Shoulder Elbow. 2017;9(2):127–32.

309. Barton J, Imboden J, Graf J, Glidden D, Yelin E, Schillinger D. Patient-physician discordance in assessments of global disease severity in rheumatoid arthritis. Arthritis Care Res. 2010;62(6):857–64.

310. Haviland J, Hopwood P, Mills J, Sydenham M, Bliss J, Yarnold J. Do Patient-reported Outcome Measures Agree with Clinical and Photographic Assessments of Normal Tissue Effects after Breast Radiotherapy? The Experience of the Standardisation of Breast Radiotherapy (START) Trials in Early Breast Cancer. Clin Oncol. 2016;28(6):345–53.

311. Takala L, Kuusinen T, Skyttä T, Kellokumpu-Lehtinen P, Bärlund M. Electronic Patient-reported Outcomes During Breast Cancer Adjuvant Radiotherapy. Clin Breast Cancer. 2020;21(3):252–70.

312. Basch E, Deal A, Kris M, Scher H, Hudis CA, Sabbatini P, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. J Clin Oncol. 2016;34(6):557–65.

313. Perreault N, Brisson C, Dionne C, Montreuil S, Punnett L. Agreement between a self-administered questionnaire on musculoskeletal disorders of the neck-shoulder region and a physical examination. BMC Musculoskelet Disord. 2008;9(1):34.

314. Atkinson T, Ryan S, Bennett A, Stover A, Saracino RM, Rogak L, et al. The association between clinician-based common terminology criteria for adverse events (CTCAE) and patient-reported outcomes (PRO): a systematic review. Support Care Cancer. 2016;24(8):3669–76.

315. Majeed H, Gupta V. Adverse Effects Of Radiation Therapy. In: StatPearls. Treasure Island: StatPearls Publishing; 2022.

316. Dörr W, Hendry J. Consequential late effects in normal tissues. Radiother Oncol. 2001;61(3):223–31.

317. Okera M, Baker N, Hayward A, Selva-Nayagam S. Oncology workforce issues: the challenge of the outpatient clinic. Intern Med J. 2011;41(6):499–503.

318. Dyer S, Yaganti S, Patel J. Stratified follow-up care for people with prostate cancer. J Prim Health Care. 2016;26(2):24–30.

319. Cancer Council Victoria and Department of Health Victoria. Optimal cancer care pathways [Internet]. 2021 [Accessed 2022 Mar 9]. Available from: https://www.cancer.org.au/health-professionals/optimal-cancer-care-pathways

320. Oosterink J, Oosterveld-Vlug M, Glaudemans J, Pasman H, Willems D, Onwuteaka-Philipsen B. Interprofessional communication between oncologic specialists and general practitioners on end-of-life issues needs improvement. Fam Pract. 2016;33(6):727–32.

321. Sandell T, Schütze H. Factors influencing the translation of shared cancer follow-up care into clinical practice: a systematic review. BMJ Open. 2022;12(8):e055460.

322. Stemler S. A Comparison of Consensus, Consistency, and Measurement Approaches to Estimating Interrater Reliability. Pract Assess Res. 2004;9(4).

323. Shrout P, Fleiss J. Intraclass Correlations : Uses in Assessing Rater Reliability. Pyschol Bull. 86(2).

324. Alventosa-Zaidin M, Pera G, Roca Saumell C, Mengual Miralles N, Zamora Sanchez MV, Gros Garcia T, et al. Diagnosis of right bundle branch block: a concordance study. Fam Pract. 2019;20:58.

325. Clark R, Rietschel R. The cost of initiating appropriate therapy for skin diseases: A comparison of dermatologists and family physicians. J Am Acad Dermatol. 1983;9(5):787–96.

326. Dossett L, Hudson J, Morris M, Lee C, Roetzheim R, Fetters MD, et al. The Primary Care Provider (PCP)-Cancer Specialist Relationship: A Systematic Review And Mixed Methods Meta-synthesis. CA Cancer J Clin. 2017;67(2):156–69.

327. Madarnas Y, Joy AA, Verma S, Sehdev S, Lam W, Sideris L. Models of care for early-stage breast cancer in Canada. Curr Oncol. 2011 May;18(Suppl 1):S10–9.

328. QSR International Pty Ltd. [Internet]. 2022. Available from: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

329. Guba, Lincoln. Naturalistic inquiry. Evaluation and Program Planning. 1985;10(2):184–5.

330. Heins M, Schellevis F, Schotman M, van Bezooijen B, Tchaoussoglou I, van der Waart M, et al. Feasibility and acceptability of follow-up for prostate cancer in primary care: a pilot study. BJGP Open. 2018;2(4).

331. Boer H, Lubberts S, Bunskoek S, Nuver J, Lefrandt JD, Steursma G, et al. Shared-care survivorship program for testicular cancer patients: safe and feasible. ESMO Open. 2022;7(3).

332. Liemburg G, Korevaar J, van Zomeren W, Berendsen A, Brandenbarg D. Follow-up of curatively treated cancer in primary care: a qualitative study of the views of Dutch GPs. Br J Gen Pract. 2022;

333. Absolom K, Eiser C, Michel G, Walters S, Hancock BW, Coleman R, et al. Follow-up care for cancer survivors: views of the younger adult. Br J Cancer. 2009;101(4):561–7.

334. Neuman H, Jacobs E, Steffens NM, Jacobson N, Tevaarwerk A, Wilke L, et al. Oncologists' perceived barriers to an expanded role for primary care in breast cancer survivorship care. Cancer Med. 2016;5(9):2198–204.

335. Lisy K, Kent J, Dumbrell J, Kelly H, Piper A, Jefford M. Sharing Cancer Survivorship Care between Oncology and Primary Care Providers: A Qualitative Study of Health Care Professionals' Experiences. J Clin Med. 2020;9(9):2991.

336. George M, Ngo P, Prawira A. Rural Oncology: Overcoming the Tyranny of Distance for Improved Cancer Care. J Oncol Pract. 2014;10(3):e146–9.

337. Thom D, Hall M, Pawlson L. Measuring Patients' Trust In Physicians When Assessing Quality Of Care. Health Affairs. 2004;23(4):124–32.

338. Birken S, Powell B, Shea C, Haines E, Alexis Kirk M, Leeman J, et al. Criteria for selecting implementation science theories and frameworks: results from an international survey. Implementation Sci. 2017;12(1):124.

339. Novick G. Is there a bias against telephone interviews in qualitative research? Res Nurs Health. 2008;31(4):391–8.

340. Sturges J, Hanrahan K. Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note. Qualitative Research. 2004 Apr 1;4(1):107–18.

341. Jenner B, Myers K. Intimacy, rapport, and exceptional disclosure: a comparison of in-person and mediated interview contexts. Int J Soc Res Methodol. 2019;22(2):165–77.

342. Sandell T, Miller A, Schütze H, Ivers R, Vijayakumar V, Dinh L. Patient self-reported follow-up for radiation oncology patients during COVID-19: feasibility and patient-clinician agreement. Journal of Radiation Oncology Informatics [Internet]. 2023 Feb 7 [Accessed 2023 Mar 25];12(2). Available from: https://jroi.org/article/view/8099

343. Walsh D, Evans K. Critical realism: an important theoretical perspective for midwifery research. Midwifery. 2014;30(1):e1-6.

344. Angarita FA, Jedrzejko N, Eisen D, Muraca M, Ash M, Osman F. Primary Care Physicians' Perspectives in Leading Breast Cancer Follow-Up Care. Clin Breast Cancer. 2022;22(4):497–505.

345. Lewis P. Realism, Causality and the Problem of Social Structure. J Theory Soc Behav. 2000;30(3):249–68.

346. Archer M. Structure, agency and the internal conversation. Cambridge, UK ; Cambridge University Press; 2003. 370 p.

347. Hillen M, Koning C, Wilmink J, Klinkenbijl J, Eddes E, Kallimanis-King B, et al. Assessing cancer patients' trust in their oncologist: development and validation of the Trust in Oncologist Scale (TiOS). Support Care Cancer. 2012;20(8):1787–95.

348. Hillen M, Onderwater A, van Zwieten M, de Haes H, Smets E. Disentangling cancer patients' trust in their oncologist: a qualitative study. Psychooncology. 2012;21(4):392–9.

349. Seetharamu N, Iqbal U, Weiner J. Determinants of trust in the patient-oncologist relationship. Palliat Support Care. 2007;5(4):405–9.

350. Ackroyd S, Karlsson J. Critical Realism, Research Techniques, and Research Designs. In: Edwards P, O'Mahoney J, Vincent S, editors. Studying Organizations Using Critical Realism: A Practical Guide. Oxford University Press; 2014.

Appendices

Appendix A. PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
Title			
Title	1	Identify the report as a systemtic	34
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	35
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	35
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	36
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	36
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	37 Table 5 Appendix B.
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	37
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	37
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	37
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	37
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	37
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	38(Narrative)
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	40-41
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA

Section and Topic	Item #	Checklist item	Location where item is reported
	13c	Desribe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 5
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	40-41
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	40
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	38 Figure 7
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	NA
Study characteristics	17	Cite each included study and present its characteristics.	40-42 Table 6
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 6
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Table 6
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Table 6
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	47-49

Section and Topic	Item #	Checklist item	Location where item is reported
	23b	Discuss any limitations of the evidence included in the review.	47-49
	23c	Discuss any limitations of the review processes used.	47-49
	23d	Discuss implications of the results for practice, policy, and future research.	47-49
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	34
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	34
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	In journal article
Competing interests	26	Declare any competing interests of review authors.	In journal article
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	In journal article

Appendix B. Systematic review search string

Databases: MEDLINE, Science Citation Index, Academic Search Complete, CINAHL, APA Psycinfo, Health Source: Nursing/Academic Edition, and Psychology and Behavioural Sciences Collection

Search String:

("general practitioner" OR "primary care physician" OR "family physician" OR "family practitioner" OR GP OR doctor OR specialist OR oncologist) AND ("model of care" OR "shared-care" OR "shared care" OR "follow-up care" OR "follow up care") AND (Cancer OR oncolog* OR neoplasm)

Limits:

Date range: 01/01/1999 - 31/12/2021

Language: English

Available: online, full-text, peer-reviewed

Appendix C. Shared Care Acceptability Survey

Acceptability of radiotherapy shared follow-up care survey

You can either complete this survey by using this paper form and returning in the reply paid envelope.

Or you can complete online:

https://uow.au1.qualtrics.com/jfe/form/SV_0uBLs9bCNU7l9vT

Or scan the QR code:

Demographics

1. Your date of birth:____________________
2. Sex: ☐Female ☐Male ☐Prefer not to say
3. Postcode: __ __ __ __
4. Country of birth: ______________________________
5. Primary language spoken at home: ______________________________
6. Do you identify as Aboriginal or Torres Strait Islander? ☐Yes ☐No ☐Prefer not to say
7. Relationship status: ☐Married ☐Single ☐De-facto ☐Divorced ☐Widow ☐Prefer not to say
8. Highest level of education:☐Year 10 ☐Year 12 ☐TAFE/Certificate
   ☐Undergraduate ☐Postgraduate ☐Prefer not to say
9. Housing:☐Rent ☐Own/Mortgage ☐Other________________ ☐Prefer not to say
10. Employment: ☐Casual ☐Part-time ☐Full-time ☐Unable to work ☐Retired ☐Prefer not to say
11. Gross income: ☐ Under $15,000 ☐ $15,000 to $29,999 ☐$30,000 to $49,999
    ☐ $50,000 to $74,999 ☐ $75,000 to $99,999 ☐Over $100,000 ☐Prefer not to say

Health-related

12. Cancer location: ☐ Breast ☐ Colorectal ☐Head/Neck ☐ Lung ☐Prostate ☐ Pelvis
    ☐Other_______________
13. Stage at diagnosis (if known): ☐Stage 1 ☐Stage 2 ☐Stage 3 ☐Stage 4
14. Primary hospital for treatment: ☐Illawarra Cancer Care Centre ☐ Shoalhaven Cancer Care Centre
15. Treatments:☐Chemotherapy ☐Oral chemotherapy ☐Surgery ☐Hormone therapy ☐ Radiotherapy
16. Years since **radiotherapy** treatment finished: ☐Less than 1 year ☐1 to 2 years ☐2 to 3 years
    ☐3 to 4 years ☐4 to 5 years ☐ 5 to 10 years ☐More than 10 years
17. In general, would you say your health is: ☐Excellent ☐Very good ☐Good ☐Fair ☐Poor
18. Please list any other health related issues (diabetes, blood pressure etc):______________________________

____

Access to healthcare

19. Do you have a regular general practitioner that you visit?: ☐ Yes ☐ No

20. Number of visits for cancer-related issues in the last 12 months:
    - General practitioner:____________
    - Surgeon:_____________________
    - Medical oncologist:_____________
    - Radiation oncologist:____________
    - Other cancer related health professionals:_________________

21. Number of visits for non-cancer-related issues in the last 12 months:
    - General practitioner: ___________________
    - Other health professionals_______________

22. How many minutes does it take to get from your home to:
    - General practitioner: __________
    - Radiation oncologist:__________

23. Main mode of transport for health appointments: ☐Walk ☐Own car ☐Family help ☐Bus
☐Train ☐Community transport Other:______________

24. How often would you like to be seen for **radiotherapy** follow-up?
☐Once a month ☐Every second month ☐Every 3 months ☐Every 6 months

☐Once a year ☐ No more follow-up appointments wanted

25. Standard follow-up is around five-years (this varies). How many years would you like routine **radiotherapy** follow-up?
☐None ☐1 year ☐3 years ☐5 years ☐10 years ☐Lifetime

Please circle your preference, 5 strongly agree to 1 strongly disagree:

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
26. I would be **satisfied** for my radiotherapy follow-up care to be shared with my general practitioner, so long as the radiation oncologist is still involved	5	4	3	2	1
27. It is **easier** for me to get to my general practitioner, compared to the hospital *(In regards to transport, time, parking, accessibility)*	5	4	3	2	1
28. I would **value** my radiation oncologist and general practitioner working together to share my follow-up care	5	4	3	2	1
29. I **understand** that shared radiotherapy follow-up care will benefit me, my doctors and the health system	5	4	3	2	1
30. I **believe** that shared radiotherapy follow-up care will benefit me, my doctors and the health system	5	4	3	2	1
31. I order to have shared follow-up care, I would **need to give up** some of my time or my values on shared-care	5	4	3	2	1
32. If I had the choice: a. I would choose to have my follow-up care with **only** my radiation oncologist	5	4	3	2	1
b. I would choose to have **shared** follow-up care with my general practitioner, so long as my radiation oncologist is involved	5	4	3	2	1
c. I have **confidence** in my choice above.	5	4	3	2	1

Appendix D. The Checklist Reporting of Survey Studies

Checklist for Reporting Of Survey Studies (CROSS)

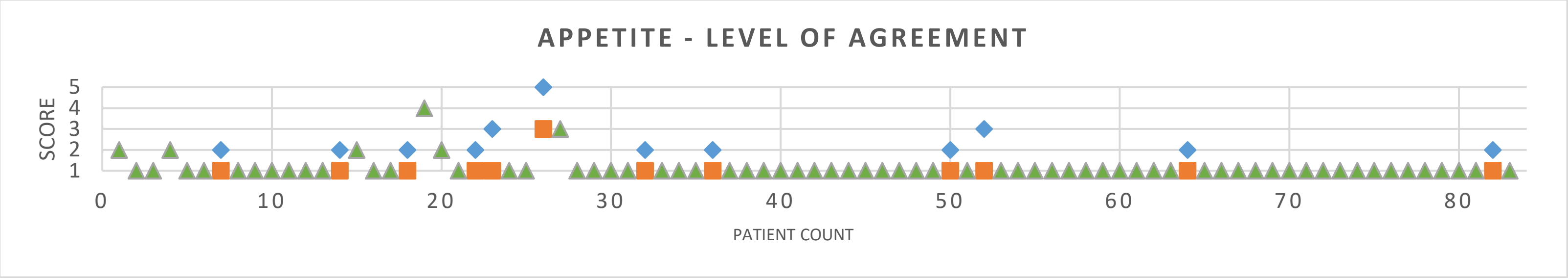
Section/topic	Item	Item description	Reported on page #
Title and abstract			
Title and abstract	1a	State the word "survey" along with a commonly used term in title or abstract to introduce the study's design.	50
	1b	Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussion, and conclusions.	51
Introduction			
Background	2	Provide a background about the rationale of study, what has been previously done, and why this survey is needed.	52-53
Purpose/aim	3	Identify specific purposes, aims, goals, or objectives of the study.	53
Methods			
Study design	4	Specify the study design in the methods section with a commonly used term (e.g., cross-sectional or longitudinal).	53
Data collection methods	5a	Describe the questionnaire (e.g., number of sections, number of questions, number and names of instruments used).	53-54
	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).	53-54
	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.	NA
	5d	Questionnaire if possible, should be fully provided (in the article, or as appendices or as an online supplement).	Appendix C
Sample characteristics	6a	Describe the study population (i.e., background, locations, eligibility criteria for participant inclusion in survey, exclusion criteria).	53
	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.	53-54
	6c	Provide information on sample size, along with details of sample size calculation.	53-54
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).	53-54
	7b	Provide information of survey's time frame, such as periods of recruitment, exposure, and follow-up days.	53
	7c	Provide information on the entry process: –>For non-web-based surveys, provide approaches to minimize human error in data entry. –>For web-based surveys, provide approaches to prevent "multiple participation" of participants.	
Study preparation	8	Describe any preparation process before conducting the survey (e.g., interviewers' training process, advertising the survey).	

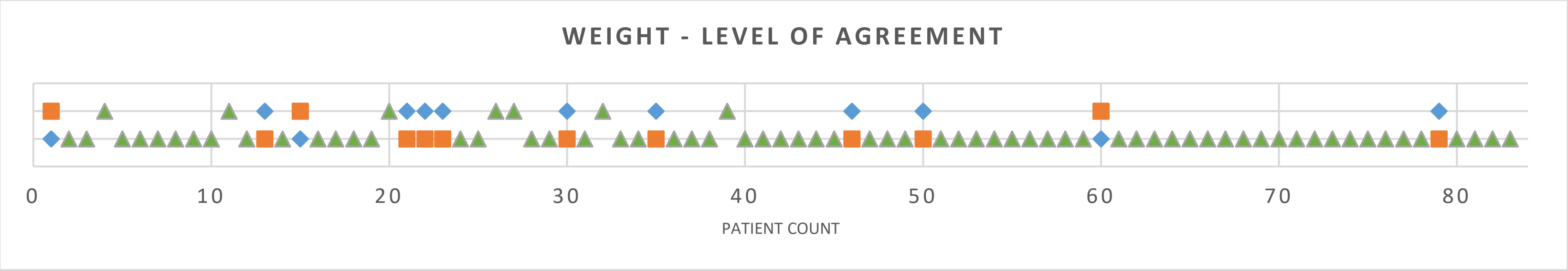
Ethical considerations	9a	Provide information on ethical approval for the survey if obtained, including informed consent, institutional review board [IRB] approval, Helsinki declaration, and good clinical practice [GCP] declaration (as appropriate).	56
	9b	Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorized access.	55-56
	10a	Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis.	
	10b	Report any modification of variables used in the analysis, along with reference (if available).	56
	10c	Report details about how missing data was 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).	56
	10d	State how non-response error was addressed.	NA
	10e	For longitudinal surveys, state how loss to follow-up was addressed.	56
	10f	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample.	
	10g	Describe any sensitivity analysis conducted.	
Results			
Respondent characteristics	11a	Report numbers of individuals at each stage of the study. Consider using a flow diagram, if possible.	57
	11b	Provide reasons for non-participation at each stage, if possible.	-
	11c	Report response rate, present the definition of response rate or the formula used to calculate response rate.	57
	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).	
Descriptive results	12	Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes.	58 Table 8
Main findings	13a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and p-values.	
	13b	For multivariable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate).	
	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).	

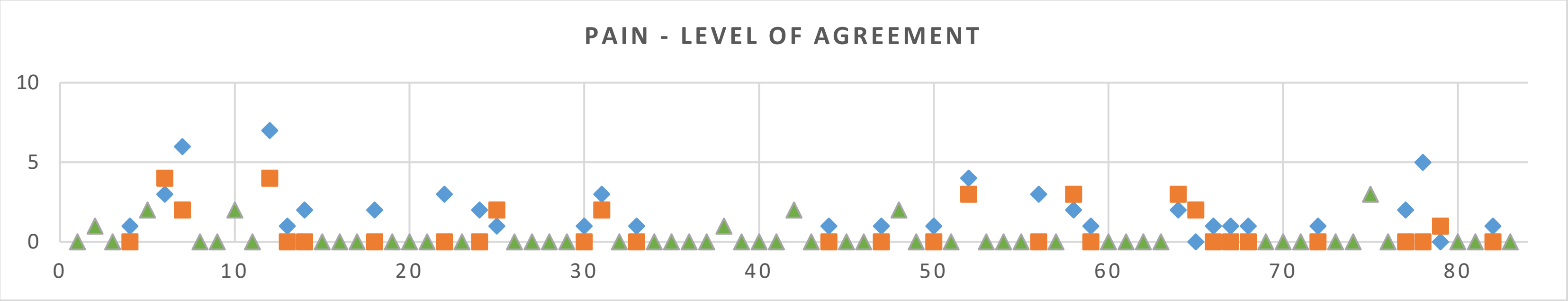
Discussion			
Limitations	14	Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders.	64
Interpretations	15	Give a cautious overall interpretation of results, based on potential biases and imprecisions and suggest areas for future research.	64
Generalizability	16	Discuss the external validity of the results.	64
Other sections			
Role of funding source	17	State whether any funding organization has had any roles in the survey's design, implementation, and analysis.	In journal
Conflict of interest	18	Declare any potential conflict of interest.	In journal
Acknowledgements	19	Provide names of organizations/persons that are acknowledged along with their contribution to the research.	In journal

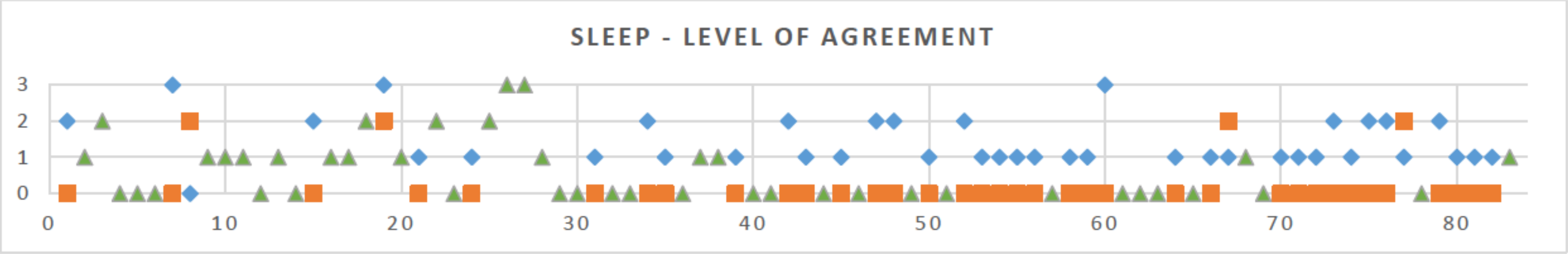
Appendix E. Discordance in patient-clinician variables

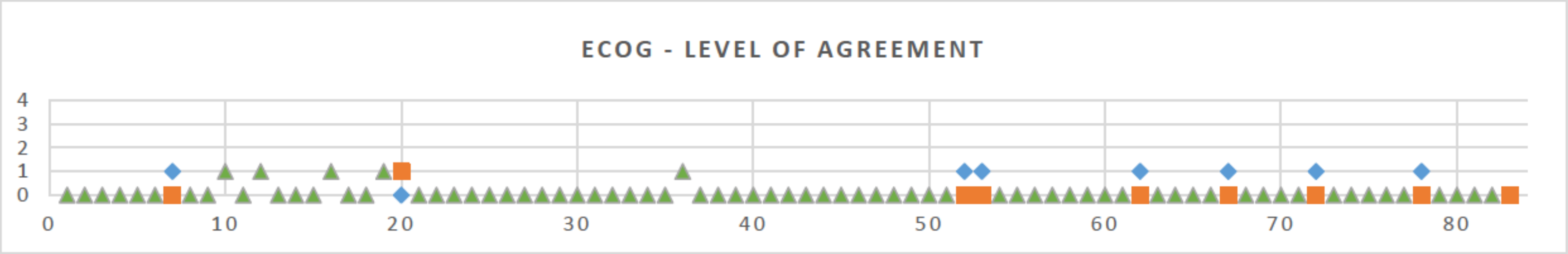
◆ Patient ■ Doctor ▲ Patient/Doctor Same Score

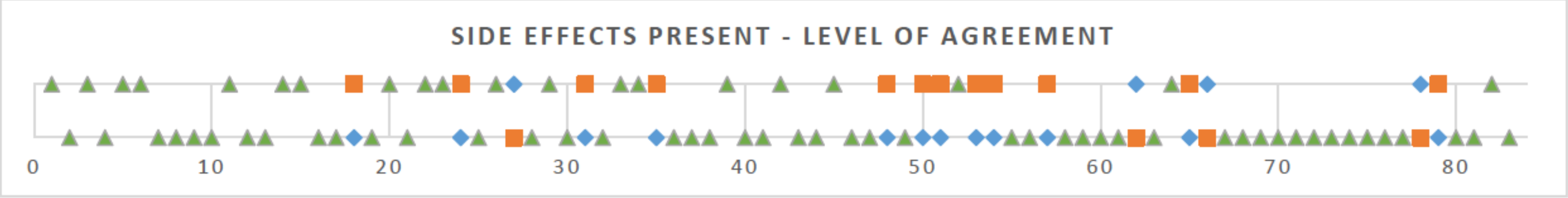

APPETITE - LEVEL OF AGREEMENT

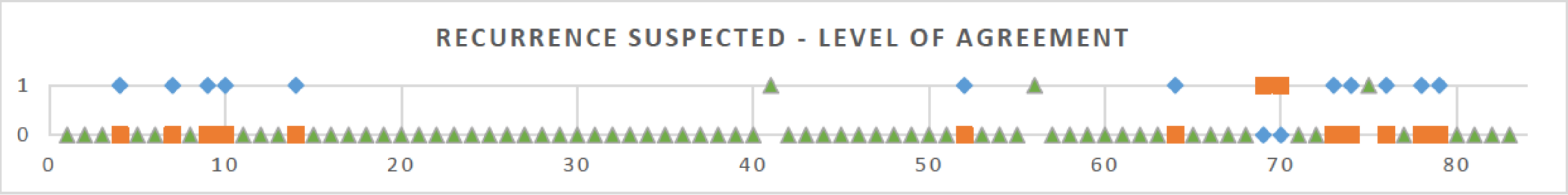

WEIGHT - LEVEL OF AGREEMENT


PAIN - LEVEL OF AGREEMENT


SLEEP - LEVEL OF AGREEMENT
3
2
1
0
0
10
20
30
40
50
60
70
80


ECOG - LEVEL OF AGREEMENT
4
3
2
1
0
0
10
20
30
40
50
60
70
80


SIDE EFFECTS PRESENT - LEVEL OF AGREEMENT
0
10
20
30
40
50
60
70
80


RECURRENCE SUSPECTED - LEVEL OF AGREEMENT
1
0
0
10
20
30
40
50
60
70
80

Appendix F. Semi-structured interview guide

PRE IMPLEMENTATION INTERVIEW GUIDE

Introductory script

- Thank participant for agreeing to take part in this research.
- Introduce the research and briefly discuss its purpose.
- Discuss the role of the interviewer: to raise topics for discussion and then to listen as the participant shares their views and experiences.
- Reassure the participant that they are free to talk about any aspect of their experience or attitudes. There are no right or wrong or even typical answers to any of the questions that we will discuss.
- Remind the participant that, with their permission, the interview will be audio-taped.
- Reassure confidentiality and the participant's right to stop the interview at any time.
- Clarify that the interview will take approximately 30 minutes.
- Ask whether the participant has any questions before beginning.

General practitioner/Radiation Oncologist

1. Role of cancer follow-up/perceived goals

- How would you describe the concept behind radiation oncology cancer follow up?
- In your view, what are the aims of radiation oncology cancer follow up?
- In your view, what do patients want from radiation oncology cancer (radiation oncology) follow up?

2. Experience of current follow up strategy

- Please describe your current role, *(for GPs if any)*, in the cancer follow up care of (Patient X)
    - How do you feel about your current role?
    - Are there any aspects of this role that you feel uncomfortable with?
    - Would you like to change anything about this role/your input?
    - What aspects of follow up care, if any, do you feel responsible for?

3. Views on hospital, specialist-led follow up

- What are views on the current hospital-led cancer follow up model for this patient?
- Are there any particular strengths of the hospital-led follow-up?
- Are there any problems with hospital-led follow up?
- Would you change anything about the current follow up?
- What impact does cancer follow up have on your clinical workload?
- Do you experience any challenges when providing cancer follow-up?

4. Follow up provider

- Who do you believe is best placed to provide cancer follow up?
    - Why do you think this provider is best placed?
    - Are there any situations where another provider would be best places to provide follow up?
    - Are there any patient factors that in your mind would make someone require a different follow-up provider?

5. Views on primary care led follow-up

Participants would then be presented with information about cancer follow-up including the evidence base for the effectiveness of follow-up and existing guidance and evidence that general practitioners can play a significant role in cancer follow up and achieve similar health outcomes. They will also be presented with the shared-care model.

- How would you feel about a GP taking a greater and/or sharing the role in cancer (radiation oncology) follow-up?

- What would you see as the potential advantages in this model?
- What would you see as the potential disadvantages in this model?

(Think about issues such as costs, convenience, confidence in treating cancer patients amongst the health care professionals, ability for the follow up to detect important recurrences etc.)

- In your view, what would patients think about this proposed shared-care model?

6. Acceptability of participating in shared-care

- Finally the general practitioners/radiation oncologists will be asked about their views on the proposed shared-care model and if they could choose between the current model, or the shared-care model, what would they choose.

7. Conclude Interview

- As this is a new area of research, we may have missed something important in this interview. Is there anything else that you would like to comment on?

Interview debriefing and closure

- Thank the participant for sharing their views.

Patient

Additional introductory script to patients:

- Reassure that their radiation oncologist and general practitioner will not have access to what the patient says in the interview – everything will be completely confidential.
- Clarify that the interview will take approximately 30 minutes.

1. Role of cancer follow up/perceived goals

- What do you believe to be the purpose of follow-up appointments following radiotherapy treatment for your cancer?
- What do expect from your cancer follow-up?
    - Have you discussed your follow-up plan with a doctor or nurse?

2. Experience of current follow up strategy

- Please can you describe the current follow-up care you are receiving?
    - Where are you receiving this follow-up?
    - What individuals or groups are providing this follow-up?
    - How frequent are these appointments?

3. Views on hospital, specialist-led follow up

- What do you think of the current follow-up plan?
- Does this current plan meet your expectations of follow-up?
- Are there any particular strengths of your current follow-up?
- Are there any problems with your current follow-up?
- Would you change anything about your current follow-up?
- What role does your GP currently play in your cancer follow-up?

4. Follow up provider

- Who do you believe is best placed to provide this follow-up?
    - Why do you think this provider/these providers is/are best placed?
    - Are there any situations where this may change and the hospital/GP may be best placed to provide follow up?
    - In which situations is the hospital/specialist best placed to provide follow-up

    - In which situations is your GP best placed to provide follow-up.

5. Views on primary care led follow up

Participants would then be presented with information about cancer follow up including the evidence base for the effectiveness of follow up and existing guidance and evidence that general practitioners can play a significant role in cancer follow-up and achieve similar health outcomes. They will also be presented with a shared-care model highlighting the radiation oncologist is overseeing the care in real-time.

- How would you feel about your GP taking a greater role and sharing in your cancer follow up?
- What would you see as the potential advantages in this approach?
- What would you see as the potential disadvantages in this approach?

(Think about issues such as costs, convenience, time, confidence in health care professionals, ability for the follow up to detect important recurrences etc.)

6. Acceptability of shared-care model

- If they knew their radiation oncologist could oversee their care, in real-time (with the transfer of medical information), would they choose usual care, or shared-care.

7. Conclude Interview

- As this is a new area of research, we may have missed something important in this interview. Is there anything else that you would like to comment on?

Interview debriefing and closure

- Thank the participant for sharing their experiences.

POST-IMPLEMENTATION SEMI-STRUCTURED INTERVIEW GUIDE

Introductory script

- Thank participant for taking part in this research.
- Briefly reiterate its purpose.
- Clarify that the interview will be shorter than the first, around 20 minutes.
- Ask whether the participant has any questions before we begin.

General practitioner/Radiation Oncologist

1. Experience of shared-care follow-up strategy

- Please can you describe your experience of shared-care for (Patient X)
    - How do you feel about your shared-care role?
    - Are there any aspects of this shared-care role that you felt uncomfortable with?
    - Would you like to change anything about this role/your input?
    - Now that you have been involved with shared-care, what aspects of follow-up care, if any, do you feel responsible for?

2. Views on shared-are

- Are there any particular strengths/advantages of shared-care follow-up?
- Are there any problems/disadvantages with shared-care follow-up?
- Would you change anything about the shared-care follow-up?
- What impact did shared-care follow-up have on your clinical workload?
- Did you experience any challenges when providing shared-care follow-up?
- In your view, what would patients think about their experience with this shared-care model?

3. Acceptability of participating in shared-care

- Finally the general practitioners/radiation oncologists will be asked if they could choose between the current model, or the shared-care model, what would they choose.

4. Conclude Interview

- As this is a new area of research, we may have missed something important in this interview. Is there anything else that you would like to comment on?

Interview debriefing and closure

- Thank the participant for sharing their views.

Patient
Additional introductory script to patients:

- Reassure that their specialist and general practitioner will not have access to what patient says in interview – everything will be completely confidential.
- Clarify that the interview will be shorter than the first, approximately 30 minutes.

1. Experience of shared-care follow-up strategy

- Please can you describe your experience of shared-care between your GP and radiation oncologist.
    - How do you feel about shared-care?
    - Are there any aspects of shared-care that you felt uncomfortable with?
- Are there any particular strengths of shared-care follow-up?
- Are there any problems with shared-care follow-up?
- Would you change anything about the shared-care follow-up?
- What impact did shared-care follow-up have on your daily life?
- How did you feel knowing your radiation oncologist could see the results of your follow-up appointment immediately?

3. Acceptability of participating in shared-care

- If they could choose between the current hospital-based model, or the shared-care model, what would they choose.

4. Conclude Interview

- As this is a new area of research, we may have missed something important in this interview. Is there anything else that you would like to comment on?

Interview debriefing and closure

- Thank the participant for sharing their views.