



# **Optimising Referral Practices to Dietary and Exercise Services for Cancer Survivors**

By

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## SUMMARY

Cancer survivors often experience short and long-term challenges to physical and psychological health, financial, and social or family functioning that limit their ability to maintain a healthy lifestyle. As such, there is an increased need for effective dietary and exercise interventions. These interventions can prevent, reduce, or reverse numerous physical and psychosocial effects of cancer and its treatment, including through their impact on other coexisting chronic medical conditions, such as cardiovascular disease or obesity. For cancer survivors to access specialised dietary and exercise care in Australia, cancer survivors need to be referred to dietitians and exercise professionals by their specialist team. Even though there is strong evidence in the literature that dietary and exercise interventions are essential and beneficial for optimising outcomes for cancer survivors, the current system of care does not comprehensively facilitate quality, systematised health-system responses to provide cancer survivors with seamless access to dietary and exercise services. Therefore, this doctoral research aimed to ultimately provide guidance to optimise dietary and exercise referral practices for cancer survivors in Australia across the survivorship trajectory.

An integrative review was conducted to examine the perspectives of medical and nurse health professionals on their roles in providing referrals to cancer survivors. Although medical and nursing professionals agree they have an important role in providing guidance and referrals for exercise and dietary services, there is a lack of role clarity regarding their roles and responsibilities with regards to providing dietary and exercise advice to cancer survivors, and a lack of standardised referral pathways to facilitate referral practices. A four-round Delphi study was then conducted to inform the development of essential elements to provide guidance to medical and nursing health professionals regarding dietary and exercise care and referrals for cancer survivors. These essential elements were distributed to a panel to establish consensus by rating the importance of each statement. The Delphi consensus study produced 24 essential element statements. The implementation of these essential elements may experience challenges that affect the extent to which they become embedded and scaled-up due to the complexity of the health system. Thus, pre-implementation work is an important element to identify factors contributing to the implementation of essential elements. Accordingly, a systems-thinking workshop based on the World Health Organisation (WHO) health system building blocks was conducted with six facilitated focus groups, including consumers, cancer specialists,

researchers and representatives of peak bodies, Cancer Council and Cancer Australia. Through the systems-thinking workshop, cognitive maps demonstrated inter-related factors that can influence referral practices across the WHO health system building blocks. Furthermore, using a systems-thinking approach enabled the identification of fifteen strategies related to the WHO health system building blocks at a policy level; to further advance practices in medical and nursing health professionals' guidance and referrals for exercise and dietary services. Overall, this doctoral research resulted in the development of a consensus framework of essential elements to guide practice as well as a causal loop diagram complemented with strategies at a policy level. This doctoral research provides valuable guidance regarding the optimisation of dietary and exercise referral practices in Australia, as well as supporting medical and nursing health professionals to do so. Future implementation research is needed to confirm the findings of this doctoral research in other samples, further refine the essential elements and tailor intervention strategies to be used in different healthcare settings. More research will also ensure successful translation at the micro- (persons and clinician level), meso- (organisational level) and macro- (policy and system level) .

## **DECLARATION**

I, Ria Elizabeth Joseph, certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed:

Date: 21/07/2023



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## LIST OF PUBLICATIONS

### Directly from the doctoral research:

**Joseph R**, Hart N, Bradford N, Wallen M, Han C, Pinkham E, Hanley B, Lock G, Wyld D, Wishart L, Koczwara B, Chan A, Agbejule OA, Crichton M, Teleni L, Holland J, Edmiston K, Naumann L, Brown T, Chan RJ. Essential elements of optimal dietary and exercise referral practices for cancer survivors: Expert consensus for medical and nursing health professionals. *Support Care Cancer*. 2022.

**Joseph R**, Hart NH, Bradford N, Agbejule OA, Koczwara B, Chan A, Wallen MP, Chan RJ. Diet and exercise advice and referrals for cancer survivors: an integrative review of medical and nursing perspectives. *Support Care Cancer*. 2022.

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## **LIST OF CONFERENCE PRESENTATIONS AND POSTERS**

### **4th Victorian Cancer Survivorship Conference 24th-25th March 2022, virtual**

- *Diet and exercise advice and referrals for cancer survivors: an integrative review of medical and nursing perspectives (e-poster presentation)*

### **Clinical Oncology Society of Australia (COSA) Cancer Survivorship Conference, 2<sup>nd</sup>-4<sup>th</sup> November 2022, Brisbane, Australia**

- *Essential elements of optimal dietary and exercise referral practices for cancer survivors: expert consensus for medical and nursing health professionals (oral presentation)*

### **COSA Cancer Survivorship Conference, 9th-10th March 2023, Adelaide, Australia**

- *Optimising referral practices to dietary and exercise services for cancer survivors (physical poster)*

### **Multinational Association of Supportive Care in Cancer (MASCC), 22<sup>nd</sup>-24<sup>th</sup> June 2023, Nara, Japan**

- *A systems-thinking study to optimise dietary and exercise referral practices in Australia (e-poster presentation)*

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## **ABBREVIATIONS**

<b>ACS</b>	American Cancer Society
<b>ACSM</b>	American College of Sports Medicine
<b>APA</b>	Australian Physiotherapy Association
<b>CDMP</b>	Chronic Disease Management Plan
<b>CLD</b>	Causal Loop Diagram
<b>COSA</b>	Clinical Oncology Society of Australia
<b>DA</b>	Dietitians Australia
<b>EMR</b>	Electronic Medical Records
<b>ESSA</b>	Exercise and Sports Science Australia
<b>GP</b>	General Practitioner
<b>HREC</b>	Human Research Ethics Committee
<b>LHNs</b>	Local Health Networks
<b>MBS</b>	Medicare Benefits Schedule
<b>MMAT</b>	Mixed Methods Appraisal Tool
<b>MNA</b>	Mini Nutritional Assessment
<b>MST</b>	Malnutrition Screening Tool
<b>MUST</b>	Malnutrition Universal Screening Tool
<b>PCP</b>	Primary Care Provider
<b>PG-SGA</b>	Patient-Generated Subjective Global Assessment
<b>PICO</b>	Population, Intervention, Comparison and Outcome
<b>PRISMA</b>	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
<b>PROSPERO</b>	International Prospective Register of Systematic Reviews
<b>SCP</b>	Survivorship Care Plan
<b>SD</b>	Standard Deviation
<b>TCA</b>	Team Care Arrangement
<b>WHO</b>	World Health Organisation

# CHAPTER ONE – INTRODUCTION

## 1.1 Chapter overview

This first chapter reviews the current literature on cancer incidence; the Australian healthcare system; cancer survivorship; models of survivorship care; the role of diet and exercise; roles and responsibilities of medical and nursing health professionals; cancer survivors' needs and preferences; dietary and exercise referral processes and practices; barriers and facilitators to providing dietary and exercise advice and referrals; current gaps in referral practices; and current progress in referral practices. Finally, the research plan, including research questions, doctoral research aims, and objectives are outlined at the end of the chapter.

## 1.2 Background

A cancer survivor is defined as a person living with a diagnosis of cancer from the time of diagnosis through the end of their life.<sup>1</sup> Worldwide, there are over 19.3 million cancer survivors<sup>2</sup> with over 1.1 million cancer survivors in Australia; a figure that continues to increase due to a growing population, higher incidence rates, early detection, improved diagnostic methods and advances in treatment.<sup>3</sup> When compared to non-Indigenous Australians, First Nations people in Australia have poorer health outcomes than the general population, including a greater cancer incidence and shorter life expectancy up to 14 years.<sup>4</sup> Although First Nations peoples' cultures differ in their participation with healthcare and their attitudes towards illness and cancer, a number of common barriers have been found to prevent access to mainstream healthcare.<sup>5</sup> All cancer survivors often experience short and long-term challenges to physical and psychological health, financial, and social or family functioning that limit their ability to maintain a healthy lifestyle.<sup>6, 7</sup> As such, there is an increased need for dietary and exercise interventions that can prevent, reduce or reverse numerous physical and psychosocial effects of cancer and its treatment, including through their impact on other coexisting chronic medical conditions, such as cardiovascular disease or obesity.<sup>8, 9</sup> Despite growing evidence that dietary and exercise health behaviours are linked to improved outcomes in cancer survivors<sup>10</sup>, some cancer survivors are still at nutritional risk (i.e., approximately 33.3%)<sup>11</sup>; do not meet current physical activity guidelines<sup>10</sup>; and do not engage in regular physical activity (i.e., 66% are sedentary per day).<sup>12, 13</sup> For cancer survivors to access specialised dietary and exercise care in Australia, cancer survivors need to be referred to dietitians and exercise professionals by their specialist team or through their general practitioner (GP).<sup>14</sup> Referrals are key to optimising



patient care when cancer survivors are referred to the appropriate healthcare service at key time points in the cancer continuum, improving patient outcomes.<sup>15, 16</sup> However, around half (53%) of the public and private hospitals in Australia that provide cancer care do not have established referral pathways for supportive care services, with only 19% of hospitals referring cancer survivors to external organisations or allied health professionals.<sup>17</sup> This highlights an issue with current practices; the importance of standardising referral processes; and the inadequacy of supportive care provided to most cancer survivors.<sup>17</sup> This doctoral research provides further insight on optimising dietary and exercise referral practices for cancer survivors in Australia across the survivorship trajectory.

### **1.3 The Australian healthcare system and countries with similar healthcare systems**

The Australian healthcare system is a hybrid one, with a large primary care workforce. It includes government-funded universal coverage of many medical costs as well as additional coverage provided by private health insurance or self-funding.<sup>18</sup> Cancer survivors can therefore attend both private and public hospitals. Coordination of cancer prevention, screening programmes, the national cancer registry, and the provision of comprehensive services for all Australian cancer survivors fall under the purview of the public health sector. Most service coordination takes place at the state level (there are seven states), and the regional levels (31 primary health networks (PHNs)).<sup>19</sup> The public and private sectors are increasingly collaborating to increase the availability of cancer services nationwide. While the cost of all inpatient and outpatient services accessible in government-owned hospitals is covered by the national health insurance, the cost of obtaining medications and healthcare services in the community is only partially subsidised.<sup>20</sup> Some cancer survivors can use optional private health insurance to further reduce the expenses of private healthcare in hospital settings as well as some additional services, such as allied health and other supportive care in community settings. However, over a third of Australian cancer survivors are already negatively impacted by high out-of-pocket expenses relative to income.<sup>20</sup> Due to the high costs, it may be challenging for Australians without private insurance or who are unable to cover out-of-pocket expenses to access healthcare from a private health facility. Furthermore, costs can be disproportionately greater for cancer survivors who live outside of major cities, need radiotherapy, and/or require chemotherapy, or have private health insurance.<sup>17</sup> Despite developments in cancer care, cancer survivors may not be able to access these services if their prognosis depends on where they live or their ability to afford appropriate care. Ultimately, better financial navigation services could

lessen the financial toxicity that cancer survivors, particularly those in rural and regional areas, endure throughout treatment and survival.

Canada and France seem to have healthcare systems that are similar to Australia's since they both offer public insurance for the basic coverage and allow cancer survivors to add private insurance on top of the public insurance.<sup>21</sup> In Canada, the provincial and territorial governments have most of the responsibility for financing, organising, and delivering publicly funded healthcare, otherwise known as Medicare.<sup>22</sup> However, Canada also has both public and private hospitals much like in Australia, as well as non-profit ones.<sup>23</sup> In Australia, Medicare is also used to provide Australian cancer survivors with free or subsidised public health services. Contrarily, the French healthcare system is founded on universal health protection with mainly public or not-for-profit hospitals, and provides 100% reimbursement of costs for patients with serious or chronic illnesses.<sup>24</sup> All health systems may face similar problems with the management of complex and evolving health demands, but their solutions will likely differ greatly. Thus, applying lessons from other countries could lead to more effective and efficient health system reforms.

Since the Australian healthcare system is complex and can be challenging to understand, it is essential that cancer survivors are adequately supported to be able to successfully navigate the system.<sup>17</sup> It can be difficult to navigate the healthcare system as a cancer survivor or as an informal carer, especially since they face various barriers. Barriers faced by cancer survivors to accessing care include a lack of personal knowledge and financial resources, a lack of health insurance coverage, distance from cancer care professionals, and a lack of cancer care resources. These challenges can arise at the start of diagnosis and continue throughout treatment, follow-up care and survivorship.<sup>25, 26</sup> For cancer survivors, well-established optimal care pathways (OCPs)<sup>27</sup> can help them to better comprehend and interact with complex healthcare systems. They can also learn what questions to ask their cancer care professionals to make sure they are receiving the best care. However, cancer survivors may require additional support at various points throughout the cancer continuum due to the complexity of cancer care. Patient navigation has been identified as a strategy for overcoming patient-level and system-level barriers, reducing cancer-related disparities, and improving access to and coordination of timely care for those most in need.<sup>28, 29</sup> This is due to the fact that patient navigation has the ability to assist cancer survivors in overcoming systemic barriers and facilitating access to high-quality care across the cancer continuum.<sup>30, 31</sup> Recently published

research on patient navigation<sup>32</sup> has demonstrated improvements in quality of life and patient satisfaction during the survivorship phase, and decreased hospital readmissions during the active treatment and survivorship care phases.

According to the providers in a national Australian survey on service gaps<sup>17</sup>, the most significant cancer service gaps were those aimed at meeting the physical and psychosocial needs and long-term needs of cancer survivors. There are still gaps in supportive care and survivorship services across Australia because less than a third of Australian organisations offer specialised services like survivorship clinics.<sup>17</sup> These gaps are in line with previous Australian<sup>33</sup> and international research<sup>34</sup> that regularly identifies a wide range of unmet physical and psychosocial requirements of cancer survivors across the cancer continuum. Other issues raised by providers included access to comprehensive cancer care for cancer survivors living in rural and remote areas as well as the cost of supportive care and survivorship services across all of Australia.<sup>17</sup> Specialised services must be developed in a number of care settings to address national gaps in supportive cancer care interventions. For example, the COVID-19 pandemic, used telehealth services (i.e., virtual care via video conferencing, remote consultation, telephonic videos, remote monitoring, provider-to-provider communication, apps and Web-based platforms) as an alternative method of healthcare delivery globally.<sup>35</sup> Australia had well-established telehealth services prior to the pandemic, similar to Canada, New Zealand, and the United States, but mainstream adoption has lagged despite mounting evidence of its clinical acceptability, appropriateness and feasibility.<sup>36</sup> A positive step towards supporting Australians through the ongoing public health crisis, the Australian Commonwealth Government's policy changes to expand the Medical Benefits Schedule (MBS) to include telephone or online health consultations can also improve access for some rural and remote cancer survivors.<sup>37</sup> However, telemedicine and online resources are still underutilised modalities that should be developed further to address service gaps.<sup>38</sup>

### **1.3.1 Barriers to accessing cancer care**

While efforts to improve cancer outcomes have traditionally focused on improving care quality, recent years have seen a growing emphasis on timely access to high-quality cancer care. Barriers to accessing care need to be addressed at the micro- (persons and clinician level), meso- (organisational level) and macro- (policy and system level). One of the major barriers to accessing quality health care for cancer survivors include inadequate health insurance, and the

inability to pay for treatment-related expenses.<sup>39</sup> Financial toxicity refers to the detrimental consequences of the financial burden of medical care on cancer survivors that may result in reduced quality of life and well-being.<sup>40</sup> Numerous barriers to cancer survivors receiving equitable access to care and achieving the best possible health outcomes may arise as a result of their financial burden. Failures in care coordination between cancer care professionals have been linked to poorer health outcomes for patients with complex medical needs and can affect cancer survivors' access to care.<sup>41</sup> A lack of care coordination can also be attributed to a lack of role clarity amongst health professionals, poor communication between specialists and primary care, a shortage of oncologists practising in the area, and a lack of referrals to specialists.<sup>42,43</sup> Another barrier reported by cancer survivors, included the inability to see a primary care provider (PCP) due to limited appointment times.<sup>44</sup> If cancer survivors are unable to see their PCP, they may not seek any other care, or may try to see a specialist, which can result in long waiting times before receiving timely care. Therefore, it is important that strategies are adopted to ensure care coordination is in place to improve continuity and bridge transitions of care for cancer survivors. Further research needs to be conducted to identify system-level factors that may influence cancer survivors' access to cancer care, as well as personalised system-level strategies to overcome any disparities in care.

Cancer survivors in regional/rural areas have identified a number of barriers to receiving cancer care, including transportation challenges, shortage of cancer care professionals, poor communication within the health system, financial strain, a lack of knowledge regarding available supportive services, and inadequate governance.<sup>45, 46</sup> By recruiting cancer care professionals and creating local support networks, these issues can be addressed in order to improve cancer survivors' access to cancer care. Barriers can also be addressed through improved infrastructure and the development of novel models of care tailored to cancer survivors living in regional/rural areas. Similarly, vulnerable groups, including adolescents and young adults (AYAs) with cancer, First Nations people, and culturally and linguistically diverse populations may face numerous barriers to accessing cancer care, and thus experience poorer health outcomes. As clinical needs change over time and with increasing age, AYA cancer survivors have reported barriers, such as a lack of availability and inappropriate support, resulting in reduced access to cancer care services. There was a lack of availability of services due to treatment-related gaps but most frequently in relation to post-treatment survivorship care. Furthermore, services that were available in the community and the hospital did not match

the needs and preferences of AYA cancer survivors.<sup>47</sup> Due to the challenges in transitioning AYA cancer survivors from treatment-focused care to long-term follow-up care, there needs to be more flexibility for AYA cancer survivors treated across different facilities. In addition, regardless of the location of treatment, it is essential that standardised referral of cancer care services are in place for AYA cancer survivors to facilitate access to such services. Even though there are several models of survivorship care available for AYA cancer survivors<sup>48</sup>, future research is required to evaluate the effectiveness of various models of care for AYA cancer survivors.

First Nations people with cancer are likely to encounter significant levels of unmet supportive care requirements due to the poor cancer prognoses and barriers they face in accessing cancer care.<sup>49</sup> Some barriers include: a lack of access to First Nations care providers and staff, such as patient navigators; disjointed relationships with cancer care professionals; communication difficulties with cancer care professionals; transport and finance; being away from family and others while receiving care; and problems with transportation as well as having to travel long distances.<sup>49, 50</sup> These barriers pose significant challenges to First Nations people with cancer maintaining their engagement with cancer care. Thus, there is a need for cancer care to be tailored specifically for the needs of First Nations people with cancer. Culturally and linguistically diverse populations also face various barriers to care, including communication problems with cancer care professionals across the cancer care continuum, a lack of culturally and linguistically appropriate cancer and treatment related information and difficulties navigating the health system. Inadequate support, a lack of funding, difficulties finding qualified interpreters, and significant time constraints are also reported by cancer care professionals as limiting their ability to provide equitable care for populations with a variety of cultural and linguistic backgrounds.<sup>51, 52</sup> As a result, culturally and linguistically diverse populations may lack knowledge about their health and treatment options, struggle to express their concerns, find it difficult to navigate the health system, and experience lower-quality care across the cancer continuum.<sup>51, 52</sup> Additionally, medical health professionals have stated that they frequently refer complex, culturally varied patients to allied health or multicultural health workers, thus limiting those patients' access to cancer specialists.<sup>53,54</sup> Tailored, culturally and linguistically sensitive programmes that help both cancer survivors and cancer care professionals are essential to achieving equitable access to care.<sup>55</sup> Overall, it is important that barriers in accessing care are addressed specifically with regards to these vulnerable populations, such as using patient navigation as a strategy.

## 1.4 Cancer survivorship

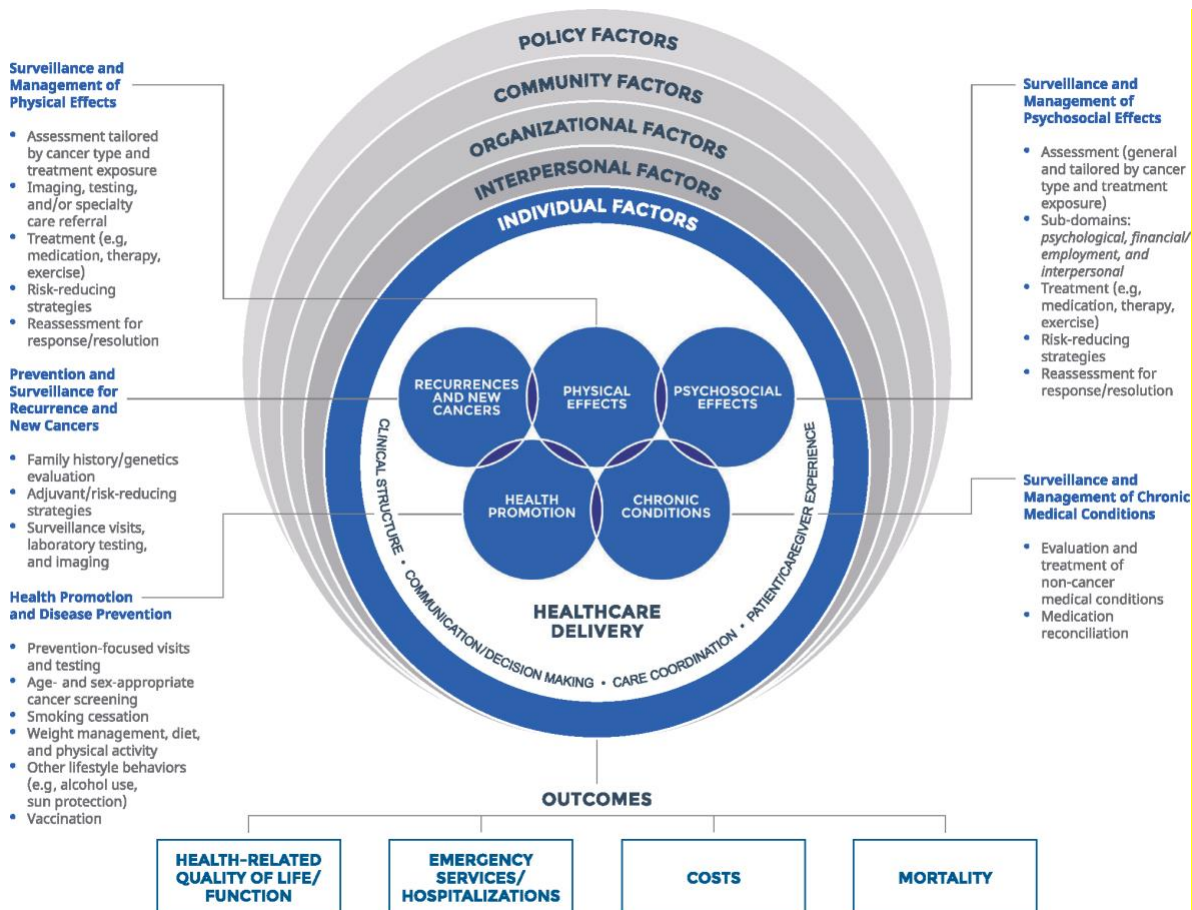
Cancer survivorship care requires evidence-based guidelines for screening and surveillance, and the ongoing evaluation of the effects of cancer and its treatment, interventions for symptom management, coordination between specialists and PCPs, and provision of sustainable and cost-effective follow-up care. It can also include personalisation of care, aiming to empower cancer survivors and support self-management.<sup>56, 57</sup> Although the definition of cancer survivorship encompasses the entire cancer journey, most of the focus described in the evidence base has primarily been on the diagnostic and treatment stages of care.<sup>58, 59</sup> Despite advocacy for survivorship interventions to be offered before, during and after cancer treatment, often post-treatment follow-up care places an emphasis on the surveillance for cancer recurrence and the screening for other cancers.<sup>57</sup> With this focus, less importance is usually given to the long-term physical and psychosocial effects of cancer and its treatment, and other chronic diseases that may develop as consequences of past cancer treatment exposures.<sup>60</sup> These include cardiovascular disease, diabetes, cancer-related malnutrition, cancer-related sarcopenia, osteoporosis, functional decline, and other chronic diseases.<sup>61</sup>

Cardiovascular disease is the primary cause of death in cancer survivors in Australia, accounting for 25% of deaths within 7 years of cancer diagnosis.<sup>62</sup> As a result, there are more unplanned hospitalisations for the complete spectrum of cardiovascular disorders, which puts additional strain on the healthcare system.<sup>62</sup> Additionally, malnutrition linked to cancer is linked to numerous negative outcomes such as: longer hospital stays, decreased survival and inability to complete treatment, muscle function, autonomy and quality of life, and higher expenditures to the health care system.<sup>63</sup> Around 40% to 80% of cancer survivors are malnourished<sup>64-66</sup> during the course of their disease and require improved symptom management and dietary and exercise interventions, yet it is under-recognised and under-treated.<sup>67-69</sup> Cancer-related malnutrition in cancer survivors can have a detrimental influence on treatment tolerance (including anti-cancer drugs, surgery, chemo- and radiation therapy), increase side effects, produce adverse responses, cause treatment interruptions, create postoperative problems, and increase readmission rates.<sup>70</sup> On the other hand, anti-cancer therapies are known to alter body composition and nutritional status. It has been demonstrated to prevent, treat, and reduce the detrimental effects of malnutrition, and it is likely to improve overall prognosis, when early dietary and exercise interventions are tailored to the needs of cancer survivors.<sup>70</sup> Cancer-related sarcopenia is associated with similar adverse consequences to cancer-related malnutrition and can occur in 60% of cancer survivors.<sup>69</sup> These concerns are

generally covered by survivorship care, which also involves monitoring for cancer's effects and providing care that goes beyond preventing cancer recurrence. As a result, managing the social and psychological aspects of cancer recovery, such as rehabilitation, adjustment, and re-integration into regular daily life, as well as monitoring for late and long-term treatment-related effects are all important concerns addressed by cancer survivorship.<sup>69</sup>

It is crucial to address the various long-term challenges facing cancer survivors by delivering supportive care, health promotion, regular monitoring, long-term follow-up, and interventions for treatment related late effects.<sup>71, 72</sup> During the post-treatment phase, not only do cancer survivors report that their concerns are not frequently addressed, but they also report a sense of loss and abandonment by the cancer care system.<sup>73</sup> Accordingly, there is an urgent need to improve support and health services to assist cancer survivors in the transition from the end of treatment to long-term follow-up, especially regarding coordination and quality of care.<sup>57, 74</sup> Since the Institute of Medicine's Lost in Transition Report<sup>75</sup> published 15 years ago, some progress has been made to improve cancer survivorship care. To effectively address and manage the late and long-term effects of cancer and its treatment, these initiatives including shifting from a relatively concentrated cancer control viewpoint to one inclusive of post-treatment surveillance, recovery, and rehabilitation.<sup>76</sup> Initiatives aimed at improving the standard of care given to cancer survivors have thus become a top priority among survivorship advocates and policy makers. Cancer Australia<sup>77</sup> has developed principles of cancer survivorship, and the Clinical Oncology Society of Australia (COSA) has a recommended Model of Cancer Survivorship Care.<sup>60</sup> The principles of cancer survivorship published by Cancer Australia were designed to direct national strategies to lessen the effects of cancer and enhance the health and welfare of those affected by it (i.e., cancer survivors, family members and carers). Contrarily, the COSA model acknowledges that the most suitable model of care will depend on a number of variables, including the type of cancer and treatments, current symptoms and concerns, risk of future issues, length of time since last treatment, as well as personal preferences of both the cancer survivor and the provider. For many different cancer types, OCPs<sup>27</sup> have been created, and they are in line with these recommendations. The OCPs outline expected standards of care as well as significant phases in a patient's cancer journey. They have the support of the National Cancer Expert Reference Group, Cancer Australia, and Cancer Council Australia and were established after extensive consultation with a variety of expert multidisciplinary teams, peak health groups, consumers, and carers.<sup>57</sup>

However, many efforts are still required to optimise the health and wellbeing of cancer survivors.<sup>78</sup> To achieve optimal outcomes for cancer survivors, it is important to understand the essential components of quality cancer survivorship care (Figure 1). Quality survivorship care should include 1) prevention, and surveillance for recurrences and new cancers, 2) surveillance and management of physical effects of cancer and its treatment, 3) surveillance and management of psychosocial effects of cancer and its treatment, 4) surveillance and management of chronic medical conditions, and 5) health promotion and disease prevention.<sup>7</sup> Optimal care for cancer survivors requires effective multidisciplinary strategies that address multifaceted processes at individual, interpersonal, organisational, community and policy levels.



**Figure 1** Cancer survivorship care quality framework<sup>7</sup>



## 1.5 Models of survivorship care

Cancer specialists (such as medical oncologists, surgical oncologists, radiation oncologists, and haematologists) have typically led follow-up care of cancer survivors. The majority of healthcare systems in high-income countries continue to use specialist-led follow-up care as their primary model of survivorship care.<sup>79-81</sup> Cancer survivors are likely to have unmet needs because follow-up appointments often focus on detection of cancer recurrence or new cancers rather than the long-term complications that can arise after cancer treatment. Commonly reported unmet needs by Australian cancer survivors include fear of cancer recurrence, uncertainty about the future, stress reduction, worry about informal carers, information about available supportive services, and complementary and alternative therapies.<sup>82</sup> Due to the high prevalence of unmet needs across psychosocial, physical and supportive care domains, it highlights the need for routinely assessing the needs of cancer survivors through the adoption of screening practices. Traditional models of care may no longer be effective due to the growing number of cancer survivors who require complex care, and reduced workforce capacity to provide cancer survivors with follow-up care.<sup>83, 84</sup>

Alternative models of cancer survivorship care for post-treatment follow-up include shared care involving cancer specialists and PCPs; PCP-led care, and nurse-led care.<sup>85, 86</sup> Shared care refers to a collaboration between cancer specialists/hospital-based oncology team and a PCP to provide follow-up care. These models aim to integrate optimal cancer-specific care with optimal generalist care, including management of comorbidities and preventive care. Given their lack of confidence in their ability to empower and support cancer survivors with regard to all aspects of survivorship care, some PCPs may favour shared care. Thus, cancer survivors remain connected with both specialised oncology-care and generalist-care providers. Factors that have been demonstrated to influence the success of shared care models include effective communication between providers, better clarity regarding the roles and responsibilities of the care team, care coordination, follow-up guidelines, and provision of information resources (e.g., survivorship care plans).<sup>87, 88</sup> PCP-led follow-up refers to care that is provided predominantly in the primary care setting, and the responsibility of care is transferred from cancer specialists to the PCP. PCPs are in the best position to provide continuing follow-up care for cancer survivors as they are already consulted by cancer survivors for routine care and the management of other chronic health conditions. Furthermore, PCPs have more frequent and multiple encounters with cancer survivors, making them more accessible than cancer specialists. From a systems perspective, current evidence suggests that PCP-led follow-up is

likely to be a cost-effective alternative to traditional follow-up for cancer survivors treated with early-stage breast, colorectal, and prostate cancers, and early-stage melanoma. However, adoption of PCP-led models has not been widespread due to disparities in viewpoints of specialists and cancer survivors<sup>89, 90</sup>, and may prefer traditional models of care.<sup>89</sup>

Nurse-led models of care are managed by specialist cancer nurses in a range of settings (such as hospital, community), and can be administered in person, by telephone, or online.<sup>84</sup> Cancer nurses have the appropriate skills and expertise to manage symptoms, support cancer survivors to self-manage, provide lifestyle-related advice, and refer to appropriate services. Nurse-led models of survivorship care have been shown to be safe, effective, feasible and appropriate for follow-up care.<sup>91</sup> In the USA, for nurse-led models of care there has been an increased emphasis on utilising the capabilities of advanced practice providers (nurse practitioners and physician assistants) to provide post-treatment survivorship care.<sup>92</sup> Additionally, a combination of these models of care can be used, employing a range of delivery methods and may incorporate self-management strategies for cancer survivors so that they can plan their own follow-up care. According to a recent review on models of care<sup>84</sup>, in comparison to specialist-led care, nurse-led and shared care models may be more advantageous from a cost standpoint. Furthermore, these models of care have been demonstrated to increase patient satisfaction due to the convenience of visiting their PCP, reduced travel distances with their PCP, lower wait time, improved quality of life, which can encourage continuity of care after treatment.<sup>84</sup>

### **1.6 The role of diet and exercise in cancer survivorship**

Clinical needs of cancer survivors change as they move through the cancer continuum. Cancer survivors may experience symptoms that affect overall recovery, including cancer-related fatigue, weight changes, nausea, vomiting, pain, altered taste and smell perceptions, and altered bowel function. These can negatively impact food intake and physical function, and typically occur during treatment, immediately after cancer treatment, or until cessation of treatment, but also often continue to persist in the post-treatment phase.<sup>93-95</sup> It is therefore important to manage the side-effects of treatment and set long-term goals to facilitate a faster and improved quality of recovery to normal physiological processes and function. Achieving this can promote a better quality of life for cancer survivors.

Diet and exercise play essential roles in cancer survivorship by promoting recovery during the immediate post-treatment phase and improving the quality of long-term survivorship by

providing targeted interventions, to reduce the frequency and severity of late complications of treatment.<sup>74,96</sup> Dietary and exercise interventions also play an important role to prevent, reduce, or reverse the physical and psychosocial effects of cancer and its treatment, including its intersection with chronic medical conditions, such as cardiovascular disease or obesity.<sup>74, 96</sup> Poor diet and physical inactivity associated with cancer treatment can increase the risk of developing other types of cancers (i.e., breast, prostate, and colon), comorbidities, or chronic diseases. There is increasing evidence that obesity, cardiovascular disease, and metabolic syndrome negatively impact the overall health, physical function, and quality of life of cancer survivors.<sup>93</sup> Obesity also influences the risk of recurrence, level of disease aggression and progression, level of treatment response and toxicity; and all three of these items influence cancer-specific survival and overall-survival as clinical endpoints of interest.<sup>95</sup> As such, there is an increased need for dietary and exercise interventions that target weight management with a focus on optimising muscle mass while reducing fat mass. These interventions can help prevent weight gain and are associated with a lower risk of obesity.<sup>93,97</sup>

Other conditions include cancer-related malnutrition, cancer cachexia, cancer-related sarcopenia, osteopenia, and osteoporosis, which can all occur as late effects of cancer and its treatment. Malnutrition caused by cancer is distinguished by weight loss, reduced muscle mass, and loss of subcutaneous fat. In contrast, cancer-related sarcopenia is distinguished by a decrease of skeletal muscle mass and strength. Both conditions have negative side effects, such as a decreased capacity for treatment completion, which can lower progression-free and overall survival. In addition, cancer-related malnutrition and sarcopenia can be present at any bodyweight or body mass index category in cancer survivors, including those classified as overweight or obese.<sup>93, 98, 99</sup> Therefore, cancer survivors who are identified at risk of cancer-related malnutrition, sarcopenia, osteopenia, or osteoporosis require individualised dietary and exercise support to maintain their weight, improve muscle mass and strength, and improve their quality of life.

Research of lifestyle interventions demonstrate the importance of healthy, balanced diets together with structured exercise in promoting cancer control and rehabilitation that may underpin improvements in overall survival.<sup>100-102</sup> Accordingly, it is important that cancer survivors are provided with quality nutritional care, physical activity guidance, and targeted exercise programs to improve lifestyle behaviours, promote recovery, improve quality of life, and possibly reduce the risk of cancer recurrence or a new cancer developing.<sup>101</sup>

## **1.7 Roles of medical and nursing health professionals**

Multidisciplinary clinical care is required to comprehensively improve lifestyle behaviour in cancer survivors. This involves a broad range of health professionals including medical practitioners (i.e., GPs, oncologists, haematologists, and cardiologists), nurses, and allied health practitioners (i.e., dietitians, exercise physiologists, cancer physiotherapists, and psychologists).<sup>103</sup> Cancer survivors in particular prefer more specific dietary advice from all members of the multidisciplinary team, but health professionals face various barriers to incorporating nutrition as a standard part of cancer care.<sup>104</sup> Allied health professionals currently provide dietary and exercise information, cross-referrals and support. However, there is a significant need for medical and nursing health professionals to ensure cancer survivors are referred to allied health professionals in the first place. Since medical and nursing health professionals interact with all cancer survivors from diagnosis and throughout treatment, this represents the vast majority of referrals to allied health professionals. Medical and nursing health professionals can provide general dietary and exercise information, referrals, and support to address three survivorship domains: 1) surveillance and management of physical effects, 2) surveillance and management of psychosocial effects, and 3) health promotion and disease prevention. However, dietary interventions should be designed and delivered by accredited practising dietitians to facilitate the provision of individualised nutritional plans that improve dietary intake and decrease nutrition-related side-effects associated with cancer and its treatment.<sup>98</sup> Similarly, exercise interventions should be designed and delivered by accredited exercise physiologists or cancer physiotherapists who can prescribe safe, high fidelity, and effective exercise medicine programs that optimise physical capacity, fitness, and function; improve body composition, psychosocial wellbeing, and quality of life; and promote cancer recovery.<sup>105</sup>

Medical and nursing health professionals involved in cancer survivorship care can play an important role in communicating evidence-based dietary and exercise guidance to cancer survivors and facilitate provision of referrals to dietary and exercise services. Generic recommendations include the encouragement to eat a healthy balanced diet and to increase daily physical activity levels.<sup>102</sup> They can also play a key role in directing cancer survivors to evidence-based diet and exercise resources<sup>106-108</sup>, such as those provided by national diet and exercise regulatory organisations (e.g., Dietitians Australia (DA), Exercise and Sports Science Australia (ESSA), and American College of Sports Medicine (ACSM)) alongside key position statements by prominent international cancer society's (e.g., COSA, American Cancer Society

(ACS)). Medical and nursing health professionals acknowledge diet and exercise as important to maintain good health and wellbeing, and support diet and exercise as integral parts of the multidisciplinary approach to quality cancer survivorship care.<sup>109-111</sup> However, there are currently no reviews exploring the perspectives of medical and nursing health professionals on their roles and responsibilities in providing dietary and exercise advice and referrals to cancer survivors. Further knowledge and support are required to better direct cancer survivors to connect with dietary and exercise professionals and services.<sup>15</sup>

Medical and nursing health professionals are important and trusted sources of information who have an integral role to assist educating cancer survivors of the importance of diet and exercise following treatment, reinforcing behaviour change, and facilitating or making appropriate clinical referrals. Cancer survivors who require further dietary and exercise support should be referred to a specialist (dietitian, exercise physiologist or physiotherapist) with experience in cancer care for individually tailored diet and exercise programs.<sup>15, 112, 113</sup> These tertiary trained specialists have partial funding (i.e., access to five Medicare rebated sessions through the Chronic Disease Management Plan (CDMP)), and knowledge and practical skills to provide effective therapy and elicit behaviour change.<sup>114, 115</sup> However, approximately 16% to 18% of cancer survivors are being referred to dietitians and exercise professionals with some cancer survivors only being referred if they asked.<sup>116, 117, 118</sup> This research demonstrates low referral rates with cancer survivors not receiving individualised dietary and exercise care from dietitians and exercise professionals. A fee-for-service financing mechanism is used to pay for the majority of healthcare received outside of public hospitals, whether it be as an inpatient or outpatient. Contrary to medical services, however, allied health services are only partially covered by public and private insurance rebates, and there are no rebates available for health professionals who take part in activities like cancer care coordination.<sup>119</sup> Therefore, it is essential that cancer survivors are encouraged and referred by their specialist team and/or their GP to access existing subsidised dietary and exercise support, including Medicare rebated sessions via the CDMP. Moreover, since there is no central cancer registry in Australia for dietitians or exercise professionals, it is currently a challenge for medical and nursing health professionals to effectively locate accredited dietitians and exercise professionals who are experienced in cancer care. Additionally, there is limited available information in Australia that has been translated to a simpler form for time-poor health professionals to access and apply in practice; and no clear, structured, or streamlined referral practices.<sup>120, 121</sup>

### **1.7.1 Roles of specialists and primary care providers**

Cancer specialists (i.e., medical oncologists, surgical oncologists, radiation oncologists, and haematologists) and PCPs (i.e., GPs) can both play an important role in referring cancer survivors to dietitians and exercise professionals by initiating discussions about, and promoting survivorship care with cancer survivors who require additional support at diagnosis, during active treatment or post-treatment. Initially, post-treatment follow-up and surveillance may primarily be provided by specialists with a focus on detection of cancer recurrence or new cancers; however, many cancer survivors transition from specialists to GPs for a portion of their post-treatment care.<sup>122,123</sup>

GPs are in the best position to help cancer survivors modify their lifestyles through updated care plans, referrals to community-based programmes, and promotion of the benefits of physical activity, a balanced diet, and weight management. Through the use of a CDMP, GPs can refer cancer survivors to services specified in their care plan after determining whether their medical problems might benefit from allied health services. However, they can often be disconnected from the cancer specialist team due to ineffective communication and poor integration of treatment plans between GPs and specialists.<sup>124</sup> Through the implementation of survivorship care plans (SCPs), improved communication between treating oncology teams may help the transition between tertiary and primary care. SCPs summarise the cancer survivors' treatment, provide education to the GP and patient about cancer survivorship and are a communication tool between oncologists and GPs. Poor healthcare transitions hinder oncologists' and GPs' opportunities to emphasise the value of diet and exercise and to make up follow-up and referrals easier for cancer survivors. This leads to the perception that these services are an add-on rather than a component of routine cancer care.<sup>125</sup> Thus, further support and education are needed to enable GPs and oncologists to optimise their role in cancer survivorship care, such as increasing professional development opportunities for those interested in this area, and tailoring exercise and nutrition resources for use within the tertiary and primary care setting.

### **1.8 Cancer survivors' needs and preferences**

Being diagnosed with cancer has been referred to as a 'teachable moment' to encourage following lifestyle and body weight recommendations. Cancer survivors are often highly motivated to seek out information and adopt healthy lifestyle changes to improve their long-term health.<sup>126</sup> They also acknowledge the importance of diet and exercise. However, it is

crucial that the support provided to cancer survivors fits their requirements and preferences in order to encourage uptake, adherence to, and efficacy of support.<sup>127</sup> Understanding the unique requirements and preferences of cancer survivors for information and support following treatment is necessary to implement a patient-centred strategy. Additionally, the community of cancer survivors in Australia comes from a variety of social, geographic, and cultural origins; these aspects are likely to have an impact on the information needs and viewpoints of cancer survivors after treatment.<sup>126, 128</sup>

Cancer survivors who want to make an independent, well-informed decision about changing their lifestyle have said they require information shortly after their cancer diagnosis.<sup>127</sup> A lack of self-efficacy to make lifestyle changes is a significant factor in needing help, as evidenced by the fact that cancer survivors who identified a need for lifestyle support indicated they could not initiate and maintain lifestyle changes without sufficient support.<sup>127</sup> In cancer care, encouraging self-management is not always practised. In contrast, cancer survivors are frequently advised to rely on cancer care professionals rather than self-manage. The utilisation of well-established change management and quality improvement techniques (such as implementation teams and champions) as well as clinician training are necessary for the successful implementation of supported self-management. Regardless of location, self-management assistance does not yet reach a number of cancer survivors, and it should be adapted to the needs of various groups. Cancer survivors want to improve their health, quality of life, and survival by fostering their ability to self-manage their health as well as the emotional, psychological, physical and functional effects of cancer and its treatment.<sup>129,130</sup> Other models, such as shared care, GP-led care, or nurse-led care may be integrated with self-management. Function, weight loss, cardiorespiratory fitness, and biomarkers linked to disease progression and survival are all positively impacted by supported self-management programmes that target lifestyle behaviours (such as physical activity, weight management, and diet).<sup>131, 132</sup> Additionally, studies have shown that post-treatment cancer survivors with unmet dietary and exercise information needs reported actively seeking out information or assistance. Beyond clinical settings, the internet was found to be a significant source for lifestyle information. However, obtaining lifestyle-related information online could result in non-evidence-based lifestyle modifications, particularly for cancer survivors with low health literacy levels.<sup>128</sup> Thus, it is crucial that cancer care professionals take into account patient-specific aspects such as ongoing effects of cancer treatment, cultural background, geographic

location, and health literacy, as well as the potential for follow-up and referral to support services.<sup>128</sup>

Cancer survivors in rural and remote areas reported difficulties obtaining dietary and exercise advice after treatment, such as cost, time to travel for consultations, and the scarcity of nearby support services. Given these obstacles, telehealth programmes could enable better access for cancer survivors in rural and isolated places for dietary guidance and support. Dietitians Australia recently released a position statement on telehealth that describes telephone support as an appropriate delivery option for dietary advice after treatment. With head and neck cancer survivors, a home-based telehealth programme was successfully tested, and the results included high patient satisfaction, a decrease in the amount of contact time needed to meet patient goals, and the elimination of transport costs.<sup>128</sup> Cancer survivors should be educated on the benefits of diet and exercise, encouraged to adopt healthy lifestyle habits, and referred to relevant allied health professionals, services and resources, utilising cancer care professionals to communicate with cancer survivors about the role of diet and exercise in cancer care.<sup>133</sup>

### **1.9 Dietary and exercise referral processes and practices**

International clinical recommendations advise that all cancer survivors be regularly assessed for nutritional risk and degree of physical activity at regular intervals.<sup>115, 134</sup> It is not feasible for all medical and nursing health professionals to provide individualised dietary or exercise advice for every cancer survivor due to time, resource, and knowledge constraints<sup>60</sup>; therefore, individualised screening of cancer survivors to identify their need for dietary and exercise services is recommended, together with the provision of referrals and connections to accredited dietitians and exercise professionals. This will be useful to identify cancer survivors who are at nutritional risk and require support from dietitians, and to evaluate their performance status, physical activity levels, and physical needs. Based on clinical indications (e.g., disease-related factors, treatment-related toxicities or side effects, comorbidities, and other chronic illnesses), it is recommended that cancer survivors are referred to exercise professionals for individualised exercise advice and prescriptions that may suit clinical need and personal preferences.<sup>115, 135</sup>

COSA has recently released a cancer-related malnutrition and sarcopenia position statement recommending all cancer survivors be screened for malnutrition and sarcopenia using the Malnutrition Screening Tool (MST); referred to a dietitian if clinically indicated; and referred to an exercise professional for individualised support.<sup>99, 115</sup> MST includes two questions about



recent unintentional weight loss and reduced appetite impacting dietary intake<sup>136</sup>, with answers graded on a scale from 0 and 5. Cancer survivors with an MST score  $\geq 2$  are classified as ‘at risk of malnutrition’ and should be automatically referred to dietitians. Dietitians then use the Patient-Generated Subjective Global Assessment form (PG-SGA) to determine their degree of malnutrition and provide individualised support.<sup>137</sup> In terms of exercise, COSA has also recently updated their exercise and cancer position statement recommending cancer survivors be referred to an accredited exercise professional with cancer experience, with few exceptions.<sup>138, 139</sup> The American Society of Clinical Oncology recommends that health professionals (1) assess physical activity for all cancer survivors at regular intervals, continuously across the cancer continuum; (2) advise cancer survivors on their current and desired level of physical activity; and (3) refer cancer survivors to appropriate exercise programs or to exercise professionals who can evaluate and refer to exercise. These three steps should occur at regular intervals considering late effects or other comorbidities, changes in treatment, and reported changes in functional status.<sup>140</sup> Furthermore, allied health professionals can also identify when cancer survivors may benefit from referral to another allied health professional. For example, accredited exercise professionals may refer cancer survivors to a dietitian who require individualised dietary advice, or to a psychologist for those reporting concerns with fear of recurrence.<sup>141</sup> Accordingly, allied health professionals play an important additional role in cancer survivorship care beyond the provision of their own services, by routinely facilitating cross-referrals to other allied health professionals in current practice.

The US Institute of Medicine recommends that all cancer survivors receive a SCP following the completion of cancer treatment; however, SCPs are inconsistently used.<sup>75, 142</sup> Typically, SCPs provide information on cancer survivor diagnosis and treatment history, potential late effects, guidelines for lifestyle modifications, and future follow-up care and surveillance.<sup>143</sup> This information can be used by primary care providers (i.e., GPs and general practice nurses) to create a CDMP (which, in Australia, includes five fully subsidised clinical consultations with allied health professionals each year), and a Team Care Arrangement (TCA) if cancer survivors require treatment from two or more health care providers (e.g., dietitians and exercise physiologists).<sup>144</sup> GPs are well placed to provide general lifestyle-related advice or referral to allied health professionals through general practice during the post-treatment survivorship phase.<sup>145</sup> However, GPs may find it difficult to offer specific advice as they have limited consultation times and are not prepared to deliver tailored dietary and exercise advice. Accordingly, GPs should refer cancer survivors to dietitians and exercise professionals<sup>74</sup>, and

thus play a key role in educating cancer survivors while addressing the relevance of diet, physical activity, and exercise for cancer survivors and making appropriate referrals.

### **1.10 Barriers and facilitators to providing dietary and exercise advice, and referrals to dietitians and exercise professionals.**

Cancer survivors not being referred to dietitians and exercise professionals can be attributed to several factors: a lack of relevant education, skills, and training for medical and nursing health professionals to make timely and appropriate referrals to appropriate allied health services<sup>146</sup>; a lack of clarity on the role of health professionals to assess, advise and refer cancer survivors to dietitians and exercise professionals<sup>147</sup>; a lack of awareness regarding the importance of diet and exercise in the management of cancer<sup>148</sup>; uncertainty around the safety of exercise for cancer survivors across treatment profiles or the disease trajectory; limited public funding<sup>144</sup>; a lack of resources<sup>108, 114</sup>; financial toxicity of cancer survivors<sup>149</sup>; and time constraints.<sup>108, 114</sup> Due to the complexity of healthcare systems, improvements in referrals to dietitians and exercise professionals requires change at multiple levels of the health system, not only at the individual level. Optimising dietary and exercise care for cancer survivors requires a better understanding of complex factors that are part of an interconnected system that may facilitate or impede referral practices. Adopting a systems-thinking approach has the ability to explore the components within a health system and how they interconnect to improve our understanding of how outcomes emerge from these interactions.<sup>150</sup> Thus, effective strategies to address system-level barriers are also required that consider different processes at individual, interpersonal, organisational, community and policy levels.

Medical and nursing health professionals are the first point of contact for most cancer survivors, often with frequent and multiple encounters, thus they are well-placed to provide lifestyle-related recommendations at multiple time periods, identified as trusted professionals with access to cancer survivors at teachable moments (i.e., at diagnosis, or during treatment). However, medical and nursing health professionals report insufficient time to provide lifestyle-related recommendations<sup>108, 114</sup> and are reluctant to discuss lifestyle factors with cancer survivors due to a lack of knowledge.<sup>146</sup> Specifically, the absence of diet and exercise components within their academic curriculum has been attributed to the lack of providing dietary and exercise recommendations to cancer survivors.<sup>114, 151</sup> Furthermore, to keep up to date with the current literature and developments in the field of nutrition and exercise science is challenging for time poor health professionals.<sup>152</sup> Therefore, expecting anything more than

basic knowledge of diet and exercise recommendations for cancer survivors is unrealistic. However, as front-line health professionals, they should educate cancer survivors about the importance and benefits of these lifestyle changes and assist them to engage with specialist allied health services.<sup>114</sup>

Clinical diet and exercise guidelines in the management of cancer<sup>115, 141, 153</sup> can be used by health professionals to understand the appropriate level of dietary and exercise support for cancer survivors based on their individual needs.<sup>99, 115, 138</sup> However, implementation of these guidelines for non-diet and non-exercise health professionals can be challenging as there is no specific guidance that helps medical and nursing health professionals with linking cancer survivors to relevant services and resources (i.e., no central cancer registry for dietitians or exercise professionals experienced in cancer care).<sup>147</sup> Furthermore, some medical and nursing health professionals may rely on different sources of information concerning diet and exercise based on what they deem credible, and their past experiences, underpinning their recommendations or referrals practices with cancer survivors and carers. Under these circumstances, dietary and exercise recommendations and referrals are inconsistently supplied and applied, resulting in poor compliance.<sup>148, 154, 155</sup> Delayed dietetic and exercise referrals can lead to nutritional and functional decline and malnutrition to become established which can lead to poorer patient outcomes.<sup>156</sup> This highlights the need for medical and nursing health professionals to help cancer survivors to understand what dietary and exercise sources and recommendations they can trust, where to find reliable evidence-based recommendations, and who they should connect with at key time points to receive specialist consultation and intervention.

Cancer survivors may experience long-term side effects and symptoms post-treatment, which can be managed through supportive care services (including diet and exercise).<sup>7</sup> As a result, medical health professionals should encourage cancer survivors to access existing services (i.e., five Medicare rebated sessions through the CDMP) with dietitians and exercise professionals for individualised dietary and exercise support. However, because of the limited number of subsidised sessions shared across available services, these alone may not be sufficient to enact sustained health behaviour change and improve health outcomes, which can discourage GPs from referring to specialists despite the evidence for substantial patient benefit.<sup>157</sup> As a result, cancer survivors will have increased out-of-pocket expenses to receive ongoing support<sup>149</sup>, whereby financial burden may limit their ability to be-able to afford further access to specialist

services (i.e., dietitians and exercise professionals). Financial toxicity is the term used to describe the financial burden or financial hardship that cancer survivors endure as a result of their cancer and its treatment, which continues to be a persistent challenge for post-treatment cancer survivors.<sup>158</sup> A systematic review canvassing 45 studies demonstrated that 47% to 49% of cancer survivors reported some degree of financial toxicity.<sup>159</sup> As a result, strategies to reduce costs, promote self-management or identify sustainable delivery modes are of utmost importance.<sup>158</sup> There is a need to advocate for the importance of dietitians and exercise professionals and their role in patient care and increase awareness of the challenges medical and nursing health professionals face in providing dietary and exercise advice and referrals to cancer survivors.

### **1.11 Current gaps in referral practices**

Inconsistencies in dietary and exercise referral processes are attributable to several factors, including: 1) a lack of established referral pathways, 2) infrequent and inconsistent diet and exercise screening practices by health professionals, and 3) a focus on acute problems rather than the provision of long-term support.<sup>38</sup> Around half (53%) of the public and private hospitals in Australia that provide cancer care do not have established referral pathways for supportive care services, with only 19% of hospitals referring cancer survivors to external organisations or allied health professionals. This highlights an issue with current practices; the importance of standardising referral processes; and the inadequacy of supportive care provided to most cancer survivors.<sup>17</sup>

Several nutrition screening tools are commonly used for monitoring cancer survivors at nutritional risk, including the malnutrition screening tool (MST) and the patient-generated subjective global assessment short form (PG-SGA SF). However, the scored PG-SGA is generally used to assess nutritional status in cancer survivors.<sup>137</sup> These tools identify cancer survivors at risk of malnutrition and cancer survivors who are malnourished but excludes patients with other nutritional problems.<sup>160</sup> However, there are no other nutrition screening tools and assessments for conditions other than malnutrition (i.e., MST, PG-SGA SF, scored PG-SGA, malnutrition universal screening tool (MUST), mini nutritional assessment (MNA)). There is no standardised screening tool for physical activity available that is specific to cancer survivors. However, current international recommendations from ACS advise the use of physical activity screening surveys, and if there is a positive response, health professionals are encouraged to provide the patient with a standardised exercise prescription form.<sup>161</sup> Further,

procedures such as the ESSA Adult Pre-Exercise Screening tool<sup>162</sup>, Physical Activity Readiness Questionnaire<sup>163</sup>, PARmed-X<sup>161</sup>, physical activity screening forms<sup>164</sup>, clinical screening and referral frameworks<sup>161</sup> or evidence-based exercise programming via electronic medical records (EMR)<sup>165</sup> are all potential options to facilitate the screening process. Screening can help determine performance status, exercise capacity, rehabilitation needs, and risk management to ensure health professionals provide safe and appropriate exercise information and guidance to cancer survivors, and referrals as indicated.<sup>141</sup> It is therefore recommended that a cohesive, accessible, and streamlined system be developed so that screening and referral become integrated into standard of care for cancer survivors.<sup>166</sup> Due to infrequent or lack of screening practices across hospitals and health professionals, cancer survivors will miss key referral opportunities for earlier assessment and support from a dietitian or exercise professional.<sup>94, 115</sup> For screening to become integrated into standard care, funding needs to be prioritised, appropriate models of care must be developed, and health services must all be standardised, and evidence based.

Post-treatment referrals to dietitians and exercise professionals are mostly provided for short-term support to address acute health problems (e.g., established weight loss and poor function) rather than providing self-care strategies that seek to improve cancer survivors' long-term outcomes.<sup>94, 138</sup> Evidence shows that the availability of most supportive cancer care services decreases with time after cancer treatment.<sup>38</sup> Even though it is important to continue providing cancer survivors with referrals for short-term support, there is also a need to provide referrals to supportive cancer care services for long-term support.

### **1.12 Current progress in referral practices**

Care coordination between medical and nursing health professionals; and allied health professionals is essential since cancer survivors all have different individual care needs. Thus, a lack of care coordination can lead to fragmented care in cancer survivors.<sup>167</sup> However, the majority of survivorship care is handled in acute specialist-led clinics, with little care coordination amongst allied health services.<sup>81</sup> There needs to be coordinated, integrated access to allied health professionals as well as self-management support as highlighted by COSA in models of survivorship care.<sup>60</sup> In order to investigate referral pathways to survivorship programs, the implementation results of a community-based survivorship care model delivered by allied health services in Australia was evaluated.<sup>168</sup> The survivorship program was successfully integrated into existing community chronic disease management programs, as

evidenced by adoption, acceptability, appropriateness, and feasibility (using the RE-AIM framework).<sup>168</sup> These findings demonstrated the program's feasibility for implementation across several community health services. This study generates evidence for a care pathway that is safe, and tailored to individual needs, which specifically aligns with principle 3 from Cancer Australia's principles of cancer survivorship.<sup>77</sup> Therefore, this research confirmed that the proposed model of survivorship care is feasible for replication in various community health settings.<sup>168</sup> Community-based models of survivorship care provide a valuable approach of supporting cancer survivors and can reduce the strain on hospital-based cancer services, making them an important addition to cancer services.

Despite the availability of evidence-based exercise guidelines around the world, most cancer survivors are not regularly physically active. Physical inactivity in cancer survivors can be attributed to a number of barriers as highlighted in the literature. A recent international scoping survey<sup>169</sup> of health care professionals' knowledge, beliefs, practices, barriers and facilitators regarding providing exercise counselling to cancer survivors was conducted. This survey is consistent with previous findings that medical and nursing health professionals, exercise professionals, and non-exercise allied health professionals agree that providing exercise guidance should be a part of standard care.<sup>10</sup> However, health professionals have reported barriers to providing exercise guidance, such as a lack of knowledge, and confusion amongst health professionals regarding when and how to provide exercise guidance to cancer survivors. A call for action has highlighted practical recommendations supporting the adoption of the EIM approach for cancer survivors. These recommendations include routinely evaluating cancer survivors' physical activity levels through screening processes, encouraging cancer survivors to increase physical activity if they are not meeting recommended activity levels, and referring cancer survivors to appropriate exercise programs. To aid health professionals, details on available exercise programs and services as well as implementation challenges were also provided. A registry detailing all available exercise programmes, higher expenditures, and a lack of support for health professionals' professional development were among the often cited implementation challenges.<sup>140</sup> To provide optimal exercise care for cancer survivors, there is an urgent need to integrate these practical recommendations as part of standard care while addressing any implementation challenges.

### **1.13 Research problem**

Despite progress in developing updated dietary and exercise guidelines for cancer survivors<sup>115, 141, 153</sup>, position statements<sup>69, 139</sup>, and models of survivorship care<sup>168</sup>, there is no standardised Australian referral framework and no structured referral process for medical and nursing health professionals to adopt.<sup>161</sup> With growing demand for referrals to dietary and exercise services for cancer survivors, a better understanding of the factors that may influence medical and nursing health professionals in providing dietary and exercise care, and referrals is required. As discussed in the literature, medical and nursing health professionals can play an important role in communicating evidence-based dietary and exercise guidance to cancer survivors and facilitate provision of referrals to dietary and exercise services.<sup>102</sup> However, a systematic disconnect exists between medical and nursing professionals providing cancer care, and allied health professionals providing specialist dietary and exercise care to cancer survivors. Therefore, it is important to first understand the perspectives of medical and nursing health professionals on their roles and responsibilities in the provision of dietary and exercise advice, and referrals to cancer survivors. Furthermore, when engaging dietitians and exercise professionals for dietary and exercise consultation, education, and interventions to cancer survivors, effective and streamlined referral processes to these services have not yet been clearly developed or standardised. Accordingly, creating a suite of essential elements for optimal referral practices to dietary and exercise services can improve outcomes for cancer survivors' by facilitating consistent cancer care. Essential elements focus on (i) cancer survivors, their families, and their caregivers; (ii) referrers; (iii) service providers; and (iv) resources and practice environments. These essential elements can ultimately inform an adaptable framework to guide policy planning and health system responses to cancer survivorship care and referral practices to dietary and exercise services.

### **1.14 Research plan**

This doctoral research seeks to enhance effective dietary and exercise referral practices across the survivorship trajectory through the development of essential elements embedded within principles of cancer survivorship established by Cancer Australia.<sup>77</sup> Developing essential element statements for dietary and exercise referral practices will support medical and nursing health professionals in optimising cancer survivors' access to specialised dietary and exercise support in Australia. Additionally, this doctoral research explores how system-level factors

within the Australian health system can influence dietary and exercise referral practices, and how they can be used to develop strategies at a policy level.

### 1.14.1 Research questions

To achieve the proposed aims, the following studies will be conducted:

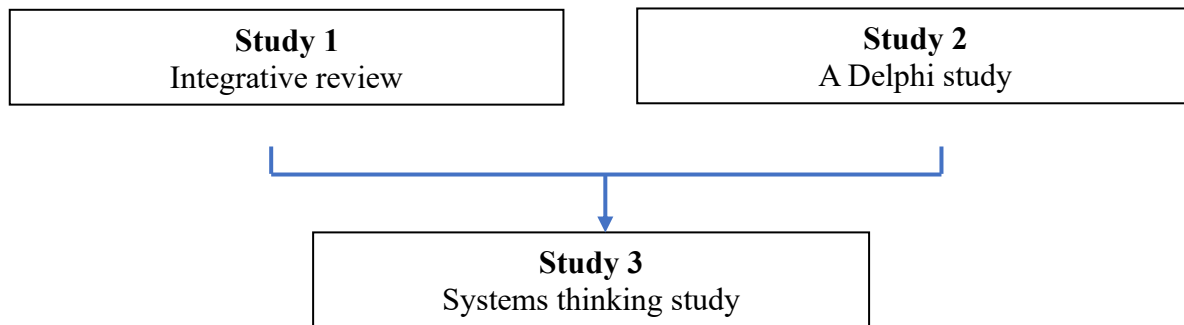
**Study 1:** An integrative review examined medical and nursing health professional perspectives (specifically oncologists, haematologists, cardiologists, cancer nurses and other generalists (GPs and practice nurses)) on their roles and responsibilities in providing dietary and exercise care to cancer survivors. Specifically, this review can shed light into current perspectives that exist among the medical and nursing health professional disciplines in terms of who provides what dietary and exercise care, and at which point they should refer to dietary and exercise professionals for specialised services. In addition, barriers and facilitators to the provision of dietary and exercise care and referrals were synthesised.

- What are the perspectives of medical and nursing health professionals and consumers on the roles and responsibilities of medical and nursing health professionals in providing dietary and exercise advice and referrals to cancer survivors?
- What are the perceived barriers and facilitators to medical and nursing health professionals in providing dietary and exercise advice and referrals to cancer survivors?

**Study 2:** A Delphi process explored expert opinion and reached a consensus on the importance of essential element statements for use by medical and nursing health professionals. Initial statements were informed by (1) Cancer Australia's Principles for Cancer Survivorship<sup>77</sup>; (2) literature review (Study 1); and (2) input from stakeholders through a workshop at the Brisbane Cancer Conference (2020) conducted by the research team. This Delphi process identified essential elements that medical and nursing health professionals can implement to provide optimal dietary and exercise care to cancer survivors, and referrals to dietitians and exercise professionals. Study 1 and Study 2 were conducted concurrently.

- From the perspectives of panel members, what are the essential elements relevant to referral practices for dietary and exercise care for cancer survivors, with consideration of (i) referrers; (ii) service providers; (iii) consumers; and (iv) resources and practice environments?





**Figure 2** Flowchart of doctoral research methodology

**Study 3:** A systems-thinking approach was used to understand and identify relevant factors in the healthcare system which can influence dietary and exercise referral practices. Specifically, Study 1 and Study 2 informed Study 3 on the following: (1) perceived lack of role clarity amongst medical and nursing health professionals regarding their roles in providing dietary and exercise advice and referrals, and a lack of established referral pathways; and (2) 24 essential elements that were highly rated by key stakeholders. The workshop was structured using a well-established health system framework (i.e., WHO’s health system building blocks framework).<sup>170</sup>

- What factors in a health system influence dietary and exercise referral practices, and how can these factors be used to develop strategies to address any system-level barriers?

#### 1.14.2 Aims

The aims of this doctoral research were to:

- Understand the perspectives of medical and nursing health professionals and consumers on the roles of medical and nursing health professionals in providing cancer survivors with dietary and exercise advice and referrals to dietitians and exercise professionals (Study 1).
- Develop essential element statements that medical and nursing health professionals can implement to facilitate optimal dietary and exercise care to cancer survivors and streamline referrals to dietitians and exercise professionals (Study 2).

- iii. Apply a systems-thinking approach to understand, from a complex system perspective, the interactions of the healthcare system which may influence referral practices (Study 3).

### **1.14.3 Objectives**

The objectives of this doctoral research were to:

- i. Conduct an integrative review of the perspectives of medical and nursing health professionals and consumers on the roles of medical and nursing health professionals in providing cancer survivors with dietary and exercise advice and referrals to dietitians and exercise professionals.
- ii. Conduct a Delphi study with cancer stakeholders (consumers, cancer specialists, allied health professionals) to inform the development of essential element statements to provide guidance to medical and nursing health professionals regarding dietary and exercise care and referrals for cancer survivors.
- iii. Conduct a systems-thinking workshop to identify system-level factors which may influence referral practices, identify innovative strategies to address these system-level factors, and develop a causal loop diagram.

### **1.15 Summary**

There is strong evidence in the literature that dietary and exercise interventions are essential and beneficial for optimising outcomes for people affected by cancer. However, the current system of care does not comprehensively facilitate quality, systematised health-system responses to provide cancer survivors with seamless access to dietary and exercise services. While medical and nursing health professionals understand the importance of dietary and exercise education and support for cancer survivors, and acknowledge their role as key conduits of referral to general practice and specialist services, they also report multiple barriers including role clarity, and a lack of standardised referral pathways. Thus, medical and nursing health professionals require better guidance and structure regarding the roles they play in providing dietary and exercise advice, and how and when to refer cancer survivors to diet and exercise professionals. This doctoral research intends to optimise dietary and exercise referral practices for cancer survivors.

This doctoral research comprises of seven chapters and are arranged as below:

**Chapter 2** provides a review of the literature on perspectives of medical and nursing health professionals and consumers on medical and nursing health professionals' roles in providing dietary and exercise guidance to cancer survivors.

**Chapter 3** describes the methodology and research design of the Delphi study, including the selection of panel members and the distribution of draft essential element statements.

**Chapter 4** presents the results of the Delphi study, and the resulting essential element statements for medical and nursing health professionals.

**Chapter 5** describes the methodology and research design of the systems-thinking study, exploring the interactions of the healthcare system which may influence dietary and exercise referral practices, to identify system-level factors and strategies to address these system factors.

**Chapter 6** presents the results of the systems-thinking study, and the prioritised system-level factors that influence dietary and exercise referral practices.

**Chapter 7** highlights the main conclusions and implications for practice and research, as well as future directions. The appendices include supporting information for the studies discussed in the previous chapters.

## **1.15 Definition of terms**

### **Cancer survivor**

#### *Conceptual definition:*

Cancer survivors can be defined as individuals living with a diagnosis of cancer from the time of diagnosis through the end of their life.<sup>166</sup>

#### *Operational study definition:*

Cancer survivors will refer to any individual living with a diagnosis of cancer with a focus on the post-treatment phase as per the integrative review (study 1). However, based on participant feedback to consider the entire cancer trajectory in the Delphi study (study 2), the conceptual definition will be adopted in subsequent chapters.

### **Diet**

#### *Conceptual and operational study definition:*

Diet is a lifestyle factor that can be used to reduce the late and long-term effects of cancer.<sup>171</sup>

A healthy diet is one that provides enough micronutrients and fluids to meet the body's physiological needs while also consuming enough macronutrients in the right amounts to support energetic and physiological needs without overeating.<sup>172</sup>

### **Dietitian**

#### *Conceptual and operational study definition:*

Dietitians are experts who use the science of food and nutrition to improve the health of people, groups, communities, and populations. They also work to prevent and treat disease.<sup>173</sup>

### **Essential elements**

#### *Conceptual definition:*

Essential elements can be defined as aspirational, governing statements that can assist health professionals, researchers, and policymakers in implementing and evaluating best practices in patient-centred care.<sup>174</sup>

#### *Operational study definition:*

Essential elements refer to statements that can help health professionals implement and evaluate best practices that seek to achieve high-quality survivorship care for cancer survivors. Essential elements consider (i) cancer survivors, their families, and their caregivers; (ii) referrers; (iii) service providers; and (iv) resources and practice environments.

## **Exercise**

### *Conceptual and operational study definition:*

Exercise is any physical activity that increases energy expenditure, involves a planned or structured movement of the body on a regular basis for a certain amount of time, and is intended to maintain or improve health-related outcomes.<sup>153</sup>

## **Exercise professional**

### *Conceptual definition:*

Exercise professionals can be defined as tertiary trained and accredited or certified individuals who provide exercise guidance for clients to help improve their health, especially those dealing with specific conditions (e.g., exercise physiologists and physiotherapists).<sup>138</sup>

### *Operational study definition:*

Exercise professionals refer to tertiary trained accredited exercise physiologists through Exercise & Sport Science Australia (ESSA), and physiotherapists certified through the Australian Physiotherapy Association; and who provide exercise guidance to cancer survivors.

## **Physical activity**

### *Conceptual and operational study definition:*

Any skeletal muscle-produced movement that involves an energy expenditure is considered to be engaging in physical activity.<sup>175</sup>

## **Causal loop diagram**

### *Conceptual and operational study definition:*

An insight on what motivates problematic system behaviour can be gained by using causal loop diagrams, a systems-thinking technique that be used to provide a visual representation of the relationships between system constituents and their interactions.<sup>176</sup>

## **Cognitive mapping**

### *Conceptual and operational study definition:*

A visual mapping approach called cognitive mapping is used to extract people's descriptions of situations and/or problems, as well as their justifications for how and why they view them.<sup>177</sup>

# **CHAPTER TWO - DIETARY AND EXERCISE ADVICE AND REFERRALS FOR CANCER SURVIVORS: AN INTEGRATIVE REVIEW OF MEDICAL AND NURSING PERSPECTIVES**

## **2.1 Chapter overview**

As discussed in the literature, medical and nursing health professionals can play an important role in communicating evidence-based dietary and exercise guidance to cancer survivors and facilitate provision of referrals to dietary and exercise services.<sup>102</sup> However, a systematic disconnect exists between medical and nursing professionals providing cancer care, and allied health professionals providing specialist dietary and exercise care to cancer survivors. Therefore, it is important to first understand the perspectives of medical and nursing health professionals on their roles and responsibilities in the provision of dietary and exercise advice, and referrals to cancer survivors. Furthermore, a lack of role clarity amongst medical and nursing health professionals has been highlighted as a barrier to providing dietary and exercise care to cancer survivors, subsequently affecting the care cancer survivors receive. This chapter provides an integrative review of recently published literature relevant to the provision of dietary and exercise advice and referrals for cancer survivors. This integrative review was conducted to understand the perspectives of medical and nursing health professionals and consumers on the roles of medical and nursing health professionals in providing cancer survivors with dietary and exercise advice and referrals to dietitians and exercise professionals. An integrative review was chosen over other review typologies because it provides a broader summary of the literature and integrates results from a variety of studies, allowing comprehensive and robust conclusions to be drawn.<sup>178</sup>

This review informs the role clarity of medical and nursing health professionals with regards to providing dietary and exercise advice and referrals and explores the following questions:

- What are the perspectives of medical and nursing health professionals and consumers on the roles and responsibilities of medical and nursing health professionals in providing dietary and exercise advice and referrals to cancer survivors?
- What are the perceived barriers and facilitators to medical and nursing health professionals in providing dietary and exercise advice and referrals to cancer survivors?

This integrative review was accepted for publication in *Supportive Care in Cancer* on 26/05/2022 (DOI: [10.1007/s00520-022-07152-w](https://doi.org/10.1007/s00520-022-07152-w)) and has been included in this chapter.

Joseph R, Hart NH, Bradford N, Agbejule OA, Koczwara B, Chan A, Wallen MP, Chan RJ. Diet and exercise advice and referrals for cancer survivors: an integrative review of medical and nursing perspectives. *Support Care Cancer*. 2022.

(RJ was the primary author of this paper and led the development of the research question, data collection, synthesis and drafting of the manuscript. OAA assisted with data collection. RJC, NHH and NB assisted with supporting RJ as PhD supervisors in conducting the review and offered comments and editing of the cited paper. All authors commented on previous versions of the manuscript, and read and approved the final manuscript).

## **2.2 Background**

As previously stated in Chapter 1, medical and nursing health professionals can play an important role in educating cancer survivors of the importance of diet and exercise, reinforcing behaviour change, and facilitating referrals to diet and exercise services. Multidisciplinary teams are considered the “gold standard” of cancer care delivery worldwide, positively contributing to the improvement of cancer care and outcomes.<sup>179, 180</sup> Multiple studies have shown that a multidisciplinary approach incorporating medical, nursing, and allied health professionals supports cancer survivors during and after treatment to develop healthy lifestyle habits that improve clinical outcomes.<sup>71, 100, 181</sup> Allied health professionals, including dietitians and exercise professionals (e.g., clinical exercise physiologists and physiotherapists), work closely with medical and nursing professionals to provide expertise to prevent, diagnose, and treat various conditions and illnesses, inclusive of cancer.<sup>182</sup> In the survivorship context, dietitians provide individually tailored nutritional plans to optimise dietary intake and decrease nutrition-related side effects of cancer and its treatment.<sup>72</sup> Clinical exercise physiologists and physiotherapists are the most appropriate health professionals to promote physical activity and are tertiary-trained to design, prescribe, and deliver safe and effective exercise interventions to cancer survivors that optimise cardiorespiratory and neuromuscular fitness, body composition, and known cardiometabolic and musculoskeletal risk factors, thus improving cancer care and recovery.<sup>73, 141</sup> Accordingly, health professionals with a diversity of clinical specialties can play important synergistic roles in providing optimal dietary and exercise care to cancer survivors. However, there is no clear, structured or streamlined referral practices.

Medical and nursing health professionals are the most constant cancer care providers throughout a patient's cancer journey, thereby playing an essential role in communicating evidence-based advice to cancer survivors, including for diet and exercise, as trusted agents for credible health information in cancer care.<sup>183, 184</sup> In this review, dietary and exercise advice includes: (1) encouraging cancer survivors to adopt a healthy balanced diet; (2) increasing physical activity levels; (3) discussing the role of diet, physical activity and structured exercise programs in cancer care and recovery; and (4) recommending adherence to diet and exercise guidelines.<sup>134, 141, 185</sup> This should be facilitated by providing cancer survivors with referrals to dietitians and exercise professionals with experience in cancer care for formal dietary and exercise assessments and interventions.<sup>14</sup> However, medical and nursing health professionals face barriers that affect their ability to provide timely and appropriate dietary and exercise advice to cancer survivors, including time constraints, limited knowledge and expertise<sup>186</sup>, and a lack of access to evidence-based resources to provide to cancer survivors.<sup>187</sup> Furthermore, it is important to determine whether medical and nursing health professionals perceive this to be within their professional roles and responsibilities when caring for cancer survivors, inclusive of providing referrals to dietitians and exercise professionals. Accordingly, the primary aim of this integrative review is to systematically harmonise existing perspectives of medical and nursing health professionals about their roles and responsibilities in providing dietary and exercise advice to cancer survivors, with referrals to allied health professionals; Secondary aims of this integrative review were to identify barriers and facilitators to providing dietary and exercise advice and referrals by medical and nursing health professionals to cancer survivors.

### **2.3 Methods**

This is an integrative review involving studies of varied methodologies, including quantitative, qualitative, and mixed-methods research.<sup>188</sup> For this review, medical and nursing health professionals constitutes cancer specialists (i.e., oncologists, haematologists, cardiologists, cancer nurses) and other generalists (GPs and practice nurses) who provide healthcare to cancer survivors. This integrative review adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Checklist<sup>189</sup>, with literature search and study selection processes illustrated below (Figure 3). The protocol of this review was registered at the International Prospective Register of Systematic Reviews (PROSPERO), registration number CRD42021225213.



### **2.3.1 Identification of studies**

The Population, Intervention, Comparison and Outcome (PICO) model was used as a search strategy tool and is presented in Appendix 1. Articles were identified from December 2011 to June 2021 using a defined search strategy (Appendix 1) across the following electronic databases: PubMed, CINAHL, PsycINFO, EMBASE, Web of Science and hand searching of bibliographies of relevant studies. The search was limited to articles from 2011 to 2021 to ensure currency of our findings that are most reflective of perspectives on medical and nursing health professionals' roles and responsibilities in current healthcare settings due to the rising number of cancer survivors and evolving evidence in diet and exercise for cancer survivors during this time. After obtaining all references, duplicates were excluded by using EndNote (Thomson Reuters, USA).<sup>190</sup>

### **2.3.2 Inclusion criteria**

Studies had to meet the following inclusion criteria: 1) published in peer-reviewed journals in English; 2) qualitative, quantitative, or mixed-method study designs; (3) reporting perspectives of medical and nursing health professionals and consumers (i.e., cancer survivors and their families or informal caregivers) on the roles and responsibilities of medical and nursing health professionals; and (4) reporting the provision of dietary and exercise advice to cancer survivors. Studies reporting broader lifestyle advice that included diet, exercise, or both were also eligible.

### **2.3.3 Study screening**

Three researchers independently screened all articles identified in the search (titles and abstracts) for relevance using a web-based application: Rayyan<sup>191</sup>, and those selected were subject to full-text assessment. Any discrepancies were resolved by consensus. One researcher (RJ) assessed the selected full-text articles against the eligibility criteria. All eligible articles were tabulated and included in the review.

### **2.3.4 Data extraction**

Two researchers independently extracted the data using a predefined data extraction form (Appendix 2). A data extraction form was developed according to Joanna Briggs Institute (JBI)<sup>192</sup> and literature associated with cancer survivorship concepts or methods. For each study, the following data were extracted: study citation, study details (e.g., citation), study methods (e.g., semi-structured interviews, cross-sectional surveys), population characteristics (e.g., type of health professional), outcome measures (e.g., perspectives of medical and nursing health

professionals), recommendation type (e.g., dietary and exercise advice), perceived role and responsibility of medical and/or nursing health professional, barriers and facilitators, study findings (including summarised themes, subthemes in qualitative studies, and conclusions), and the quality of evidence.

### 2.3.5 Quality appraisal

The Mixed Methods Appraisal Tool (MMAT, Version 2018) was used to critically appraise included studies (Appendix 4) Critical appraisals were conducted by the doctoral candidate (RJ). For qualitative studies (i.e., semi-structured interviews), five questions appraised the methodological quality of the articles in terms of the following aspects: data sources, collection and analysis, context, and researchers' influence on the data. Quantitative descriptive studies (i.e., cross sectional surveys) were appraised by five questions regarding the sampling strategy, representativeness, appropriateness of measurements, and response rate. For mixed-methods studies (i.e., cross sectional surveys and semi-structured interviews), five questions appraised the rationale for using a mixed-methods design, integration of qualitative and quantitative data, and discrepancies between qualitative and quantitative results (Table 1).

**Table 1** Critical appraisals using the MMAT

Studies	Methodological quality criteria					Overall responses from the Mixed Methods Appraisal Tool	Quality
	1	2	3	4	5		
<b>Qualitative</b>							
Baker, 2015	✓	✓	✓	✓	✓	QUAL=5	100%
Balneaves, 2020	✓	✓	✓	✓	✓	QUAL=5	100%
Brandenburg, 2017	✓	✓	✓	✓	✓	QUAL=5	100%
Cheville, 2012	✓	✓	✓	✓	✓	QUAL=5	100%
Coa, 2014	✓	✓	✓	✓	✓	QUAL=5	100%
Hausman, 2018a	✓	✓	✓	✓	✓	QUAL=5	100%
Koutoukidis, 2018	✓	✓	✓	✓	✓	QUAL=5	100%
Roberts, 2019	✓	✓	✓	✓	✓	QUAL=5	100%
Waterland, 2020	✓	✓	✓	✓	✓	QUAL=5	100%
<b>Quantitative descriptive</b>							
Alderman, 2020	✓	✓	✓	✗	✓	QUAN=4	80%

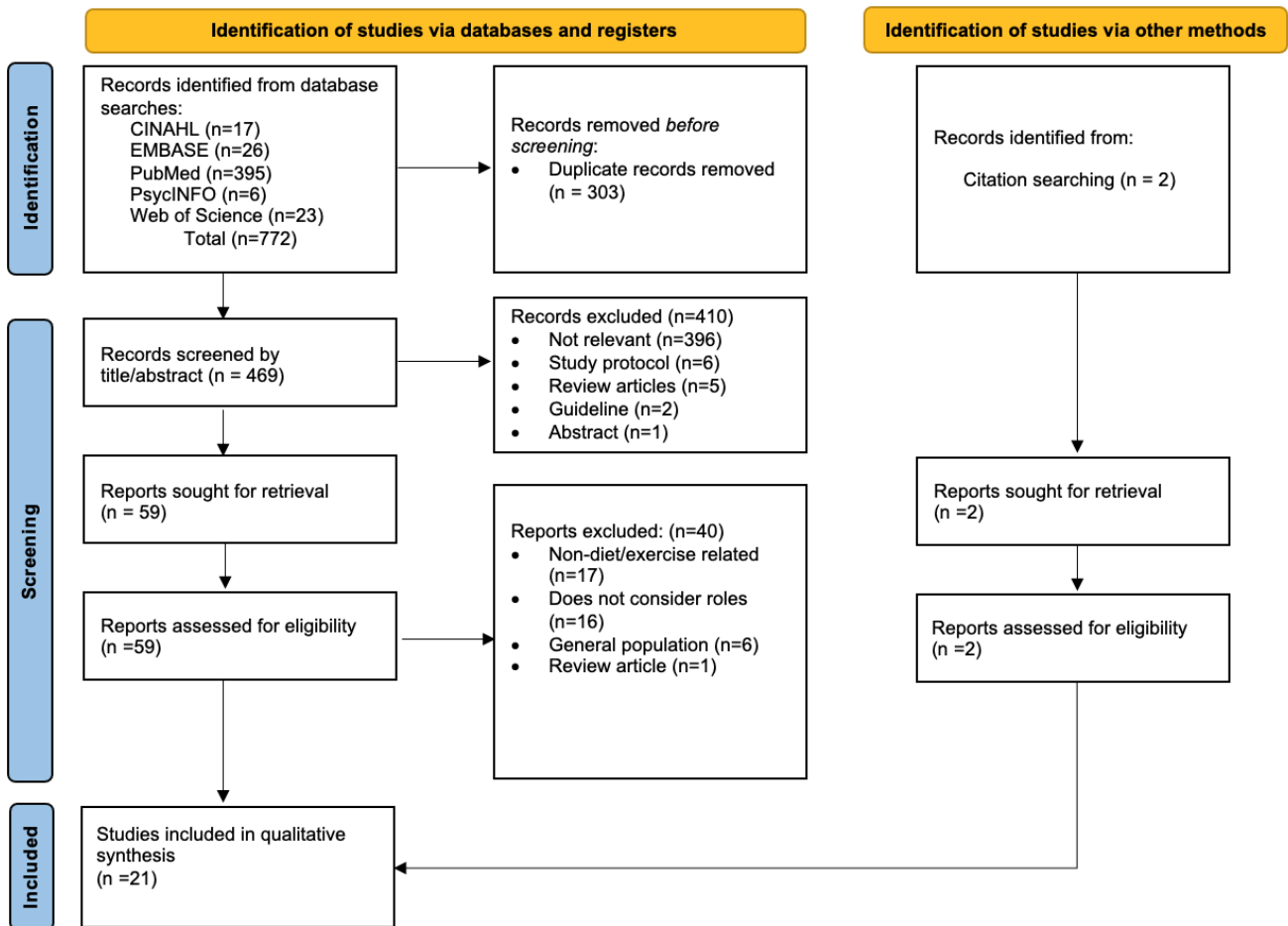
Chan, 2018	✓	✓	✓	✗	✓	QUAN=4	80%
Hausman, 2018b	✓	✓	✓	✗	✓	QUAN=4	80%
Keogh, 2017	✓	✓	✓	✗	✓	QUAN=4	80%
Kiss, 2020	✓	✓	✓	✗	✓	QUAN=4	80%
Ligibel, 2019	✓	✓	✓	✗	✓	QUAN=4	80%
Puhringer, 2015	✓	✓	✓	✗	✓	QUAN=4	80%
Spellmann, 2014	✓	✓	✓	✗	✓	QUAN=4	80%
Wallace, 2015	✓	✓	✓	✗	✓	QUAN=4	80%
Williams, 2013	✓	✓	✓	✗	✓	QUAN=4	80%
<b>Mixed methods</b>							
Anderson, 2013	✓	✓	✓	✗	✓	MM=4	80%
Kassianos, 2017	✓	✓	✓	✗	✓	MM=4	80%

### 2.3.6 Data synthesis and analysis

Extracted data were analysed by the doctoral candidate (RJ) according to the stages described by Whitemore and Knaf<sup>188</sup>, using a mixed methods synthesis.<sup>193</sup> This process was checked by co-supervisors (RJC, NH and NB). Firstly, a segregated synthesis analysis was performed on each study design. Data reduction was performed on categories that were relevant to the review questions. The next step was data display, converting data from individual sources into a matrix display to assemble data across all study designs. Data comparisons between the matrix displays resulted in sub-themes and main emerging themes. The emerging themes were categorised into a table format. Quantitative data was then translated to qualitative data for a mixed-methods synthesis. This involved conversion into narrative interpretations of quantitative results from all studies (including quantitative portions of mixed methods studies). Due to the heterogeneity of included studies, extracted data from quantitative and qualitative studies were combined using the convergent integrated approach according to JBI methodology for mixed methods systematic review.<sup>193</sup> This involved assembling the converted quantitative data with the qualitative data. Assembled data were categorised and synthesised based on similarity in meaning to produce a set of integrated findings (Appendix 3).

## 2.4 Results

The search strategy yielded 772 articles in which 303 duplicates were identified and removed. After screening titles and abstracts, 61 articles were selected for full-text review. Forty articles were excluded following full-text review as they did not meet the inclusion criteria. Ultimately, 21 articles (10 quantitative, 9 qualitative and 2 mixed method) met the inclusion criteria and were subjected to quality appraisal (Figure 3).

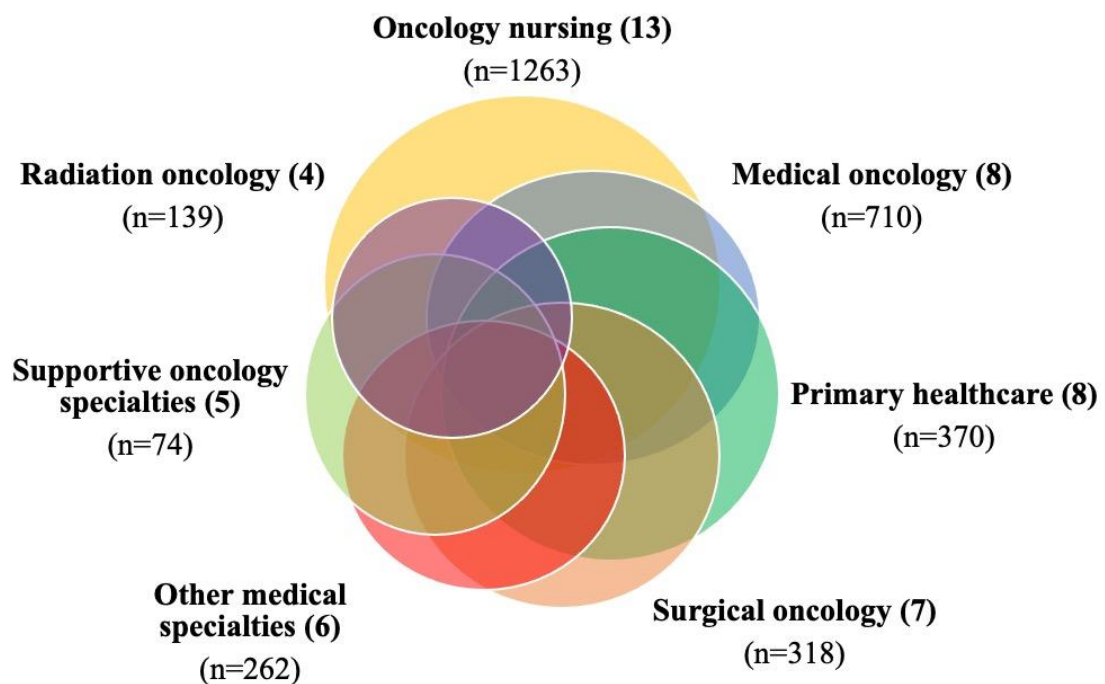


**Figure 3** Flow diagram of literature search and selection process (PRISMA)

### 2.4.1 Study characteristics

Of the 21 articles, 16 included medical and nursing health professionals, three included cancer survivors, and two included both, totalling 3,401 medical and nursing health professionals and 264 consumers with diverse cancer types (Figure 4). The nine qualitative studies explored the perspectives of 167 medical and nursing health professionals and 54 cancer survivors regarding medical and nursing health professionals providing dietary or exercise advice to cancer survivors as well as barriers and facilitators through semi-structured or in-depth interviews.

These were conducted in the USA (n=3)<sup>8, 194, 195</sup>, UK (n=2)<sup>196, 197</sup>, Australia (n=1)<sup>198</sup>, Canada (n=1)<sup>181</sup>, Germany (n=1)<sup>199</sup>, and the Netherlands (n=1).<sup>200</sup> Of the 10 quantitative studies, 2812 health professionals and 222 cancer survivors were surveyed across Australia (n=5)<sup>99, 201-204</sup>, Australia and New Zealand (n=2)<sup>205, 206</sup>, Germany (n=1)<sup>207</sup>, UK (n=1)<sup>184</sup>, and USA (n=1)<sup>208</sup> about their perspectives regarding medical and nursing health professionals providing dietary or exercise advice, as well as barriers and facilitators to cancer survivors. Two mixed-methods studies explored perspectives of medical and nursing health professionals on providing weight management and dietary advice to cancer survivors. These studies were conducted in the UK (n=2)<sup>209, 210</sup> and explored the perspectives of 418 medical and nursing health professionals. Overall, the total sample included a mixture of professions, including cancer nurses, GPs, and cancer specialists (i.e., oncologists, medical oncologists, radiation oncologists, surgeons, and urologists), as well as consumers (i.e., cancer survivors, families, and caregivers). The following interventions were reported: general dietary and exercise advice, promotion of changes to diet and physical activity, and the provision of weight management advice.



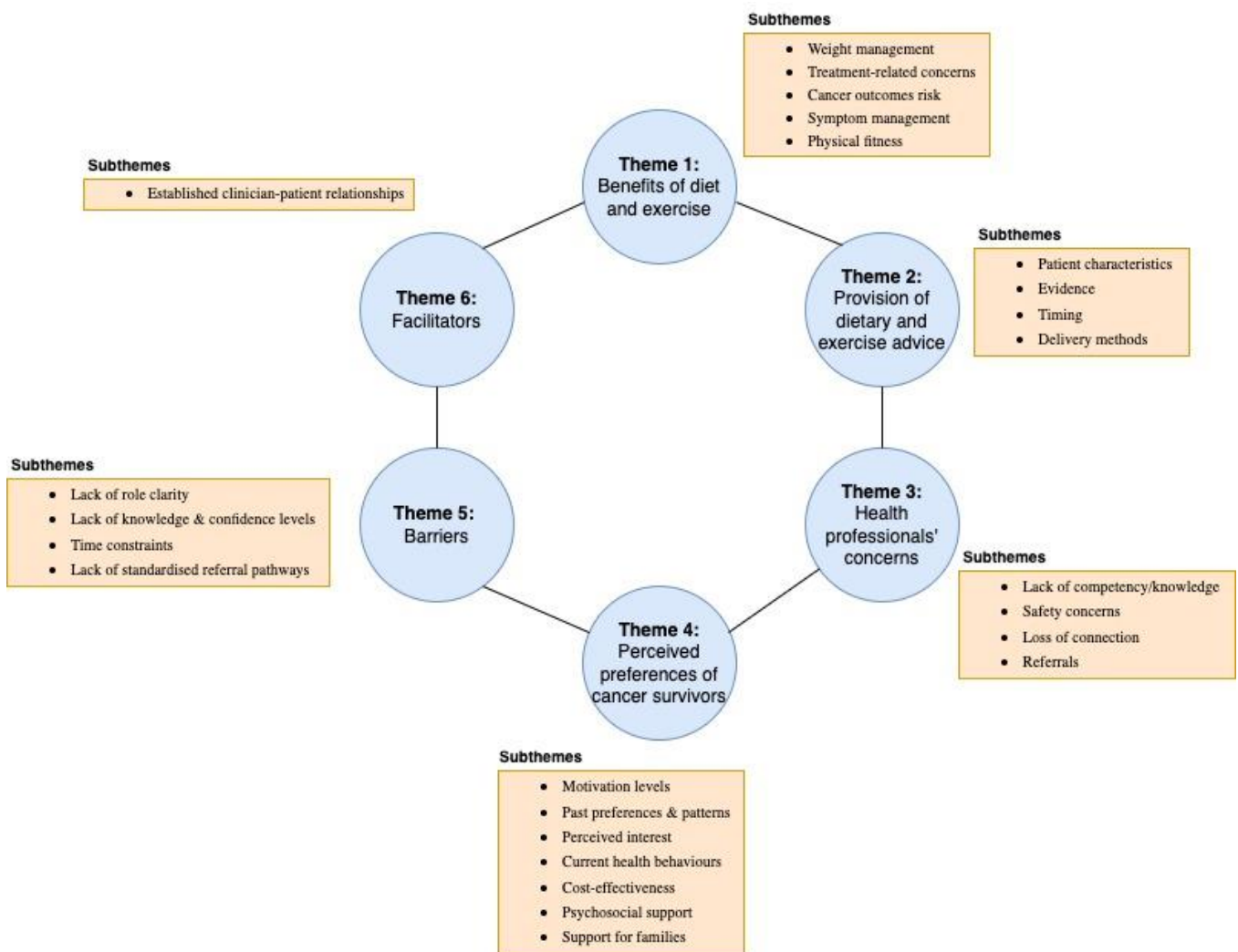
**Figure 4** Distinct specialities across included studies (n=number of participants)

### 2.4.2 Methodological quality of the studies

All nine qualitative studies met 100% of the quality criteria, with no obvious methodological limitations as appraised using the MMAT. In addition, among the 10 quantitative and 2 mixed-methods studies, all met 80% of the quality criteria. Methodological limitations such as unclear response rates, in particular nonresponse bias, was identified in 12 studies.

### 2.4.3 Main themes

Six themes were identified in the analysis and subsequently synthesised: (1) benefits of diet and exercise; (2) provision of dietary or exercise advice; (3) health professionals' concerns for providing dietary or exercise advice; (4) perceived preferences of cancer survivors; (5) barriers and (6) facilitators to providing dietary or exercise advice and referrals by medical and nursing health professionals (Figure 5).



**Figure 5** Themes and subthemes of included studies

### **2.4.3.1 Roles and responsibilities of medical and nursing health professionals**

#### **1. Benefits of diet and exercise**

Medical and nursing health professionals acknowledged that diet and exercise play an important role in maintaining health while improving clinical outcomes for cancer survivors, and that dietary and exercise support form part of a multidisciplinary approach to cancer care.<sup>74, 96, 210</sup> It is of critical importance that medical and nursing health professionals convey and promote this message to cancer survivors.<sup>171, 210</sup>

#### **2. Provision of dietary and exercise advice**

Most medical and nursing health professionals perceived their role to include the provision of regular advice to cancer survivors to achieve or maintain a healthy weight, increase physical activity, and eat a healthy and balanced diet across multiple treatment stages.<sup>8, 208</sup> Some medical and nursing health professionals perceived their role to include empowering cancer survivors to adopt a healthier lifestyle by recommending small, achievable changes to their habitual diet or physical activity behaviour.<sup>8, 196</sup> The provision of dietary and exercise advice was dependent on multiple factors, including patient preferences, strength of the evidence, optimal timing, and delivery methods. Medical and nursing health professionals highlighted that tailoring advice on diet, physical activity, or exercise should consider the cancer survivor's cognitive ability, relationship with their health professionals, physical condition, and overall well-being.<sup>196, 198, 210</sup> Cancer survivors' current health behaviours; perceived interest in diet, physical activity, or exercise; motivation levels; and past preferences and patterns were also considered.<sup>197</sup> This suggests that medical and nursing health professionals who provide dietary and exercise advice consider cancer survivors' individual needs and preferences. However, medical and nursing health professionals had varying perspectives on when cancer survivors were most motivated to make changes. Several suggested the optimal timing to provide dietary and exercise advice should be provided at diagnosis or during treatment and re-enforced at each follow-up appointment to enact meaningful health behaviour changes.<sup>195</sup> As a result, cancer survivors could establish, maintain, or progress habitual dietary, physical activity and exercise behaviours that would help prevent, reduce, or reverse side-effects relating to treatment, and prevent potential weight gain.<sup>181, 206</sup> Other medical and nursing health professionals thought dietary and exercise advice should wait until after treatment because treatment itself is a big adjustment for cancer survivors (e.g., physical, and psychosocial effects of treatment).<sup>195</sup> Overall, medical and nursing health professionals believed they should provide dietary or

exercise advice to cancer survivors at key time points when they are motivated and likely to make changes.

Medical and nursing health professionals also reported that a combination of verbal and written dietary and exercise information (i.e., advice on a healthy balanced diet and physical activity, and referrals to structured exercise) was preferred as cancer survivors are overwhelmed with information during their cancer journey, which may have pedagogical implications.<sup>196</sup> It is unknown if medical and nursing health professionals provide advice on the recommended food groups for a healthy diet, and principles that underpin the prescription of physical activity or exercise (i.e., frequency, intensity, time, and type).

### **3. Health professionals' concerns**

Some medical and nursing health professionals did not consider themselves as competent, responsible, or appropriate to provide clinical outcome-specific dietary and exercise advice (e.g., weight management) to cancer survivors, given their limited knowledge of the topic, their clinical role, training, or other higher priorities during short consultations.<sup>8, 196, 199, 203</sup> Medical health professionals have reported uncertainty with what to recommend, and fears of potential safety risks to cancer survivors, such as physical overexertion and psychological stress during physical activity or exercise.<sup>197, 207</sup> Other concerns reported included potential loss of connection with the cancer survivor, and fear of potentially setting expectations that may not be achievable as cancer survivors' goals can change during cancer treatment.<sup>197</sup> In contrast to medical health professionals, cancer nurses had fewer concerns and were more likely to discuss diet, physical activity, and exercise with cancer survivors.<sup>197, 202, 204, 205</sup> Overall, these studies highlighted the preference of most medical and nursing health professionals to refer cancer survivors to outside resources and field specialists, including dietitians and exercise professionals for advice, assessment and interventions regarding healthy eating, physical activity, exercise counselling, or supervised exercise programs.<sup>8, 199, 201, 205</sup> Even though there is variability in medical and nursing health professionals' views on their ability to provide dietary and exercise advice to cancer survivors, the consensus was to refer to dietitians and exercise professionals.

### **4. Perceived preferences of cancer survivors**

Despite growing evidence that dietary and exercise health behaviours are linked to improved outcomes in cancer survivors<sup>102</sup>, few cancer survivors reported receiving dietary and exercise



advice from their health professionals<sup>171</sup>, whereby some cancer survivors reported this lack of encouragement as a major reason for not committing to engaging in a healthy diet or more physical activity.<sup>194</sup> Cancer survivors emphasised the valuable role of GPs in their follow-up care, including the provision of significant support for managing physical and psychological effects for cancer and its treatment and health promotion.<sup>184, 200, 210</sup> In addition, cancer survivors' welcomed guidance on diet and exercise, as well as referral to dietitians and exercise professionals, particularly in the immediate post-treatment phase, because of the uncertainties of cancer and treatment-related side effects.<sup>200</sup> GP care was not limited to the cancer survivors alone; relatives also consulted the GP for issues about coping with cancer in the family. This was highly valued and provided security for cancer survivors knowing family members were also cared for.<sup>200</sup> Several cancer survivors highlighted a preference to receive exercise guidance from their cancer specialist who provided general encouragement for cancer survivors to "stay active", while others indicated they were unsure whether to seek advice from medical or nursing health professionals on this topic.<sup>194</sup> In contrast, some cancer survivors had no preferences to which specific health professional provided dietary or exercise advice, so long as it is received from a professional with whom they have a trusting relationship.<sup>200</sup> No studies in this review included nursing health professionals, thus the perceived preferences of cancer survivors for nurses as valuable agents of diet and exercise advice, and suitable health professionals for referral to allied health need to be explored in future research.

#### **2.4.3.2 Barriers and Facilitators**

##### **Barriers to providing dietary and exercise advice, and referrals to allied health.**

###### ***1. Lack of role clarity***

Medical and nursing health professionals had different views regarding their perceived roles, with a lack of clarity observed. Even though most cancer nurses and GPs perceived their roles to involve the discussion of diet, physical activity, and exercise<sup>197, 198, 201, 202, 204-206, 210</sup>, some did not perceive it to be part of their role given their limited knowledge on the topic and other priorities during patient interactions.<sup>196, 211, 212</sup> Cancer specialists felt they were less likely to provide dietary and exercise advice than primary care providers, as they believed it was not their role and that cancer survivors engaged with primary care for surveillance.<sup>195</sup> However, cancer specialists did perceive their role to include providing referrals to other health professionals or community programs.<sup>181</sup> There was a preference amongst medical and nursing health professionals to refer cancer survivors to allied health professionals<sup>199</sup>, with GPs

preferring a dietitian or exercise professional to be the primary care provider responsible for providing dietary and exercise advice.<sup>201</sup> Therefore, cancer nurses and GPs may perceive their roles to be different from cancer specialists with regards to providing dietary and exercise advice, but medical and nursing health professionals perceive referral to be part of their role.

## ***2. Lack of knowledge and confidence***

Medical and nursing health professionals recognise that positive changes in diet and exercise in cancer survivors is likely beneficial, however few receive training within their curriculum on the importance of diet, physical activity, or exercise.<sup>8, 201, 203, 208, 209</sup> As a result, medical and nursing health professionals report a lack of confidence in providing appropriate advice and are less likely to provide information on healthy diet and physical activity to cancer survivors.<sup>199, 210</sup> Furthermore, several studies involving nearly 1000 medical and nursing health professionals reported that only some were aware of dietary and exercise guidelines for management of cancer survivors'.<sup>197, 208</sup> Those aware of these guidelines reported feeling as if they were still not the ideal health professional to provide this advice to cancer survivors.<sup>196, 201</sup>

## ***3. Time constraints***

Medical and nursing health professionals all reported that a common and considerable barrier to promoting healthy eating, physical activity and exercise for cancer survivors is lack of time during consultations to discuss dietary and exercise advice.<sup>181, 197, 198</sup>

## ***4. Lack of standardised referral pathways***

Medical and nursing health professionals report assessing dietary patterns and physical activity levels during and after cancer treatment, and providing general dietary, physical activity, and weight management advice. However, this often did not result in referrals to allied health professionals or diet and exercise professionals to enact and support lifestyle change.<sup>208</sup> This could be attributed to limited guidance and little information available to medical and nursing health professionals, as there is currently no standardised referral framework and no structured referral process for them to adopt. Therefore, there is a need to provide information on how, and when, to refer cancer survivors, inclusive of the necessary clinical information required to standardise and streamline the process, and connectivity to these services.

## **Facilitators to providing dietary and exercise advice and relevant referrals.**

### ***5. Established clinician-patient relationships***

Cancer survivors are under the routine care of cancer specialists, and cancer nurses throughout the cancer continuum, which enables an established and trusted relationship.<sup>197</sup> Cancer nurses have the most frequent time and opportunity to interact with cancer survivors providing greater opportunities to intervene, educate, and refer to supportive care services.<sup>205</sup> GPs can also contribute to increasing the referral patterns to specialists due to their positive attitudes toward, and knowledge of the benefits of diet and exercise for cancer survivors.<sup>198, 201</sup> Therefore, medical and nursing health professionals are well-positioned to inform cancer survivors about diet and exercise as a trusted source.

#### **2.4.3.2 Findings from emerging literature (primary studies)**

##### *Descriptive characteristics of included primary studies*

An updated search on the perspectives of medical and nursing health professionals on their roles and responsibilities in providing dietary and exercise advice and referrals was conducted. Of 188 unique records identified, a total of two relevant primary studies<sup>169, 213</sup> published since June 2021 was included. Of the two studies, both included medical and nursing health professionals totalling 193 medical and 223 nursing health professionals. Both studies investigated the perspectives of medical and nursing health professionals about their knowledge, beliefs, practices, and barriers and facilitators regarding physical activity or exercise advice through online questionnaires, however one study specifically focused on exercise guidance and referral for cancer survivors from an international perspective.<sup>169</sup> One study was conducted in Morocco<sup>213</sup>, and the other study was conducted internationally.<sup>169</sup>

##### *Key findings*

One study<sup>169</sup> found that the majority of medical and nursing health professionals agreed that exercise counselling should be part of their routine care, and they were likely to advise them to keep active before, during and after cancer treatment. Another study<sup>213</sup> showed that medical and nursing health professionals recognise the benefits of physical activity, however medical health professionals were more favourable to physical activity compared to nursing health professionals with the improvement of survival by increasing physical activity. Medical and nursing health professionals also indicated that they were less likely to provide specific exercise guidelines or advice, or refer cancer survivors to an exercise program or exercise professional. However, they believed that exercise professionals should be primarily responsible for discussing exercise with cancer survivors, followed by nursing and medical health professionals.<sup>169</sup>

### *Barriers and facilitators*

The most common barriers to providing physical activity or exercise advice included safety concerns, time constraints, and not knowing how to screen cancer survivors for their suitability and safety to exercise, limited availability of or access to suitable programs, lack of funding or resourcing, cost to cancer survivors, lack of knowledge, lack of information, and the perception of patients and institutional or structural barriers.<sup>169, 213</sup> Facilitators included the availability of resources for cancer survivors, practitioner education sessions and having an exercise professional as part of the clinical team.<sup>169</sup>

## **2.5 Discussion**

Most medical and nursing health professionals considered diet and exercise interventions beneficial to cancer survivors according to the results of our integrative review, consistent with earlier evidence.<sup>214</sup> Even though there was variability of views on their roles and responsibilities in providing advice on diet, physical activity, or exercise to influence behaviour change in cancer survivors<sup>195</sup>, there was overall confidence that their role should be to provide referrals to dietitians and exercise professionals.<sup>199, 201, 205</sup> This suggests that there is a lack of clarity between medical and nursing health professionals regarding their roles and responsibilities in providing dietary and exercise advice. This could be attributed to several factors, including poorly defined roles. Clarifying professional roles can ensure the appropriate implementation of medical and nursing health professionals' role regarding dietary and exercise advice to cancer survivors and therefore ensuring better care of the cancer survivor.<sup>215, 216</sup> This could be achieved by using a consensus process to facilitate role clarity and establish consensus between professional groups.<sup>217</sup> Better guidance is required for medical and nursing health professionals, in terms of what advice they should provide, when to provide the advice, as well as how and when to refer cancer survivors to dietitians and exercise professionals.

Medical and nursing health professionals identified that providing dietary and exercise advice to cancer survivors remains an ongoing issue for them due to various health-professional and patient-centred barriers. As a result, additional training is required to assist medical and nursing health professionals to provide physical activity, adequate weight management and dietary and exercise advice as part of routine practice, and resources.<sup>201, 209</sup> This may include continuing professional development for medical and nursing health professionals where this type of training could be offered.<sup>101</sup> It is important that these programs and opportunities are evaluated,

with outcomes addressing the reaction, learning, behaviour and results levels.<sup>218</sup> Embedding this additional training within university programs has the potential to improve their dietary and exercise management skills and confidence levels that can positively impact patient health outcomes.<sup>219-221</sup> Ideally, resources should include clear information on specific dietitians and exercise professionals who can provide proper assessment, programming, and support; and information on referral pathways to reach these specialists or community services.<sup>207</sup> Overall, it is important to equip medical and nursing health professionals with the tools and education necessary to deliver consistently, and high-quality holistic care.

Many cancer survivors have reported high levels of trust in their usual GP, and hence value the involvement of their GPs for their dietary and exercise advice and referrals.<sup>200</sup> Therefore, cancer survivors may be more likely to follow their GP's advice, resulting in more beneficial health behaviours. Not only are GPs integral in cancer detection as the first point of contact for cancer survivors, but they are also able to provide care and key referrals in the post-treatment follow-up phase. This can include ongoing support and follow-up to assist maintenance of lifestyle changes.<sup>73, 222</sup> Furthermore, many GPs have established relationships with cancer survivors, so they are well placed to support them (i.e., providing general lifestyle-related advice).<sup>198</sup> Thus, GPs can play a key role in counselling cancer survivors about diet and physical activity or exercise if given proper resources, training, and support throughout the cancer care continuum.

## **2.6 Limitations and strengths**

This review has several limitations. While a strength of this review pertains to the global nature of studies included, these were all from Western countries that were high-income, thus the findings of this review may not reflect those of other cultures, or those that are low-to-middle income countries with different health system priorities. Cancer survivors in various settings have been included in this review, however, these studies did not define the diagnoses and care context. Accordingly, not all findings are generalisable to all settings and health systems. Nevertheless, the major strength of this review is that it addresses the perspectives of medical health professionals, nursing health professionals, and cancer consumers (cancer survivors, families, and caregivers). Another strength is the integrated review method, which facilitates inclusion and integration of different sources and types of information in a single review.

## **2.7 Summary**

This review demonstrated that there is a robust evidence base for the commonly faced barriers and facilitators by medical and nursing health professionals in the provision of dietary and exercise advice to cancer survivors and referrals to allied health professionals. One of the frequently reported barriers is a lack of role clarity between medical and nursing health professionals regarding their roles and responsibilities in providing dietary and exercise advice to cancer survivors. The review also raises a number of questions which have come about as a result of the assumptions made in the reviewed literature. Assumptions include a general consensus between medical and nursing health professionals regarding their roles to provide referrals to dietitians and exercise professionals, and variability of views on the provision of dietary and exercise advice. For example, medical and nursing health professionals have self-reported that their role includes referring cancer survivors to dietitians and exercise professionals but do not have the knowledge and confidence to provide dietary and exercise advice. However, the literature demonstrates low referral rates to dietitians and exercise professionals, and cancer survivors have reported that they receive dietary and exercise advice from their medical and nursing health professionals, which contradicts the findings from this review. In addition, the findings from this review demonstrate that the perceived preferences of cancer survivors do not include nursing health professionals, thus the perceived preferences of cancer survivors for nurses as valuable agents of diet and exercise advice, and suitable health professionals for referral to allied health need to be explored in future research. Since a lack of a role clarity amongst medical and nursing health professionals was identified as a common barrier with regards to the provision of dietary and exercise advice to cancer survivors, and referrals, the following chapter (chapter three) will examine the development of essential element statements. Essential element statements have the capacity to improve role clarity amongst medical and nursing health professionals and provide better guidance with regards to what dietary and exercise advice to provide as well as how and when to refer cancer survivors to dietitians and exercise professionals for individualised dietary and exercise support.

## CHAPTER THREE – METHODS: DELPHI STUDY (STUDY 2)

### 3.1 Chapter overview

As highlighted in Chapters 1 and 2, there is a lack of clarity between medical and nursing health professionals regarding their roles and responsibilities in providing dietary and exercise advice to cancer survivors. Thus, medical and nursing health professionals require better guidance and structure regarding the roles they play in providing dietary and exercise advice, and how and when to refer cancer survivors to diet and exercise professionals. This chapter provides details of the research plan for a Delphi study, that aimed to develop and achieve consensus on essential element statements that medical and nursing health professionals can implement to facilitate optimal dietary and exercise care to cancer survivors and streamlined referrals to dietitians and exercise professionals. To achieve the proposed aims, this chapter describes the target population, human research ethics approval, data collection, and data analysis plan for this Delphi study. Based on participant feedback to consider the entire cancer trajectory in this Delphi study, the conceptual definition (Chapter 1) will be adopted in subsequent chapters. The following chapter (Chapter 4. Results: Delphi Study) outlines the results, discussion and implications of this study.

This Delphi study provides guidance for medical and nursing health professionals with regards to optimal dietary and exercise care for cancer survivors and explores the following question:

- From the perspectives of panel members, what are the essential element statements relevant to referral practices for dietary and exercise care for cancer survivors, with consideration of (i) referrers; (ii) service providers; (iii) consumers; and (iv) resources and practice environments?

This Delphi study was accepted for publication in *Supportive Care in Cancer* on 16/12/2022 (DOI: [10.1007/s00520-022-07509-1](https://doi.org/10.1007/s00520-022-07509-1)) and has been included in this chapter.

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(RJ was the primary author of this paper and led the development of the research question, data collection, synthesis and drafting of the manuscript. RJC, NHH and NB assisted with supporting RJ as PhD supervisors in conducting the Delphi study and offered comments and editing of the cited paper. All authors commented on previous versions of the manuscript, read and approved the final manuscript).

### **3.2 Background**

Dietary and exercise interventions play an important role toward managing the physical and psychosocial effects of cancer.<sup>223</sup> For these interventions to be successful, a multidisciplinary approach involving medical, nursing, general practice, and allied health professionals (e.g., dietitians, exercise physiology, physiotherapy) is essential.<sup>103</sup> However, a systematic disconnect exists between medical and nursing health professionals providing cancer care, and allied health professionals providing specialist dietary and exercise interventions to cancer survivors, where cancer survivors do not reliably receive information, support, or referrals to dietary and exercise interventions.<sup>224</sup> Medical and nursing health professionals are a vital centrepiece to supporting positive health behaviour change of cancer survivors as trusted agents of credible health information, with regular engagement at key moments of cancer care transition.<sup>102, 205, 225</sup> Acknowledging diet and exercise as cornerstones of quality supportive care<sup>109-111</sup>, medical and nursing health professionals can educate cancer survivors on the importance of diet and exercise, reinforce behaviour change, facilitate referrals to GPs and allied health professionals<sup>226</sup>, and direct cancer survivors to evidence-based diet and exercise resources<sup>106-108</sup>, such as those provided by international and national diet and exercise organisations and cancer societies.<sup>14, 115, 141, 153, 227, 228</sup>

While medical and nursing health professionals understand the importance of dietary and exercise education and support for cancer survivors, and acknowledge their role as key conduits of referral to general practice and specialist services<sup>10, 214</sup>, they also report multiple barriers including inadequate resourcing, time, knowledge, role clarity, and a lack of standardised referral pathways.<sup>10</sup> To overcome these barriers, guidance is required for medical and nursing health professionals, in terms of what advice they should provide, when to provide the advice, as well as how and when to refer cancer survivors to dietitians and exercise professionals.<sup>10</sup>

Indeed, cancer survivors should be referred to dietitians and exercise professionals, ideally with experience in cancer care, for individually tailored diet and exercise programs.<sup>15, 112, 113</sup>

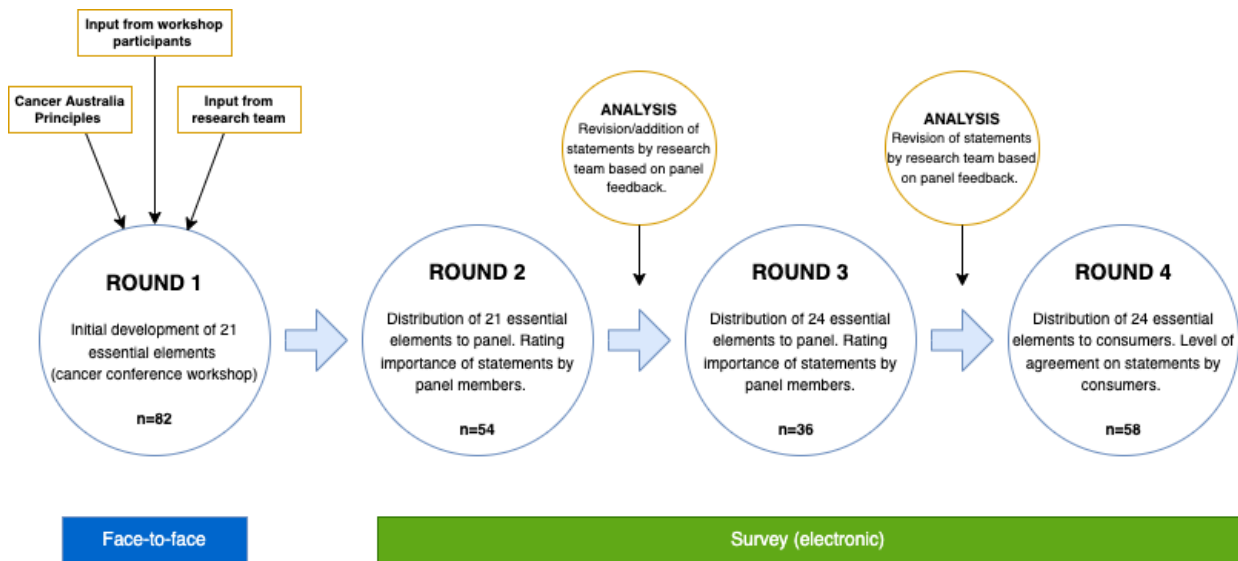


Collaboration with medical and nursing health professionals, given they also have knowledge, resources, and practical skills can provide effective therapy and support behaviour change.<sup>114</sup> <sup>115</sup> Unfortunately, there is limited consensus among medical and nursing health professionals on the best process to engage dietitians and exercise professionals and effectively facilitate personalised dietary and exercise consultation, education, and interventions for cancer survivors.<sup>10</sup> For example, moderate-intensity aerobic training at least three times per week, with resistance training at least two times per week is recommended for most cancer survivors.<sup>153</sup> However, the provision of dietary and exercise support can vary vastly between primary care providers based on when cancer survivors will be most receptive to receiving guidance.<sup>229</sup> Providing structured guidance, and a systematic standardised approach will help medical and nursing health professionals to overcome professional-level and service-level barriers to refer cancer survivors to dietitians and exercise professionals and ultimately, optimise dietary and exercise care for cancer survivors. Accordingly, the aims of this study were to (1) develop, and (2) achieve expert consensus on essential elements of optimal dietary and exercise referral practices that medical and nursing health professionals in Australia can implement to streamline referrals to dietitians and exercise professionals for cancer survivors.

### **3.3 Methodology and research design**

#### **3.3.1 Study design**

A Delphi consensus process was used comprising four rounds (one face-to-face, and three survey rounds [Figure 6]). Initial statements were drafted in Round 1 based on Cancer Australia's Principles for Cancer Survivorship<sup>77</sup> and input from cancer stakeholders (e.g., consumers [i.e., cancer survivors, families and informal caregivers], cancer specialists, allied health professionals) at a cancer pre-conference workshop. Rounds 2 and 3 were used to iteratively develop and establish consensus regarding essential elements among consumers, health professionals, and researchers.<sup>230</sup> As the number of consumer participants was minimal in Round 1 and 2; an extra round (Round 4) was performed to ensure adequate consumer representation and obtain acceptability of the final statements. Delphi flexibility is important to ensure that the panel is representative of all stakeholders affected by the study's outcomes.<sup>231</sup> Ethical approval was provided by the Human Research Ethics Committee of Queensland University of Technology (HREC ID: 2000000940). Informed consent for participation was obtained from all study participants (Appendix 5 and 6). Data were collected and managed in accordance with the World Medical Association's Declaration of Helsinki.



**Figure 6** Delphi Consensus Process

### 3.3.2 Round 1: Workshop - Development of Initial Statements

Participants attending a cancer conference were invited to attend a face-to-face pre-conference workshop, with facilitated activities structured following Cancer Australia’s Principles for Cancer Survivorship.<sup>77</sup> Consistent with these principles, cancer survivors were defined as any individual living with cancer from diagnosis to end of life. Initial statements were developed by workshop participants (i.e., stakeholders from medicine, nursing, and allied health professions; consumers; and Cancer Council Queensland). Workshop facilitators comprised of clinician-researchers from cancer nursing and allied health professions, as well as consumer advocates. Cancer Australia’s Principles of Cancer Survivorship were chosen to guide essential elements of optimal dietary and exercise referral practices as they provide a national framework that guides policy, planning, and health system responses to cancer survivorship, focusing on the care, health and wellbeing of people affected by cancer (i.e., cancer survivors, families and informal caregivers).<sup>77</sup> Essential elements were then embedded within these principles as aspirational, governing statements to support medical and nursing health professionals to implement and evaluate best practices and achieve high-quality dietary and exercise support for cancer survivors.<sup>77</sup>

Co-designing essential elements required consideration of (i) referrers; (ii) service providers; (iii) consumers; and (iv) resources and practice environments. Referrers primarily included medical and nursing professionals (e.g., GPs and cancer specialists) caring for cancer survivors.

Service providers included hospitals, health services, and community-based organisations with cancer services (e.g., public and private health sectors, or virtual health services). Consumers referred to people affected by cancer (i.e., cancer survivors, families and informal caregivers). Prior to facilitating draft statements, a presentation regarding the value and importance of diet and exercise for cancer survivors was provided, followed by focus groups to develop essential elements. Stakeholders were divided into six focus groups, each with two facilitators having at-least 5-years' experience in cancer care each. Facilitators asked participants to brainstorm relevant essential elements based on Cancer Australia's Principles of Cancer Survivorship including 1. consumer involvement in person-centred care; 2. support for living well; 3. evidence-based care pathways; 4. coordinated and integrated care, and 5. data-driven improvements and investment in research.

Focus groups ran for two rounds of 60 minutes each, with two allocated principles per round, per table, to ensure essential elements were discussed for each principle across two groups, resulting in each group discussing four of the five principles in total. Facilitators were tasked with (1) reviewing definitions and outcomes underpinning each principle to suggest changes specific to diet and exercise support for cancer survivors; and (2) establishing draft essential elements of optimal referral practices to dietitians and exercise professionals that will guide implementation. Prior to the conclusion of the workshop, each facilitator presented their input to all stakeholders to enable broadened discussions. All focus group input was synthesised after the workshop by two researchers with oversight from RJC and NHH. Each proposed essential element was categorised under one of the principles with constructive discussions (e.g., based on relevancy to referral practices) by the research team to produce initial representative statements outlining essential elements of optimal dietary and exercise referral practices.

### **3.3.3 Round 2 to Round 4: Surveys – Reaching Consensus**

#### ***3.3.3.1 Panel selection***

Workshop participants (Round 1) and members of Queensland's Collaborative of Cancer Survivorship network were invited to join the consensus stakeholder panel via email. The panel was evaluated by the research team to ensure appropriate representation from a range of cancer specialists and primary care disciplines including allied health professionals (dietitians, exercise physiologists, physiotherapists, and occupational therapists), consumers, medical practitioners, nurses, and health services researchers; and leadership from Cancer Council Queensland, with no standard criteria available to define panel members.<sup>232</sup> Sample size was

based on the number of cancer care professionals attending a local cancer conference, who signed up separately for the pre-conference workshop. To ensure a suitable sample size and increase response rates, a snowball sampling approach was used, whereby panel members were encouraged to send survey invitations to other relevant participants in their networks.<sup>233</sup>

### **3.3.3.2 Stakeholder surveys (Round 2 and Round 3)**

Drafted essential element statements determined in Round 1 were distributed to the consensus stakeholder panel using an online survey (KeySurvey; v8.1; WorldAPP, Hampshire, UK) in accordance with Delphi consensus process methods to establish expert consensus on the importance of determined essential element statements for optimal dietary and exercise referral practices. A free-text response was available to participants within each section of the survey to allow for suggested changes to each statement or new statements if required. Data on participant demographics were collected, including their current profession and role, and time (in years) working in cancer care. Two rounds of online survey were provided to achieve consensus, with participants asked to rate the importance of drafted statements using a five-point Likert scale (1=not important, 2=slightly important, 3=important, 4=fairly important, 5=very important), demonstrated to produce stable findings in Delphi studies [46]. Participants were given four weeks to complete each round and were invited to every round independent of the previous round. Those who did not respond to Round 2 were permitted to participate in Round 3, to allow for better representation of expert opinion and to reduce the chance of false consensus.<sup>234</sup> Consensus for each round was defined *a priori* as an agreement of  $\geq 75\%$  of panel members<sup>232</sup> scoring 3 or more, as per the five-point Likert scale. Responses from Round 2 were used to revise statements (if required) or create new statements for the next round. Refined statements and new statements were re-distributed to all panel members to confirm consensus with outcomes of the previous round.

### **3.3.3.3 Consumer survey (Round 4)**

Beyond the consumers and consumer organisation (Cancer Council Queensland) involvement in developing the initial and revised statements from prior rounds; a cohort of diverse cancer survivors and their caregivers were invited to participate in a final survey round. Consumer input is key to enhancing the appropriateness of the essential elements as they are likely to be consistent with the general needs and preferences of cancer survivors.<sup>235, 236</sup> This involved a wide range of consumer networks and consumer types (i.e., adolescent and young adult cancer survivors; parents of childhood cancer survivors; advanced and metastatic cancer survivors)

identified from existing networks of the research team and organisations such as Cancer Voices. Participants were asked if they agreed with each statement (i.e., Yes/No), and to clarify their answers if needed, inclusive of alternate suggestions for any revisions. Delphi flexibility is important to ensure that the panel is representative of all stakeholders affected by the study's outcomes.<sup>231</sup>

### **3.3.4 Data analysis**

Focus group data from Round 1 were categorised under the principles of cancer survivorship using a deductive thematic approach. All findings from Round 2 and 3 were reported and analysed using descriptive statistics (frequencies and central tendency). Mean and standard deviation (SD) and number (n; %) were calculated for each statement and count data were expressed as n (%). For Round 4, the quantitative analysis included percentages for each level of agreement (i.e., Yes/No questions) for each statement. Consensus levels achieved during Round 4 were not used to exclude statements, but to determine consumer acceptability (i.e., % of consumers who agreed with the statements) of the essential elements. Consensus was defined as  $\geq 75\%$  for all rounds (level of importance, and consumer acceptability).

### **3.4 Summary**

In this doctoral research, mixed methods have been employed for the development of essential element statements with consideration of referrers, service providers, consumers, and resources and practice environments (chapters three and four), as well as exploration of current practices and cohort demographics through use of focus groups, an online Delphi consensus process and an online demographics survey. In chapters five and six of this doctoral research, mixed methods utilising focus groups and an online demographics survey will also be discussed. A Delphi consensus process enabled key stakeholders to develop and achieve consensus on essential element statements (chapters three and four). The individual methods for each study are discussed in the relevant chapters, with each being a stand-alone study by lending themselves to comparison and which cumulatively add wider meaning and context to the overarching research topic and title of this doctoral research. Essential element statements generated from this doctoral research is intended to contribute to the rationale for future practice based recommendations for optimising dietary and exercise referral practices for cancer survivors in Australia.

## **CHAPTER FOUR – RESULTS AND DISCUSSION: DELPHI STUDY (STUDY 2)**

### **4.1 Chapter overview**

This chapter contributes to the overall aim of this doctoral research by presenting the essential element statements developed in the Delphi study, to provide guidance to health professionals with regards to dietary and exercise advice and referrals. Specifically, this chapter outlines the results, discussion and implications of the Delphi Study introduced in Chapter 3. The essential element statements presented in this chapter were developed to improve role clarity amongst medical and nursing health professionals regarding their roles on providing dietary and exercise advice and referrals to cancer survivors, which was highlighted as a key barrier in the literature (Chapters 1 and 2).

### **4.2 Results**

#### **4.2.1 Demographics**

Eighty-two (n=82) panel members participated in Round 1, 54 completed Round 2 (59% response rate) and 36 completed Round 3 (39% response rate). In Round 4, 58 consumers participated. Table 1 presents the demographics of participants in Rounds 1 to 3; demographics were not collected for Round 4. Gender distribution was consistent across the first three rounds, with a higher percentage of females in Round 1 (82%), Round 2 (87%), and Round 3 (75%). Stakeholders were primarily nurses (22%), dietitians (19%), exercise professionals (16%) across the first three rounds, and consumers in the final round (Round 4) (100%). In Rounds 2 and 3, most respondents worked in clinical (42%) and research roles (63%), 23% with dual roles (e.g., clinical and research). Respondents worked in cancer care ranging from <5 years to  $\geq 20$  years.

**Table 2** Demographic characteristics of Delphi participants

Characteristics <sup>1,2</sup>	PARTICIPANTS		
	Round 1 (n=82)	Round 2 (n=54)	Round 3 (n=36)
<b>Gender</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
Female	67 (82)	47 (87)	27 (75)
Male	15 (18)	7 (13)	9 (25)
<b>Profession</b>			
Consumer	3 (4)	3 (6)	1 (3)
Dietitian/Nutritionist	15 (18)	11 (20)	6 (17)
<i>Exercise Professional<sup>3</sup></i>	<i>8 (10)</i>	<i>11 (20)</i>	<i>9 (25)</i>
Exercise Physiologist	4 (5)	8 (15)	6 (17)
Physiotherapist	4 (5)	3 (6)	3 (8)
Medical Practitioner	6 (7)	4 (7)	3 (8)
Nurse	16 (20)	13 (24)	9 (25)
Researcher	6 (7)	1 (2)	1 (3)
NGO <sup>4</sup>	5 (6)	1 (2)	0 (0)
Other (not specified)	8 (10)	0 (0)	1 (3)
<i>Other Allied Health</i>	<i>15 (18)</i>	<i>10 (19)</i>	<i>6 (17)</i>
Occupational Therapist	1 (1)	1 (2)	1 (3)
Pharmacist	1 (1)	1 (2)	0 (0)
Psychologist	3 (4)	3 (6)	2 (6)
Radiation Therapist	5 (6)	3 (6)	2 (6)
Speech Pathologist	4 (5)	2 (4)	1 (3)
Social Worker	1 (1)	0 (0)	0 (0)
<b>Role</b>			
Administrative		1 (2)	0 (0)
Clinical		23 (43)	15 (41)
Education		12 (22)	12 (33)
Management		5 (9)	2 (6)
Research		31 (57)	25 (69)
Others		3 (6)	0 (0)
<b>Cancer care experience (Years)</b>			
0 to 4		14 (26)	10 (28)
5 to 9		10 (19)	7 (19)
10 to 14		11 (20)	8 (22)
15 to 19		5 (9)	2 (6)
20 or more		14 (26)	9 (25)

<sup>1</sup> Role and cancer care experience were not collected in Round 0

<sup>2</sup> Demographic characteristics of consumers were not collected in Round 3

<sup>3</sup> Exercise physiologists and physiotherapists

<sup>4</sup> Non-governmental organisation

Group responses to each essential element across the five principles are presented in Table 2. Consensus (90% or more) was achieved for all 24 statements after 2 rounds (Figure 7). Statements that were significantly modified or newly created in Round 2 were put forward for rating in Round 3. Revisions included using more proactive language or splitting statements into two separate statements. Following Rounds 2 and 3, eleven statements (n=11) reached consensus with no changes; ten statements (n=10) reached consensus with minor changes, and three new statements (n=3) were developed based on panel feedback (Appendix 7). These three new statements were related to education on diet and exercise for people affected by cancer and referrers; and investing in research for dietary and exercise referral practices. In Round 4, consumer acceptability was achieved for 15 of the 24 statements (63%) resulting in no revisions to those statements, with consumer feedback leading to the revision of wording in 9 of the 24 statements (37%) in Round 4 (Appendix 8).

Levels of consensus and means for each of the essential elements in Rounds 2 and 3 (importance), and levels of consumer agreement in Round 4 (consumer acceptability) are summarised in Table 3. Overall levels of consensus were higher in Rounds 2 and 3 (99%) than in Round 4 (80.4%). In Rounds 2 and 3, overall mean ratings of importance were highest for Principle 1 and 2 (4.7), followed by Principle 4 and 5 (4.6), and lastly Principle 3 (4.5). The highest rated elements from each of the principles included statements relating to education on diet and exercise (Principle 1 and 2); evaluation of needs for referrals at key transition phases (Principle 2); evaluation of needs for referrals based on evidence-based guidelines (Principle 3); clear communication in healthcare (Principle 4); and translation of research into practice (Principle 5). In Round 4, essential elements with the highest levels of agreement (90% or more) included statements relating to education on diet and exercise, evaluation of needs for referrals at key transition phases, translation of research into practice, and investments in research (Table 2).



**Table 3** Level of consensus by round for the essential elements of optimal dietary and exercise referral practices (ranked in order of importance)

<b>Principle 1: Consumer involvement in person-centred care</b>						
<b>Outcome</b>						
People affected by cancer are empowered to participate in shared decision-making and supported toward self-management according to their preferences. <sup>60, 237</sup> Informed and engaged consumers lead to better health outcomes and improved safety <sup>238, 239</sup> .						
<b>Essential Elements</b>		<b>R1 Consensus (≥75% rated a score ≥3)</b>	<b>Mean (SD) (5-point Likert scale)</b>	<b>R2 Consensus (≥75% rated a score ≥3)</b>	<b>Mean (SD) (5-point Likert scale)</b>	<b>R3 Agreement (% agreement of consumers)</b>
<b>Element 1</b>	People affected by cancer are informed about the benefits of diet and exercise for the management of cancer.	New element		100	4.8 (0.40)	77.6
<b>Element 2</b>	People affected by cancer are provided with information on dietary and exercise services available to support healthy lifestyles.	98.2	4.8 (0.59)	No changes		79.3
<b>Element 3</b>	People affected by cancer are advised to access existing dietary and exercise services available to support healthy lifestyles.	98.2	4.7 (0.74)	100	4.6 (0.49)	74.1
<b>Element 4</b>	People affected by cancer are empowered to take control of their health.	98.2	4.6 (0.71)	100	4.6 (0.69)	75.9
<b>Element 5</b>	People affected by cancer are provided with referrals to dietitians and exercise professionals when required.	98.2	4.6 (0.71)	100	4.6 (0.69)	74.1
<b>Principle 2: Support for living well</b>						
<b>Outcome</b>						
Supportive care needs* of people affected by cancer are assessed to determine appropriateness of referrals to dietary and exercise services. <sup>240</sup> People affected by cancer are supported to make informed lifestyle choices to promote wellness, manage treatment related side effects and co-morbidities, and reduce risk of second and recurrent cancers <sup>79</sup> *Includes physical, psychological, social (including educational, financial, and occupational issues), cultural, information and spiritual needs.						
<b>Essential Elements</b>		<b>R1 Consensus (≥75% rated a score ≥3)</b>	<b>Mean (SD) (5-point Likert scale)</b>	<b>R2 Consensus (≥75% rated a score ≥3)</b>	<b>Mean (SD) (5-point Likert scale)</b>	<b>R3 Agreement (% agreement of consumers)</b>
<b>Element 7</b>	People affected by cancer are best supported when referrers are informed about the benefits of diet and exercise for the management of cancer.	New element		100	4.8 (0.47)	94.8
<b>Element 6</b>	People affected by cancer are best supported when their needs for referrals to dietitians and exercise professionals are evaluated at key transition phases (at diagnosis, during treatment, end of treatment or long-term follow up).	100	4.6 (0.65)	100	4.6 (0.65)	91.4
<b>Element 9</b>	People affected by cancer are best supported when general practitioners (GPs) develop and review relevant Chronic Disease Management (CDM) plans and incorporate dietary and exercise referrals for optimal care.	100	4.6 (0.63)	No changes		89.7
<b>Element 8</b>	Referrers are informed about the available dietary and exercise community programs, support groups and other services, and how to refer to these services.	96.3	4.3 (0.97)	100	4.9 (0.28)	77.6
<b>Element 10</b>	People affected by cancer are best supported when models of care in the community are adapted to optimally support healthy lifestyles and sustainable lifestyle change.	100	4.5 (0.67)	97.2	4.6 (0.73)	89.7

<b>Principle 3: Evidence-based care pathways</b>						
<b>Outcome</b>						
People affected by cancer receive consistent, safe, high-quality evidence-based dietary and exercise cancer care in line with Optimal Care Pathways, <sup>240</sup> according to their individual circumstances and needs.						
<b>Essential Elements</b>		<b>R1 Consensus (≥75% rated a score ≥3)</b>	<b>Mean (SD) (5-point Likert scale)</b>	<b>R2 Consensus (≥75% rated a score ≥3)</b>	<b>Mean (SD) (5-point Likert scale)</b>	<b>R3 Agreement (% agreement of consumers)</b>
<b>Element 12</b>	Referrals to dietitians and exercise professionals are based on individualised needs in accordance with evidence-based dietary and exercise guidelines.	100	4.8 (0.58)	100	4.7 (0.51)	75.9
<b>Element 15</b>	Referrals are directed to dietitians and exercise professionals (i.e., exercise physiologists, physiotherapists) with experience in cancer care (where possible) with consideration of risks.	94.4	4.6 (0.92)	100	4.6 (0.61)	79.3
<b>Element 13</b>	Referrals to dietitians and exercise professionals are based on regular screening of individual needs at key transition phases to facilitate timely referrals to appropriate services.	100	4.6 (0.69)	99.9	4.5 (0.60)	81.0
<b>Element 14</b>	Dietary and exercise referrals are prioritised for Indigenous people, CALD populations and other vulnerable populations.	98.1	4.5 (0.77)	97.2	4.5 (0.77)	74.1
<b>Element 11</b>	Referrals to dietitians and exercise professionals are based on grading systems or validated screening tools where possible to assist in identifying individual needs.	96.2	4.3 (0.82)	100	4.3 (0.74)	65.5
<b>Principle 4: Coordinated and integrated care</b>						
<b>Outcome</b>						
People affected by cancer receive holistic patient-centred dietary and exercise services coordinated and integrated across treatment modalities, providers, and health settings. This includes public and private sectors, as well as specialist, primary, community-based, and not-for-profit services. Dietary and exercise care is delivered in a logical, connected, and timely manner for optimal continuity and to meet the individual needs of people affected by cancer.						
<b>Essential Elements</b>		<b>R1 Consensus (≥75% rated a score ≥3)</b>	<b>Mean (SD) (5-point Likert scale)</b>	<b>R2 Consensus (≥75% rated a score ≥3)</b>	<b>Mean (SD) (5-point Likert scale)</b>	<b>R3 Agreement (% agreement of consumers)</b>
<b>Element 17</b>	Between people affected by cancer, referrers, and service providers, there are clear, timely and effective bilateral communication processes adopted by various methods (e.g., email, telephone, shared medical records).	100	4.7 (0.49)	100	4.8 (0.50)	72.4
<b>Element 16</b>	Between people affected by cancer, referrers, and service providers, care is coordinated and integrated to develop and implement dietary and exercise referral pathways.	100	4.7 (0.49)	No changes		74.1
<b>Element 20</b>	People affected by cancer can access various modes of dietary and exercise service delivery (e.g., using telehealth) based on their individual needs and preferences.	98.2	4.7 (0.64)	No changes		74.1
<b>Element 19</b>	People affected by cancer have routine evaluations of their dietary and exercise plans to improve quality of care.	96.2	4.5 (0.86)	No changes		69.0

<b>Element 18</b>	People affected by cancer have dietary and exercise care plans, assessments, and updates on progress and outcomes which service providers feedback to referrers.	92.6	4.3 (0.94)	No changes	74.1	
<b>Principle 5: Data-driven improvements and investment in research</b>						
<b>Outcome</b>						
National collection and reporting of key cancer data, including consumer experience and outcome data, provides an indicator for high quality care, influences health service improvements and informs investment in research. Published research in cancer survivorship enriches the evidence base and informs improvements to enhance the care and outcomes of people affected by cancer.						
<b>Essential Elements</b>		<b>R1 Consensus</b> (≥75% rated a score ≥3)	<b>Mean (SD)</b> (5-point Likert scale)	<b>R2 Consensus</b> (≥75% rated a score ≥3)	<b>Mean (SD)</b> (5-point Likert scale)	<b>R3 Agreement</b> (% agreement of consumers)
<b>Element 22</b>	Dietary and exercise referrals can be optimised by translating research into practice, innovation, and improvements in cancer care.	100	4.9 (0.54)	No changes		94.7
<b>Element 23</b>	Research for dietary and exercise referral pathways should be continually invested in, and strengthened, to optimise outcomes for people affected by cancer.	New element		100	4.6 (0.65)	94.7
<b>Element 21</b>	Dietary and exercise referrals can be optimised by collecting and evaluating quality data on the referral process and care outcomes using validated instruments and standardised protocols, where appropriate.	98.2	4.5 (0.75)	No changes		84.2
<b>Element 24</b>	Investment in research for dietary and exercise referral practices should be produced in partnership with public and private sectors, organisations representing people affected by cancer, and consumers together with governing bodies and industry.	New element		97.2	4.5 (0.84)	93.1

### 4.3 Discussion

This consensus study is the first to investigate the perspectives of local representatives in Australia from diverse clinical and educational backgrounds, including consumers, regarding the optimisation of dietary and exercise support and referral practices for cancer survivors. The Delphi method enabled panel members to achieve consensus on 24 essential elements of optimal dietary and exercise referral practices. These essential elements provide a foundation for medical and nursing health professionals to promote consistent dietary and exercise support and referral practices for cancer survivors in order to help optimise quality survivorship care.

Key areas of consensus (mean rating of 4.8 or higher) revolved around the importance of informing cancer survivors and referrers about the benefits of diet and exercise for the management of cancer; the use of clear, timely, and effective bilateral communication processes between cancer survivors, referrers, and service providers; and evaluating cancer survivors' needs for referrals to dietitians and exercise professionals at key transition phases (Table 3). Despite the high levels of agreement among panel members in Rounds 2 to 3 (ranking importance; ranging from 92.6% to 100%; mean 99.0% importance), levels of agreement were lower for consumers (ranking acceptability; ranging from 65.5% to 94.8%; mean 80.4% acceptance) in Round 4. However, health professionals and consumers may have different expectations, experiences, and therefore opinions of what constitutes optimal dietary and exercise care due to differences in education, health literacy, or knowledge of care needs. Varying levels of acceptability with consumers for some statements could also relate to, or be influenced by, their personal experiences of cancer care, exemplified by a recent US national survey of cancer survivors (n=2419), where few participants reported receiving referrals to dietitians (25%), exercise programs (14.7%), or weight management programs (4.5%).<sup>224</sup>

Panel members recommended the addition of two new essential elements regarding education on the benefits of diet and exercise for cancer survivors and referrers. In order for cancer survivors to feel empowered to take action and seek access to dietary and exercise services and referrals (e.g., CDMP through their GP to facilitate five medicare-rebated consultations by dietitians or exercise professionals each year), it is imperative that cancer survivors are aware about the benefits of diet and exercise in the first place. Moreover, cancer survivors who value diet and exercise may be more likely to engage with dietary and exercise services and engage in appropriate self-management strategies.<sup>241</sup> Many medical and nursing health professionals have established relationships with cancer survivors, so they are well placed to educate cancer

survivors about the importance and benefits of diet and exercise as it relates to cancer treatment and cancer outcomes.<sup>15, 112, 113</sup> This could be achieved by utilising evidence-based dietary and exercise guidelines and appropriate resources.<sup>115, 153, 227</sup> However, medical and nursing health professionals may face various barriers to providing this education, due to their self-reported lack of role clarity, knowledge and confidence, awareness of guidelines/resources, and time constraints.<sup>10</sup> Overcoming these barriers may help facilitate better education for cancer survivors.

Evaluation of cancer survivors' needs for referrals at key transition phases was considered an important element by all panel members, including consumers. Although international clinical guidelines recommend all cancer survivors be regularly evaluated for nutritional risk and physical activity levels, there needs to be a greater emphasis on screening at key transition moments.<sup>115, 134</sup> As the clinical needs of cancer survivors will change as they move through the cancer continuum, timely detection of needs throughout the different stages of the cancer care trajectory is crucial and can be supported using screening and assessment. Individualised screening of cancer survivors can identify their need for dietary and exercise services, together with the provision of referrals to dietitians and exercise professionals. However, due to infrequent or lack of screening practices across hospitals and health professionals, cancer survivors are likely to miss key referral opportunities for earlier assessment and support from a dietitian or exercise professional.<sup>71, 242</sup> For screening to become integrated into standard care, funding needs to be prioritised, appropriate models of care must be developed, and health services must all be standardised, and evidence-based.

#### **4.4 Strengths and limitations**

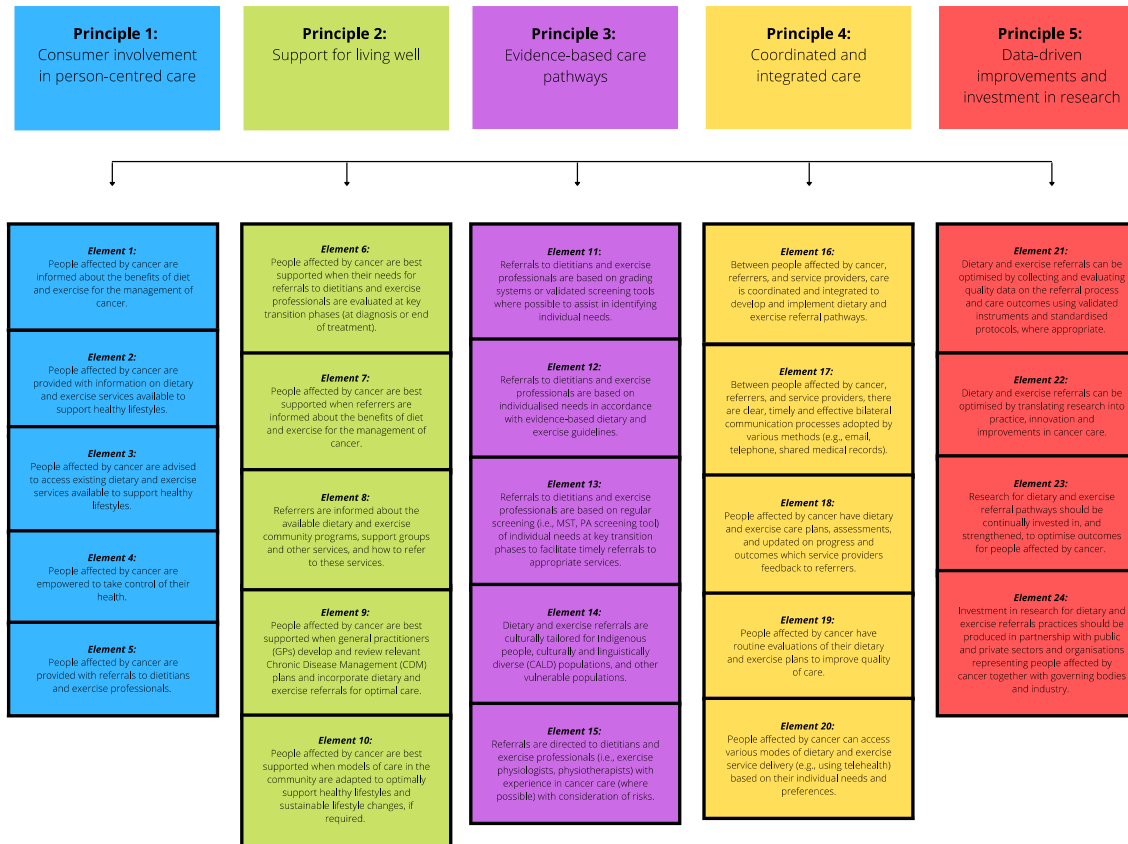
One of the strengths of this study was the wide representation of health professions across rounds, however, results could be strengthened with more representation from medical practitioners, specifically GPs. Despite efforts to recruit and include GPs, GPs who were invited were not able to engage. Therefore, their perspectives were underrepresented in this study due to challenges in recruitment. Another limitation was the limited role of the consumer in round 3 due to the lack of representation compared to the other three rounds. There was also a possibility that consumers in round 4 rated their acceptability of essential elements based on their personal experiences, rather than what they thought were important for optimal dietary and exercise care for all cancer survivors, which may have led to lower acceptability for some essential elements. Nonetheless, this provided a good representation of unique points of view

from consumers of diverse backgrounds. A further limitation was that the initial essential elements were developed by participants at a cancer conference. Therefore, health professionals attending this conference were more likely to be invested in survivorship care and may not be representative of all health professionals. Lastly, the essential element statements were all worded as “diet and exercise” together thus we were unable to determine whether there may have been any different findings if the same statements were assessed separately for diet and exercise

#### **4.5 Summary**

In summary, the findings of this study, although only an exploratory snapshot of what is occurring Australia wide, has highlighted an urgent need for a foundation for medical and nursing health professionals to promote standardised dietary and exercise care for cancer survivors. This study has provided insight into the importance of informing cancer survivors and referrers about the benefits of diet and exercise for the management of cancer; the use of clear, timely, and effective bilateral communication processes between cancer survivors, referrers, and service providers; and evaluating cancer survivors’ needs for referrals to dietitians and exercise professionals at key transition phases. Going forward, it is clear that dissemination of essential element statements to medical and nursing health professionals is crucial in working towards consistent provision of dietary and exercise advice, and referral practices for cancer survivors. Chapter five aims to explore the system-level factors influencing dietary and exercise referral practices on which future research could be based.

# Essential Elements of Optimal Dietary and Exercise Referral Practices



Adapted from the Principles of Cancer Survivorship by Cancer Australia.

**Figure 7** Summary chart of the essential elements of optimal dietary and exercise referral practices

## **CHAPTER FIVE – METHODS: SYSTEMS-THINKING STUDY**

### **(STUDY 3)**

#### **5.1 Chapter overview**

This chapter provides details of the research plan for a systems-thinking study, that aimed to understand and identify relevant factors in the healthcare system which may influence referral practices and strategies to address these system-level factors. To achieve the proposed aims, this chapter describes the target population, human research ethics approval, data collection, and data analysis plan for this systems-thinking study. The following chapter (Chapter 6. Results: Systems-Thinking Study) outlines the results, discussion and implications of this study.

This systems-thinking study provides a better understanding of complex factors that may facilitate or impede dietary and exercise referral practices for cancer survivors and explores the following question:

- What factors in a health system influence dietary and exercise referral practices, and how can these factors be used to develop strategies to address any system-level barriers?

This systems-thinking study was submitted to BMC Health Services Research on 01/06/2023 and has been included in this chapter.

Joseph R, Hart NH, Bradford N, Crawford-Williams F, Wallen MP, Tieu M, Knowles R, Han CY, Milch VE, Holland JH, Chan RJ. Systems-thinking to optimise dietary and exercise advice and referral practices for cancer survivors in Australia. BMC Health Services Research (under review).

(RJ was the primary author of this paper and led the development of the research question, data collection, synthesis and drafting of the manuscript. RJC, NHH and NB assisted with supporting RJ as PhD supervisors in conducting the systems-thinking study and offered comments and editing of the cited paper. All authors commented on previous versions of the manuscript, read and approved the final manuscript).



## 5.2 Background

There is increasing evidence that obesity, cardiovascular disease, and metabolic syndrome negatively impact the overall health, physical function, and quality of life of cancer survivors.<sup>93</sup> Other conditions including cancer-related malnutrition, cancer cachexia, cancer-related sarcopenia, osteopenia, and osteoporosis can all occur as late effects of cancer and its treatment. Diet and exercise interventions for cancer survivors can prevent, reduce, or reverse multiple adverse physical and psychosocial effects of cancer and its treatment, through their impact on other coexisting chronic medical conditions, such as cardiovascular disease or obesity.<sup>8, 9</sup> As such, there is an increased need for routine dietary and exercise interventions that target weight management with a focus on optimising muscle mass while reducing fat mass to be incorporated into standard cancer care.<sup>93, 97</sup> Cancer survivors at risk for other cancer-related conditions, such as malnutrition, sarcopenia, and osteoporosis would also require individualised dietary and exercise support to maintain their weight and improve muscle mass and strength.<sup>171, 181</sup>

For the majority of cancer survivors, a targeted, coordinated multidisciplinary approach incorporating medical, nursing, and allied health professionals (i.e., dietitians and exercise professionals) is required to maximise improvements in nutritional status, physical functioning, and overall quality of life.<sup>71, 100, 181</sup> It is important to recognise that cancer care professionals have different roles and responsibilities in terms of providing dietary and exercise care to cancer survivors. While medical and nursing health professionals play an important role in communicating the benefits of improving diet and participating in exercise to cancer survivors, and reinforcing positive behaviour change, they may require additional support to provide recommendations for cancer survivors with metastatic disease, comorbidities, treatment complications, or late-effects.<sup>10, 169</sup> In such circumstances, medical and nursing health professionals' roles should include facilitating referrals to dietitians and exercise professionals for individualised dietary and exercise support to meet the complex needs of cancer survivors.<sup>10</sup> Dietary interventions should be designed and delivered by accredited practising dietitians to facilitate the provision of individualised nutritional plans that improve dietary intake and decrease nutrition-related side-effects associated with cancer and its treatment.<sup>98</sup> Similarly, exercise interventions should be designed and delivered by qualified exercise professionals (i.e., clinical exercise physiotherapists, physiotherapists) who can prescribe safe and effective exercise programs that increase cardiorespiratory fitness and physical function; improve body

composition, psychosocial wellbeing, and quality of life; and promote cancer recovery.<sup>105</sup> Accordingly, health professionals with a diversity of clinical disciplines can play important synergistic roles in providing optimal dietary and exercise care to cancer survivors.

In the current context, cancer survivors may or may not receive dietary and exercise advice from medical (primary care and specialist oncology care), nursing, and allied health professionals as part of their routine cancer care<sup>10</sup>, but not always directly from dietitians and exercise professionals. For cancer survivors to access specialised dietary and exercise care<sup>14</sup> in Australia, cancer survivors need to be initially referred to dietitians and exercise professionals by their specialist team or through their GP. If referred by a GP, cancer survivors can access subsidised dietary and exercise services via CDMPs.<sup>144</sup> However, around half (53%) of the public and private hospitals in Australia that provide cancer care do not have established referral pathways for supportive care services, with only 19% of hospitals referring cancer survivors to external organisations or allied health professionals.<sup>17</sup> This highlights a gap with current referral practices; the importance of standardising referral processes; and the inadequacy of supportive care provided to cancer survivors.<sup>17</sup>

Consensus for the essential elements of diet and exercise referral practices have recently been identified.<sup>16</sup> However, optimising referral practices requires a better understanding of complex factors that are part of an interconnected system that may facilitate or impede referral practices. To our knowledge, only factors at an individual level have been investigated.<sup>15, 94, 169, 243</sup> There is a paucity of evidence aiming to understand these factors at a system level, how they are interconnected and how to devise innovative strategies that target them effectively. Systems-thinking involves the exploration of characteristics and components within a system through a holistic and complexity lens, focusing on how components of the system are interconnected and how they interact in complex ways, to improve understanding of how healthcare outcomes may emerge from these interactions.<sup>150, 244, 245</sup> WHO's health system building blocks, categorises health systems in terms of six building blocks: (1) financing, (2) health workforce, (3) information, (4) medical products and technologies, (5) leadership/governance, and (6) service delivery.<sup>246</sup> These building blocks provide a conceptual framework for identifying system-level factors and relationships between factors that interact in ways that may influence dietary and exercise referral practices in a cancer setting. The aim of this study was to pioneer a systems-thinking approach using the WHO health system building blocks in cancer care to

(1) identify relevant system-level factors related to dietary and exercise advice and referral practices; (2) understand the interactions between factors across different building blocks of the healthcare system and to (3) identify innovative strategies that leverage existing synergies and create or promote new ones between various system-level factors, ultimately optimising dietary and exercise advice and referral practices.

## **5.3 Methods**

### **5.3.1 Study design**

A systems-thinking approach was used to explore dietary and exercise advice and referral practices, framed by the WHO health system building blocks framework<sup>247</sup> (Appendix 9), through a facilitated workshop with groups of key stakeholders. Stakeholders were recruited from different healthcare settings, and included cancer consumers/consumer representatives, multidisciplinary care providers, including primary care, specialist oncology care and dietitians and exercise allied health professionals, researchers, and representatives of Cancer Council (not-for-profit organisation) and Cancer Australia (the Australian Government agency for cancer control). Systems-thinking approaches have been used frequently in public policy.<sup>248</sup> Although its application in health settings is limited, it has been used to address complex problems such as obesity and diabetes<sup>249</sup>, and was shown to effectively highlight the complexity of a problem. Cognitive mapping was used to explore the characteristics of, and interactions within, the Australian healthcare system that may impact dietary and exercise referral practices and were subsequently mapped to the WHO health system building blocks framework (Appendix 9). This technique creates a visual representation of a group's findings for a process or concept, such as illustrating the relationships between identified factors.<sup>250</sup> Once any relationships were identified, the cognitive maps were consolidated into a causal loop diagram to describe a set of interlinked feedback loops representing the processes involved in implementing healthcare system changes.<sup>251</sup> Ethics approval was provided by the Human Research Ethics Committee of Flinders University (HREC ID: 5566). All stakeholders provided written consent prior to any participation in the study (Appendix 10). Data were collected and managed in accordance with the World Medical Association's Declaration of Helsinki.

### **5.3.2 Part 1: Pre-workshop preparation**

Potential stakeholders, including cancer care professionals (including specialists and primary care professionals), researchers, policy makers and consumers/consumer representatives were identified and invited to participate via existing networks of the research team (Appendix 11). Prior to the workshop, participant demographics were obtained via online questionnaire, including gender, age, location of occupation, current profession, and time (in years) working in cancer care (if applicable). A workshop booklet was also distributed, comprising of an overall workshop outline and background information on the (1) workshop methodology and (2) relevant material relating to the essential elements of dietary and exercise referral practices<sup>10</sup> (Appendix 12); and the WHO health system building blocks framework (Appendix 9). These components were also communicated in the form of a presentation at the start of the workshop, and each group was allocated one WHO building block to consider. Prior to the workshop, participants were pre-assigned to a WHO health system building block group discussing one of the WHO building blocks by the research team based on their previous experiences, knowledge, and expertise in those areas. Facilitators of each group were tasked with (1) reviewing the principles of cancer survivorship<sup>77</sup> and essential elements of dietary and exercise referral practices<sup>16</sup>; and (2) familiarising themselves with the semi-structured workshop guide (Appendix 13) to promote discussions within the groups as they apply to their group's allocated WHO building block throughout each session.

### **5.3.3 Part 2: Workshop**

The systems-thinking workshop was divided into three sessions:

1. Identification of contextual factors in the healthcare system related to dietary and exercise referral practices (approximately 60 minutes)
2. Discussion of the relationships between the factors across the WHO health system building blocks (approximately 100 minutes)
3. Identification and discussion of innovative strategies that may address the identified system-level barriers to foster dietary and exercise referral practices for cancer survivors (approximately 150 minutes)

#### ***5.3.3.1 Session 1: System-level factors***

Each group was allocated one WHO building block and involved small-group discussions on the functions of the healthcare system and identifying system-level factors impacting referral practices related to their allocated WHO building block. Participants used individual sticky

notes for each factor to develop a group cognitive map written on paper, highlighting factors that may influence dietary and exercise referral practices for cancer survivors.

#### **5.3.3.2 Session 2: Interactions between WHO building blocks**

This session was divided into two parts. Firstly, there were small-group discussions within each group to explore how the WHO building block allocated to each group interacted with the other building blocks and identify relationships between them. Participants were asked to build upon their cognitive maps by drawing relationships between the system-level factors using markers. The strength of relationships between factors were not considered. Secondly, a facilitator from each small group summarised and presented their cognitive maps, including the identified relationships to the full stakeholder group.

#### **5.3.3.3 Session 3: Innovative strategies**

The third session was divided into two parts. Firstly, there were small-group discussions within each group to identify and summarise innovative strategies that would leverage system-level facilitators and address system-level barriers to optimise dietary and exercise referral practices for cancer survivors. Secondly, the facilitator from each small group shared their group's top five strategies related to their WHO building block with the full stakeholder group for each WHO building block, which was summarised and presented by the group facilitator. Participants were then encouraged to translate strategies into specific actions, timelines, and responsibilities (i.e., key stakeholders) to reach a desired outcome. At the end of session 3, participants were asked to complete a workshop evaluation including questions on the systems-thinking methodology, content, and organisation.

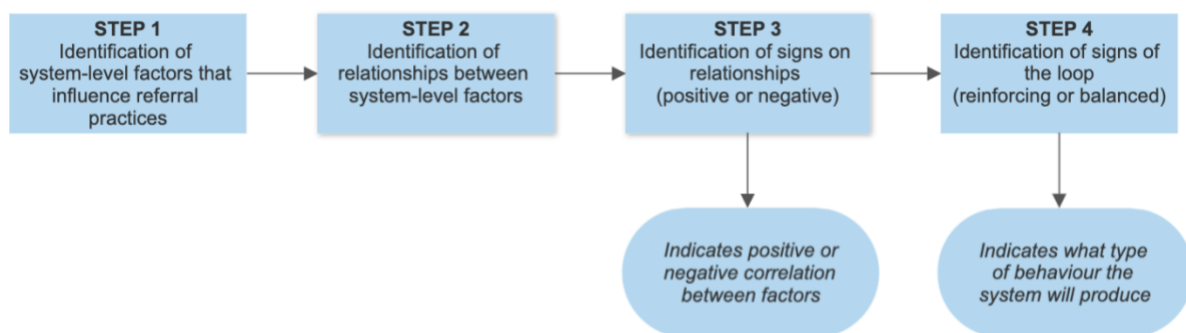
### **5.4 Data analyses**

Demographic characteristics of participants were descriptively analysed and reported, and count data were expressed as n (%). The doctoral candidate (RJ) used a deductive thematic approach<sup>252</sup> to analyse qualitative data from the systems-thinking workshop. Data were categorised under the WHO health system building blocks framework. Common themes that emerged across the WHO building blocks were grouped into further categories. Strategies that were identified in the third session were tabulated in relation to identified system-level factors. Vensim (Ventana Systems, Inc; Harvard, USA)<sup>253</sup>, a computer software package was used to develop a causal loop diagram with reference to notes and audio-recordings alongside the cognitive maps, ensuring that all relationships discussed were accurately reflected in the

diagram. Once the factors were identified, Vensim was used to link the factors together and highlight the direction of the relationships.

### 5.4.1 Causal loop development

One-headed arrows were drawn between factors highlighting these relationships, as well as indicating the causal direction of the perceived causal effect. If factor A moved in the same direction as factor B, the link from factor A to B was labelled with a '+'; if factor B changed in a direction opposite of factor A (i.e., as A increases, B decreases), the link from A to B was labelled with '-'. Once the links were completed, the type of behaviour it produced was then determined. A series of arrows that close to form a loop were labelled as either a reinforcing or balanced loop. The dynamics of any system stem from the interaction of two types of feedback loops: reinforcing and balanced loops. Specifically, reinforcing loops tend to amplify whatever is happening in the system. Whereas balanced loops counteract and oppose the change.<sup>254</sup> To determine whether a causal loop was reinforcing or balancing, the number of '-'s were counted. If there was an even number of '-'s (or none present), the loop was reinforcing and was labelled "R". If there was an odd number of '-'s, it was a balancing loop and was labelled "B".<sup>255</sup>



**Figure 8** Development of causal loop diagram

## 5.5 Summary

In this chapter, a systems-thinking workshop was used to identify system-level barriers, facilitators and potential strategies to address the identified barriers, as well as cohort demographics through use of an online demographics survey. Focused discussion in the workshop enabled the exploration of current dietary and exercise referral practices, barriers,

facilitators and potential strategies (chapters five and six) through the use of a systems-thinking approach.

## CHAPTER SIX – RESULTS AND DISCUSSION: SYSTEMS-THINKING STUDY (STUDY 3)

### 6.1 Chapter overview

This chapter contributes to the overall aim of the doctoral research by presenting the system-level factors, innovative strategies to address these system-level factors and a causal loop diagram, to highlight specific leverage points at which dietary and exercise referral practices can be improved. Specifically, this chapter outlines the results, discussion and implications of the systems-thinking study introduced in Chapter 5. The system-level factors discussed in this chapter were identified by participants using the essential elements presented in Chapter 4 as a guide.

### 6.2 Results

#### 6.2.1 Demographics

Twenty-seven stakeholders participated in the systems-thinking workshop. Table 1 presents the demographic characteristics of participants. There were more females (63%) than males (33%), as well as one person preferring not to disclose (4%). Participants were predominantly based in South Australia (44%) and Queensland (30%) and were mainly nursing professionals (22%), dietitians (19%), exercise professionals (19%), and medical practitioners (15%). Of these, participants were primarily employed with dual roles as dietitians/researchers (19%) and exercise professionals/researchers (11%). Consumers and/or consumer representatives (7%) also participated in this workshop. The median years of experience in cancer care was 9 years (IQR = 4 years, 18 years).

**Table 4** Demographic characteristics of workshop participants

Characteristics	Number	Percent
	n	%
<b>Sex</b>		
Female	17	63
Male	9	33
Prefer not to say/other	1	4
<b>Age group</b>		
18-24	0	0
25-34	6	22
35-44	11	41
45-54	4	15
55-64	3	11
65 or older	2	7



Prefer not to say	1	4
<b>Ethnicity</b>		
Australian	19	70
Asian	4	15
European	1	4
<i>Other</i>	2	7
British Australian	1	4
British	1	4
Prefer not to say	1	4
<b>State/Territory</b>		
Australian Capital Territory	1	4
New South Wales	3	11
Northern Territory	0	0
Queensland	8	30
South Australia	12	44
Tasmania	0	0
Victoria	3	11
Western Australia	0	0
<b>Profession</b>		
Consumer	2	7
Dietitian	5	19
Exercise Physiologist	4	15
Physiotherapist	1	4
Medical practitioner	4	15
Nurse	8	30
Researcher	9	33
<i>Other</i>	4	15
Policy advocate	1	4
Retired researcher	1	4
Nurse Practitioner	1	4
CEO NFP Patient Support Organisation	1	4
<b>Role</b>		
Clinical	11	41
Education	5	19
Management	7	26
Research	15	56
<i>Other</i>	2	7
Consumer involvement in research	1	4
Consumer/researcher	1	4
<b>Cancer care experience (years)</b>		
0 to 4	8	30
5 to 9	6	22
10 to 14	7	26
15 to 19	4	15
20 or more	2	7

The views of participants on system-level factors influencing dietary and exercise referral practices for cancer survivors were grouped into six main categories as per the WHO building blocks (Appendix 9). Six cognitive maps (Appendix 14) were developed by participants and consolidated into one causal loop diagram (Figure 2), to highlight the relationships between factors.

### ***6.2.2 Session 1: System-level factors***

Several barriers (Appendix 15) were identified by participants as hindering access to dietary and exercise services within each of the WHO health system building blocks. These included financing barriers (i.e., lack of funding, out-of-pocket costs for patients, and resource allocation); service delivery barriers (i.e., infrequent and inconsistent screening practices, inadequate use of guidelines and standards, and insufficient allied health sessions through the CDMP); health information barriers (i.e., lack of training and continuing professional development, conflict role identity of health professionals, lack of awareness of resources and services, and lack of digital and health literacy); leadership/governance barriers (i.e., fragmented leadership and responsibilities, lack of care coordination and involvement of all stakeholders from the beginning resulting in a fragmented system); workforce barriers (i.e., limited staff capacity and services, time constraints and patient demand); and medical products/technology barriers (i.e., lack of communication pathways between health professionals and patients, lack of connections between information systems, and technologies not being supported by healthcare systems).

### ***6.2.3 Session 2: Interactions between WHO building blocks***

The causal loop diagram shown in Figure 2 represents the non-linear causal relationships in the health system based on the relationships identified by participants in this systems-thinking study. There are many (n=7) causal loops within the causal loop diagram, reflecting the complexity of the system and all these loops demonstrate reinforcing feedback loops, causing accelerated growth or decline.

#### **6.2.3.1 Reinforcing loop 1 (R1): Funding/Resource utilisation**

Greater involvement of peak bodies can result in increased funding and increased resource utilisation. An increase in funding and resource utilisation can decrease patient financial responsibility, which can improve access to dietary and exercise services. An increase in the level of awareness of resources/services can also result in greater utilisation of resources.

System-level factors related to the financing, service delivery, and leadership/governance building blocks are considered important in this causal loop.

#### **6.2.3.2 Reinforcing loop 2 (R2): Resource allocation**

Improved resource allocation can decrease patient financial responsibility and it can also increase health services capacity resulting in increased access to dietary and exercise services. System-level factors related to the financing and health workforce building blocks are considered important in this causal loop.

#### **6.2.3.3 Reinforcing loop 3 (R3): Workforce capacity**

Increased patient demand can increase health worker load and reduce health services capacity, resulting in reduced access to dietary and exercise services. System-level factors related primarily to the health workforce building block are considered important in this causal loop.

#### **6.2.3.4 Reinforcing loop 4 (R4): Health education**

Increases in health education can result in increased clarity of role responsibilities among interprofessional team members, which can increase the level of awareness regarding resources/services that are available in terms of dietary and exercise support, ultimately increasing access to dietary and exercise services. An increase in the level of awareness of resources/services can also result in greater utilisation of resources. System-level factors related to the information and service delivery building blocks are demonstrated to be important in this causal loop.

#### **6.2.3.5 Reinforcing loop 5 (R5): Digital & health literacy**

Increases in health education can improve digital and health literacy, which can increase healthcare interoperability across healthcare settings, and can result in increased access to dietary and exercise services. System-level factors related to the information and medical products, vaccines & technologies building blocks play important roles in this causal loop.

#### **6.2.3.6 Reinforcing loop 6 (R6): Digital health communication**

Increased healthcare interoperability across healthcare settings can improve communication levels between healthcare organisations, healthcare providers and patients, and therefore

increase standardised screening and referral practices, ultimately increasing access to dietary and exercise care. System-level factors related to the medical products, vaccines & technologies, information, and service delivery building blocks are the most influential in this causal loop.

#### **6.2.3.7 Reinforcing loop 7 (R7): Screening & referral practices**

An increase in standardised screening and referral practices can increase the level of awareness regarding resources/services that are available in terms of dietary and exercise support, which can result in increased care coordination, ultimately improving access to dietary and exercise services. System-level factors related to the service delivery, information and leadership/governance building blocks are considered important in this causal loop.

#### **6.2.4 Session 3: Innovative strategies**

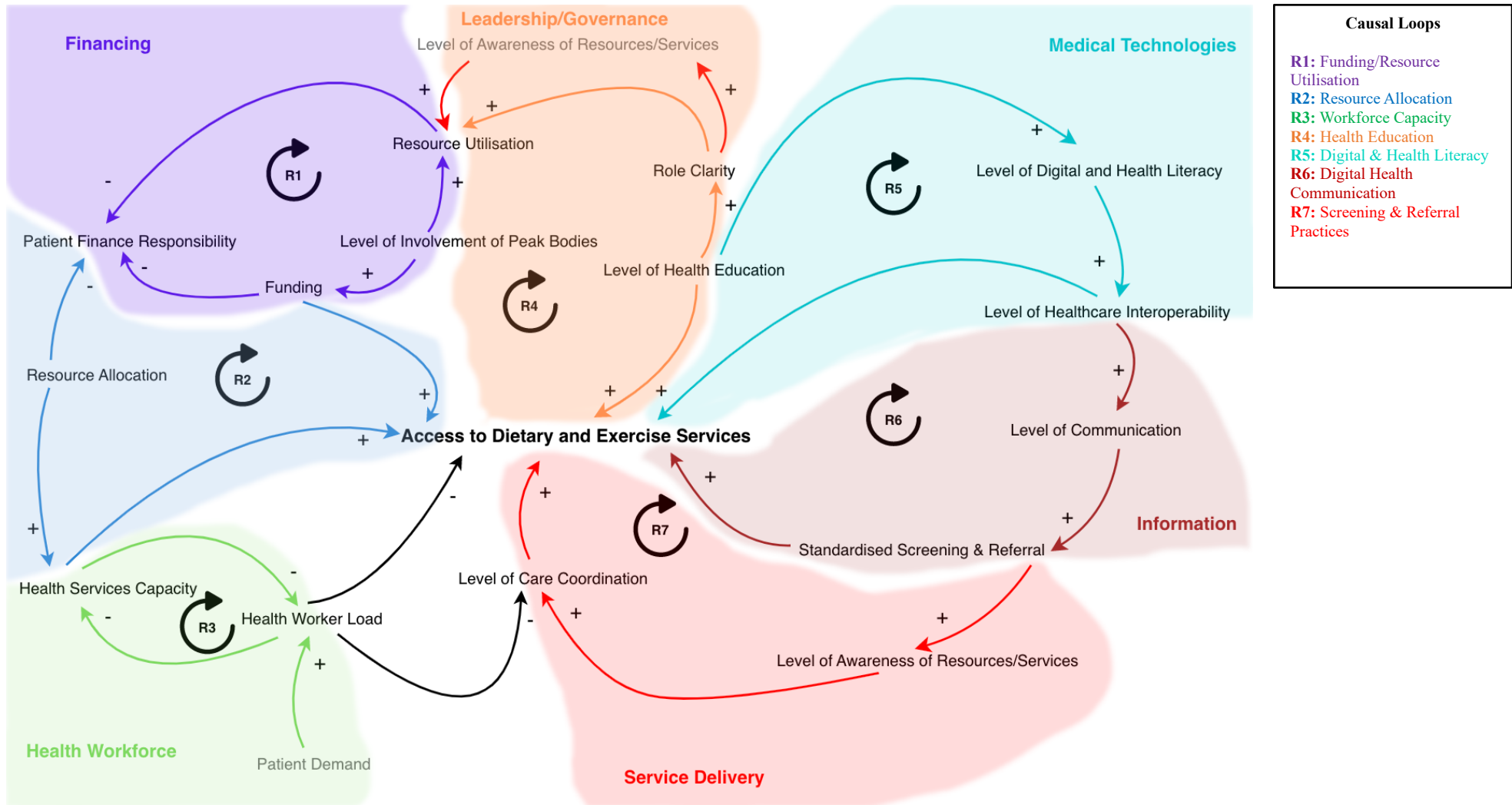
In considering the numerous system-level barriers (Appendix 15) identified by workshop participants, 15 respective strategies were identified across the six groups that can be used to address each of the causal loops within the causal loop diagram. These strategies can be used to further advance practices in health professionals' guidance and referrals for dietary and exercise services (Table 5).

#### **6.2.5 Workshop evaluation**

Overall, most of the participants clearly understood the objectives of the workshop with 87% strongly agreeing and 13% agreeing. Few participants (38%) had adopted a systems-thinking perspective before, and 25% reported that their organisations regularly use systems-thinking in a systematic way. Although, 62% were not familiar with using systems-thinking, 75% believed their organisations would benefit from using systems-thinking, and 87% expressed interest in receiving further training in applying a systems-thinking approach. Other areas of cancer survivorship that could benefit from a systematic systems-thinking exercise were identified by participants. These areas included navigation, supportive care access and cancer screening as well as referrals, shared follow-up and survivorship care, psychosocial, financial and sexual care, workforce mapping/planning, infrastructure planning, patient experience relating to treatment and managing side effects of treatment, behaviour change, and health literacy. Participants indicated the following as some of the general workshop recommendations: shorter sessions with more prompting questions for each session, rotation of groups to enhance

diversity of perspectives, the need for more panel discussions and digital interactions using own devices, and additional pre-workshop reading.

**Figure 9** Causal loop diagram



**Table 5** System-level strategies

Causal Loop	System-Level Strategies
<b>R1</b>	Evaluation of standardised pre and post-measures to define success of survivorship programs which are linked to funding outcomes across private and public settings.
	Successful embedment of nutrition and physical activity requires a system that incentivises or encourages general practitioners and hospital systems to assess cancer survivors' status of nutrition and physical activity. For example, such assessment information needs to be collected and reported and linked to activity-based funding (e.g., blood pressure checks, smoking cessation).
<b>R2</b>	There needs to be coordinated, advocacy efforts to lobby for an increased number of allied health sessions for cancer survivors.
	There needs to be system-level and organisation-level efforts to integrate dietary and exercise referrals into existing models of care (i.e., chronic disease management plan, cardiac rehabilitation) as well as developing necessary models of care/funding mechanisms to enable care.
<b>R3</b>	Collaborating with universities to recruit students from university placements to improve capacity numbers and future training workforce.
	Staff are provided with incentives to specialise, resulting in a more skilled workforce (e.g., increased pay rates, increased job opportunities, reimbursements on successful completion).
	Advocating for nurse practitioners to provide referrals to chronic disease management plans for cancer survivors instead of solely general practitioners, which provides flexibility for general practitioners.
<b>R4</b>	Successful optimisation of dietary and exercise services requires information-giving and self-management education, referral for appropriate services, and direct care (from cancer professionals, and exercise and nutrition specialists). To facilitate further system optimisation, implementation of a stepped-care model including development of consensus competency frameworks with clear role delineation will be essential.
	Development of a competency framework which defines the essential components for role clarification among different health professionals, as well as providing training and resources in relation to this framework.
<b>R5</b>	Acknowledging and leveraging on the role of “navigation” or “navigators” to enable integrated systems to facilitate optimal care for all cancer survivors. Cancer survivors should be provided with self-management and practical support to access care so that they know where to go and what they need, to empower them to act.
	A centralised, coordinated repository of dietary and exercise services (Exercise & Sports Science Australia, Dietitians Australia, Australian Physiotherapy Association etc) in one place with one organisation responsible for collation and maintenance (e.g., Cancer Council, Cancer Australia, Clinical Oncology Society of Australia) is important to promote trustworthiness of information.
<b>R6</b>	Closing the loop between health professionals and cancer survivors by sharing medical information through existing digital platforms such as “My Health Record” to ensure clear, timely and effective bilateral communication processes are adopted.
	Technology and information platforms (including information about why cancer survivors should be referred for services, understanding connections between exercise/nutrition and their health outcomes-website, documents etc.) should be co-designed and implemented in partnership with consumers.
<b>R7</b>	Development of standard assessment tools that are cancer-specific to assess patient needs and preferences in relation to dietary and exercise support, and triage care accordingly. Implementation of these tools can facilitate referrals to dietitians, clinical exercise physiologists and physiotherapists across multiple settings.
	Implementation of standardized screening processes into referral processes (e.g., automated system to screen for care needs and referral pathways, use of electronic patient-reported outcome measures, artificial intelligence, and electronic medical records to flag things automatically).

### 6.3 Discussion

This systems-thinking study is the first to explore the complex, interconnected relationships between factors and relationships of the health system that influence referral practices for diet and exercise from diverse perspectives of consumers, clinicians, and leaders from not-for-profit organisations, peak professional organisations, and the government. While discussions during the workshop reaffirmed common priority leverage points as per the causal loop diagram and actions to improve dietary and exercise referral practices, the findings also showcased the potential of collaboration and development of knowledge across diverse stakeholder groups, and of applying complexity and systems-thinking approaches to improve referral practices. Financing, information, leadership/governance, and service delivery were identified by participants to be the central WHO health system building blocks that influenced access to dietary and exercise care in comparison to the building blocks for medical technologies and workforce.

Out-of-pocket costs and a lack of sufficiently functional funding mechanisms for services were flagged by participants as key barriers influencing their access to dietary and exercise services, which can affect cancer survivors' overall health outcomes.<sup>256, 257</sup> Participants recommended that major changes to the financing of allied health services in Australia are required to address the needs of cancer survivors to ensure access to timely and comprehensive dietary and exercise support. Access to subsidised allied health services may play a significant role in starting the care planning process for both patients and GPs.<sup>149</sup> Given the inherent complexity of cancer, cancer survivors often need support from different health professions to ensure optimal outcomes for their cancers, co-existing chronic conditions and overall quality of life.<sup>258</sup> The current CDMP and TCA items, funded under the MBS<sup>144</sup>, allow access to five allied health sessions per year for people with a chronic disease. These five sessions must be shared across all allied health specialities so cancer survivors may not be able to access an adequate number of sessions to meet their individual needs particularly for dietary and exercise services. Furthermore, there is limited provision for more intensive dietary and exercise interventions where greater complexity or risk is demonstrated in cancer survivors, thus the number of sessions are insufficient. Without a mechanism for further subsidisation, the system limits people who require but cannot afford allied health services from accessing it. As such optimal care is only available to those who are able to pay for the additional services required through the private healthcare system.<sup>149</sup> There is a need to determine optimal strategies at different levels (providers, cancer centre, hospital and government agencies) to address costs of care in



order to minimise financial toxicity, promote access to high value care, and reduce health disparities. There is limited evidence synthesizing the cost-effectiveness of dietary and exercise interventions for cancer survivors. These interventions may be cost-effective by enhancing the quality of cancer care at no additional costs, however further research on the cost-effectiveness of dietary and exercise interventions is required for policy makers to take into consideration.<sup>259-262</sup> Due to the growing burden of chronic disease and the need to focus on system integration, primary health care reform has been a focus for the Australian government over the past decade. Draft reforms were released by the Australian government in 2021<sup>263</sup> with recommendations for the management of complex chronic diseases using fee-for-service and blended payment methods, as well as funding for extended consultations to better meet patients' needs and provide affordable care.<sup>264, 265</sup>

Future policy efforts should advocate for more funding and alternative financing so that cancer survivors can receive appropriate referrals to the adequate allied health services they require. There needs to be coordinated, advocacy efforts to lobby for an increased number of subsidised sessions for cancer survivors in Australia and streamlining referrals to these sessions. Participants recommended applying a similar level as the Group Allied Health Services for people with Type 2 Diabetes (i.e., including education, dietary and exercise interventions) as a reference point for future advocacy efforts.<sup>266</sup> Consequently, government funding and policies are critical to dietary and exercise care provision so there is a need to leverage existing resources as well as advocating for better access to allied health and support services through adequate funding models to improve patient outcomes.

Breakdowns in networks and poor interprofessional communication pathways were perceived by participants as major barriers to optimal referrals to dietitians and exercise professionals (i.e., clinical exercise physiologists and physiotherapists), as well as communication between healthcare providers and their patients across settings. For example, GPs can often be disconnected from the cancer specialist team due to ineffective communication and poor integration of treatment plans between GPs and cancer specialists.<sup>124</sup> It is well established that poor communication in cancer care can have a negative impact on patients' treatment choices, symptom control, and quality of life.<sup>267</sup> Integrated systems that use or build upon existing electronic health records (e.g., My Health record) have the potential to facilitate shared cancer care through improved GP-specialist communication. Early involvement of GPs and two-way communication between acute and primary care throughout the cancer continuum is paramount

to ensure optimal patient care, including optimal referral practices. Such communication and intersectoral connection should continually be supported by a capable, navigation and digital infrastructure. Since cancer care is highly complex, there also needs to be a more integrated and coordinated approach between peak bodies and accredited bodies, healthcare providers, and cancer centres, through the establishment of integrated and networked cancer services to improve access, quality, and continuity of dietary and exercise services.

The Australian health care system provides a wide range of services, but is complex to navigate which can limit effective connection of cancer survivors with health care providers that address their individual needs.<sup>17, 38</sup> Effective communication between healthcare providers and patients is a necessity to meet patient needs and to provide high-quality services such as ensuring that patients are aware about the existing dietary and exercise resources/services that they can access (e.g., GPMP<sup>144</sup>, Optimal Care Pathways<sup>27</sup>, Cancer Council online resources).<sup>268</sup> Beyond better communication, there is a need for recognition and clarification of the roles of cancer care professionals across the cancer care continuum, taking into account the essential contributions of GPs, cancer specialists, and allied health professionals and avoiding significant overlap in crucial cancer care provision, resulting in better care coordination.<sup>10</sup> Communication-related barriers can be addressed by adopting standardised screening and referral processes, using screening tools at key transition points to identify patients' needs and streamline referrals to dietitians and exercise professionals. Adoption of healthcare interoperability across different settings can promote continuity and clarity within the patient care team and patient-centred care.

Participants highlighted fragmented leadership/responsibilities as another key barrier to dietary and exercise referrals and information involving peak bodies and accredited bodies such as the Australian Physiotherapy Association (APA), Exercise and Sports Science Australia (ESSA), Dietitians Australia (DA), COSA, Cancer Councils, Nutrition Australia, Fitness Australia, care providers, GPs, local health networks (LHNs), and leadership mentoring systems. Whilst many of these organisations play an important role in providing national leadership and fostering improvements in the integration of networked cancer services, it remains a challenge to integrate and coordinate care across the individual healthcare services that cancer survivors access. Participants suggested that this could be achieved through the development of a centralised repository of dietary and exercise services which is accessible to people regardless of location using digital technologies, with one organisation responsible for collation and

maintenance. Peak bodies and accredited organisations can each undertake key roles such as coordinating the development of information about the available cancer services in each state and territory for GPs and cancer survivors. This information benefits both providers and cancer survivors as GPs are supported to have optimal referral practices and cancer survivors are reassured of the best system-based care.

#### **6.4 Strengths and limitations**

This study is the first to use a systems-thinking approach with a complexity lens to explore referral practices in cancer care. The use of a complex system mapping process and use of the WHO building blocks process is a novel process in cancer survivorship and across a number of areas in healthcare. This study has some limitations. Given the qualitative nature, perspectives of the participants might be subjected to their experiences and perspectives. However, the workshop participants represented a range of diverse perspectives including experts in the fields (i.e., researchers, healthcare professionals, consumers, and policy makers). Despite efforts to recruit and include GPs, GPs who were invited were not able to engage. Therefore, their perspectives were underrepresented in this study due to challenges in recruitment. Overall, this study provided outputs that have the potential to inform implementation and strengthen health systems at various levels in terms of dietary and exercise referral practices.

#### **6.5 Summary**

In summary, cancer survivors may face numerous barriers to accessing care, not only at the individual level, but also at the provider and system level. Chapter six explored the system-level barriers and facilitators that influence dietary and exercise referral practices based on WHO's health system building blocks framework, the identification of potential strategies that can be used to address these barriers, and the development of a causal loop diagram. Essential element statements, the causal loop diagram, and the system-level strategies generated from this doctoral research create clinically relevant, practical and translatable evidence, designed by key stakeholders to address an important clinical issue. Since each of the system-level strategies are linked with corresponding causal loops within the causal loop diagram, it is important that this causal loop diagram and system-level strategies are considered prior to implementing essential elements in practice. The findings will contribute to optimising dietary and exercise referral practices for cancer survivors, and can be attributed to the methods and participants.

## **CHAPTER SEVEN – SUMMARY AND CONCLUSION**

### **7.1 Chapter overview**

In this final chapter, all the studies and implications for practice are discussed with regards to the perspectives of medical and nursing health professionals on their roles and responsibilities on provision of dietary and exercise advice and referrals to cancer survivors; the contribution of essential elements to standardising dietary and exercise care for cancer survivors, and the contribution of a causal loop diagram and strategies to address potential causal loops to further optimise dietary and exercise care for cancer survivors. Recommendations for the use and applicability in health care settings of essential elements, causal loop diagram, and innovative strategies are discussed. The final section of this chapter serves to conclude this doctoral research and presents a discussion of the quality of all three studies and recommendations for future research.

### **7.2 Rationale for research**

This doctoral research aimed to optimise dietary and exercise referral practices for cancer survivors in Australia across the survivorship trajectory. With growing demand for referrals to dietary and exercise services for cancer survivors, a better understanding of the current gaps in referral practices was required. As highlighted in the literature (Chapter 1), medical and nursing health professionals can play an important role in educating cancer survivors of the importance of diet and exercise, reinforcing behaviour change, and facilitating referrals to diet and exercise services.<sup>102</sup> However, a systematic disconnect exists between medical and nursing professionals providing cancer care, and allied health professionals providing specialist dietary and exercise care to cancer survivors. Therefore, it was important to first understand the perspectives of medical and nursing health professionals on their roles and responsibilities in the provision of dietary and exercise advice, and referrals to cancer survivors. Medical and nursing health professionals perceived a lack of role clarity, and a lack of established referral pathways to be key barriers to referral practices. Thus essential elements were developed and embedded within principles of cancer survivorship established by Cancer Australia.<sup>77</sup> Developing essential element statements for dietary and exercise referral practices will support medical and nursing health professionals in optimising cancer survivors' access to specialised dietary and exercise support in Australia. The implementation of these essential elements may experience challenges that affect the extent to which they become embedded and scaled-up due to the complexity of the health system. Thus, pre-implementation work is an important element

to identify factors contributing to the implementation of essential elements. This doctoral research adopted a systems-thinking approach to identify system-level factors within the Australian health system that can influence dietary and exercise referral practices. Using a systems-thinking approach enabled development of a causal loop diagram and identification of strategies at a policy level. It is important to undertake and report research such as this to improve our understanding on the factors influencing dietary and exercise referral practices, and develop strategies to address any barriers. The overall findings, strengths, limitations, implications of the research undertaken in this doctoral research and recommendations for future research are discussed below.

### **7.3 Discussion of findings**

Even though there is strong evidence in the literature (Chapter 1) that dietary and exercise interventions are essential and beneficial for optimising outcomes for cancer survivors, the current system of care does not comprehensively facilitate quality, systematised health-system responses to provide cancer survivors with seamless access to dietary and exercise services. The integrative review (Chapter 2) of existing literature on the perspectives of medical and nursing health professionals on their roles and responsibilities in providing dietary and exercise advice and referrals to cancer survivors is the first original contribution of knowledge from this doctoral research. This review demonstrated that some, but not all, medical and nursing health professionals felt it was their role to provide generic dietary and exercise advice to cancer survivors based on their individual needs, preferences, or strength of available evidence. Although medical and nursing health professionals understand, and agree, that referring cancer survivors to allied health professionals form part of their role, there is still a lack of clarity between medical and nursing health professionals regarding roles and responsibilities in providing dietary and exercise advice to cancer survivors. Thus, medical and nursing health professionals require better guidance and structure regarding the roles they play in providing dietary and exercise advice, and how and when to refer cancer survivors to diet and exercise professionals.<sup>10</sup> Furthermore, even though barriers and facilitators to providing dietary and exercise advice were identified, there is limited evidence on barriers and facilitators specific to referral practices, which require further research.

The Delphi study (Chapters 3 and 4) was the first to investigate the perspectives of local representatives from diverse clinical and educational backgrounds, including consumers

regarding the optimisation of dietary and exercise support and referral practices for cancer survivors. The Delphi method enabled panel members to achieve consensus on 24 essential elements of optimal dietary and exercise referral practices. The findings from this research strongly emphasized the importance of education for cancer survivors and referrers regarding the benefits of diet and exercise as cancer survivors are more likely to feel empowered to take action and seek access to dietary and exercise services and referrals if they value these services. The importance of effectively assessing and monitoring cancer survivors' needs for referrals to dietitians and exercise professionals and ensuring clear communication processes between cancer survivors and their healthcare providers was also highlighted. This is because the clinical needs of cancer survivors will change as they move through the cancer continuum, thus timely detection of needs throughout the different stages of the cancer care trajectory is crucial and can be supported using screening and assessment. Individualised screening of cancer survivors can identify their need for dietary and exercise services, together with the provision of referrals to dietitians and exercise professionals. Accordingly, essential elements identified in this research can help provide guidance to medical and nursing health professionals to streamline referrals to dietitians and exercise professionals. However, optimising referral practices also requires a better understanding of complex factors that are part of an interconnected system that may facilitate or impede referral practices.

The use of a complex system mapping process and use of the WHO building blocks process (Chapters 5 and 6) is a novel and innovative process that explored the complex, interconnected relationships between factors and relationships of the health system that influence referral practices for diet and exercise from diverse perspectives of consumers, clinicians, and leaders from not-for-profit organisations, peak professional organisations, and the government. Furthermore, the development of a causal loop diagram enabled visualisation of the complex web of factors that influence dietary and exercise referral practices and highlighted specific leverage points at which dietary and exercise referral practices can be improved. There were close linkages between financing, leadership/governance, and information and the other WHO building blocks. Challenges affecting particular building blocks seemed to have ramification in other building blocks directly or indirectly. For example, healthcare capacity/services seemed to influence the frequency and consistency of screening and referral practices, thus access to dietary and exercise services. It is therefore essential to apply system wide approaches when evaluating health systems due to close linkages that exist between system-level factors.

#### **7.4 Overall strengths and limitations**

Firstly, study 2 was conducted in Queensland and study 3 was conducted in South Australia. Even though some aspects of the Australian healthcare system are the same nationwide, parts of healthcare managed by states, territories and local governments may vary such as screening services and public hospitals. Therefore the generalisability of findings should be interpreted with caution due to the variability in cancer care across different states. On the other hand, there is no evidence to indicate the findings do not apply to other states in Australia. With respect to individual studies, the integrative review (Chapter 2) presented new findings to contribute to the body of literature examining the perspectives of medical and nursing health professionals on their roles and responsibilities regarding the provision of dietary and exercise advice, and referrals. Since the review included mixed-methodologies and addresses the perspectives of medical and nursing health professionals and cancer consumers, sufficient data was collected to discuss findings in relation to the roles and responsibilities of medical and nursing health professionals. With regards to the Delphi study (chapters three and four), participants were not selected based on expertise which is typical in the Delphi approach, instead participants were selected opportunistically as they were cancer care professionals already attending a local cancer conference. This was appropriate for the purpose of the study, as it enabled us to capture valuable input from a diverse range of cancer care professionals. Furthermore, the Delphi study and the systems-thinking workshop (chapters five and six) included qualitative methodologies so perspectives of the participants may be subjected to their experiences and perspectives. Despite efforts to recruit and include GPs, GPs who were invited were not able to engage. Therefore, few GPs were included in the Delphi study and the systems-thinking workshop, which may impact the research as GPs perspectives are not accurately reflected in terms of optimising dietary and exercise referral practices. However, both studies purposively recruited participants who represented a range of diverse perspectives including those of researchers, other healthcare professionals, consumers, and policy makers. Future research involving the replication of focus groups in other states and territories should consider strategies that might facilitate better representation from primary health care professionals, and may offer a broader stakeholder view on key themes presented in this doctoral research. The systems-thinking workshop was framed using the WHO building blocks framework which has the inability to capture the interactions between the elements of a health system. However, for the purpose of the study, the framework was adapted to the specific research question and context (i.e., exploring the interactions/relationships between the building blocks). Despite its limitations, WHO's health system framework is a valuable tool, providing common language

and reference for researchers and policymakers. The systems-thinking workshop design enabled the full complexity of healthcare to be considered and provided a richer, deeper understanding of the system-level barriers than what was identified in the literature review, through the use of a systems-thinking approach. Overall, this research provided outputs that have the potential to inform implementation and strengthen health systems at various levels (i.e., provider and patient level) in terms of dietary and exercise referral practices.

## **7.5 Implications for practice**

### **7.5.1 Need for clarity on roles and responsibilities of medical and nursing health professionals**

Although medical and nursing health professionals understand, and agree, that referring cancer survivors to allied health professionals form part of their role, there is a lack of clarity between medical and nursing health professionals regarding their roles and responsibilities in providing dietary and exercise advice to cancer survivors. Medical and nursing health professionals also agree that dietitians and exercise professionals should be responsible for discussing diet and exercise with cancer survivors, however additional education and practical support are needed to facilitate the provision of referrals to dietitians and exercise professionals.<sup>169</sup> A lack of clarity between medical and nursing health professionals can be attributed to several factors, including poorly defined roles, a lack of standardised referral pathways, and various health-professional and patient-centred barriers.<sup>10</sup> In multidisciplinary teams, poorly defined roles can lead to conflict and reduce the efficacy of care and services provided to cancer survivors.<sup>215</sup> A lack of standardised referral pathways to allied health services can also lead to unmet needs and fragmented care in cancer survivors. Emphasis should be placed on providing better guidance and structure to medical and nursing health professionals by clearly defining the roles they play in providing dietary and exercise advice, and by clearly defining the process of how and when to refer cancer survivors to diet and exercise professionals. Ultimately, dietary and exercise education needs to be integrated at the appropriate level for medical and nursing health professionals as well as greater interaction with dietitians and exercise professionals in clinical settings (i.e., multidisciplinary teams, case conferences). Interprofessional collaboration (i.e., face-to-face or digital communication) may lead to enhanced awareness and referrals amongst medical and nursing health professionals, as well as better integration of services to improve patient outcomes.



### **7.5.2 Referral guidance for medical and nursing health professionals**

Since essential elements recognise the role that medical and nursing health professionals play in the provision of dietary and exercise care to cancer survivors, they have the potential to improve role clarity between medical and nursing health professionals, which was identified as a major barrier to the provision of dietary and exercise advice to cancer survivors in the literature (Chapters 1 and 2). Although a lack of role clarity and lack of standardised referral practices<sup>10</sup> have been highlighted as key barriers to referring cancer survivors to dietitians and exercise professionals in the literature, there is currently no existing research on this topic with regards to the development of essential elements. These essential elements can help guide medical and nursing health professionals on what dietary and exercise advice to provide, how and when to refer cancer survivors to dietitians and exercise professionals. Ideally, cancer survivors should be informed about the benefits of diet and exercise, encouraged to follow a healthy balanced diet and participate in physical activity, and then provided with referrals to dietitians and exercise professionals for individualised support, thus streamlining access to dietary and exercise services.

### **7.5.3 Use of essential elements**

Essential elements can be implemented across different healthcare settings (i.e., hospitals, cancer centres) to help standardise dietary and exercise care for cancer survivors. This information can be used to ensure quality of care provision for cancer survivors and establish measures in which to evaluate the care provided. Essential elements can also be tailored for application in different settings, including public and private settings, metropolitan, regional/rural areas, and in other countries with similar healthcare systems. For example, consideration of different delivery modes (i.e., expanded use of telehealth) to cater to varying accessibility (i.e., regional/rural areas) and preferences of diet and exercise service providers. Healthcare systems around the world may face similar problems with the management of complex and evolving health demands, but their solutions will likely differ greatly. Thus, applying lessons from other countries could tailor essential elements for use in similar healthcare systems. In terms of policy, essential elements can be considered a building block within the health system that promotes quality supportive cancer care among cancer survivors, thus can be considered standard of care by health professionals and policy makers. A logical step forward would be around implementation or evaluation of referral practices as informed by these principles.

#### **7.5.4 Factors influencing dietary and exercise referral practices**

Cancer survivors may face numerous barriers to accessing dietary and exercise care, not only at the patient-level, but also at the provider and system level. To our knowledge, only factors at an individual level have been investigated<sup>15, 94, 169, 243</sup>, such as a lack of role clarity, lack of knowledge and confidence, time constraints, and lack of advice or referrals from a health professional.<sup>10, 169</sup> There is a paucity of existing research aiming to understand these factors at a system level, how they are interconnected and how to devise innovative strategies that target them effectively. Since this is the first study to use a systems-thinking approach to identify system-level factors that influence dietary and exercise referral practices; system-level barriers identified from this research can be considered by health professionals, researchers and policy makers prior to the implementation of essential elements in practice. These system-level factors can also be used to aid the implementation of other interventions related to dietary and exercise referral practices. Strategies to address these barriers can also be implemented, adapted, and changed as necessary to ensure cancer survivors are receiving optimal dietary and exercise care. Addressing barriers to dietary and exercise referral practices require system-level strategies, such as provider training on the provision of dietary and exercise advice and referrals to improve role clarity, leveraging the role of “navigation” or “navigators to enable integrated systems to facilitate optimal care for all cancer survivors, or lobbying for an increased number of allied health sessions for cancer survivors. Since these strategies are also linked to corresponding causal loops within the causal loop diagram, they can be used to change the direction of causal loops within the causal loop diagram which can directly or indirectly influence other system-level factors. Causal loop diagrams have the potential to inform local action plans for implementation using identified strategies to address leverage points and for mitigating possible future risks in the system.

#### **7.6 Recommendations for future research**

The findings highlight potential future research areas. These include the following:

1. The findings might not be representative as participants were mainly based in Queensland or South Australia, and purposeful sampling was employed. Therefore, future studies using systems-thinking methodology involving the replication of focus groups in other states and territories should be conducted to overcome this limitation. These findings could then be analysed to compare key similarities and differences between states and territories, highlighting actions that are relevant across all states

and territories. On the other hand, there is no evidence to indicate the findings do not apply to other states and territories in Australia.

2. Future research should be undertaken with consideration for strategies that might facilitate better representation from primary care professionals, specifically GPs to offer a broader stakeholder view on key themes presented in this doctoral research. Strategies could be identified through online surveys and semi-structured interviews with primary care professionals to identify key barriers and facilitators to participating in research studies. These findings could then be linked to appropriate implementation strategies using the Consolidated Framework for Implementation Research (CFIR) ERIC mapping tool.
3. The findings from this research highlights some clinical implications that could benefit from further research, including addressing the specific barriers and facilitators to the provision of dietary and exercise advice to cancer survivors and to further identify barriers and facilitators to referral to relevant allied health professionals. Developing a working group of individuals with expertise in the provision of dietary and exercise advice, referrals and implementation science should be one of the first steps to addressing these barriers and facilitators. This working group can help separate the barriers and facilitators into prioritised actions for implementation. Addressing barriers and facilitators to the provision of dietary and exercise advice and referrals can help improve cancer survivors' access to dietary and exercise services at key time points.
4. Future research could also evaluate the implementation of essential elements of dietary and exercise referral practices in practice as informed by this causal loop diagram and system-level strategies. Since there are twenty-four essential elements, each element should be prioritised by key stakeholders based on feasibility, and linked to appropriate system-level strategies identified in the systems-thinking workshop. An implementation plan can be developed by researchers with consideration for the system-level barriers and potential strategies. Prior to the development of the implementation plan, the strategies will need to be translated to actionable statements by key stakeholders to address these barriers in practice.
5. Following the implementation of essential elements in practice, future studies may examine the cascading effects of optimised referral practices, examining how referrals lead to subsequent care and outcomes/experiences for cancer survivors.

## **7.7 Conclusions**

For cancer survivors to access specialised dietary and exercise care in Australia, cancer survivors need to be referred to dietitians and exercise professionals by their specialist team or GP. However, medical and nursing health professionals face various barriers to the provision of dietary and exercise advice and referrals to cancer survivors, including a lack of role clarity and lack of established referral pathways as highlighted in this doctoral research. Improved role clarity amongst medical and nursing health professionals can be achieved through the use of essential element statements developed in this doctoral research, to provide better guidance in terms of what advice they should provide, when to provide the advice, as well as how and when to refer cancer survivors to dietitians and exercise professionals. Prior to the implementation of these essential elements, a systems-thinking approach enabled a better understanding of the system-level factors influencing dietary and exercise referral practices, and potential strategies to address system-level barriers. This doctoral research provides valuable guidance regarding the optimisation of dietary and exercise referral practices in Australia, as well as supporting medical and nursing health professionals to do so. More research is needed to tailor intervention and implementation strategies for different healthcare settings.

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## APPENDICES

### Appendix 1: Literature search methods (study 1)

Stages	Search terms and keywords (PubMed)
Stage 1 (Initial search)	(perspective* OR view* OR perception* OR attitude* OR belief*) AND ("general practitioner*" OR GP* OR nurse* OR oncologist* OR doctor*) AND (role*) AND (diet OR nutrition OR "healthy eating" OR exercise OR "physical activity" OR activity OR training OR lifestyle OR "lifestyle advice" OR "health promotion") AND (cancer)
Stage 2	Hand searching of bibliographies of relevant studies

PICO	Inclusion Criteria	Exclusion Criteria
<b>Population</b>	Studies with medical and nursing health professionals (including oncologists, haematologists, cardiologists, cancer nurses and other generalists (GPs and practice nurses)) regardless of age, gender, and experience.	Studies that consider dietary and/or exercise recommendations provided to the general population.

<b>Interest</b>	Studies in which the perspectives of health professionals and consumers on the roles and responsibilities of health professionals in providing dietary and/or exercise recommendations to cancer survivors were investigated.	Studies that do not investigate the perspectives of medical and nursing health professionals.
<b>Context</b>	Studies based in oncology settings (acute care hospitals, ambulatory care clinics, private oncologists' offices, radiation therapy facilities, or primary care).	Studies that are not based in oncology settings.
<b>Types of studies</b>	All qualitative and/or quantitative studies will be included. Specifically, all qualitative data collection methods (e.g., focus groups and individual interviews) and quantitative studies (e.g., surveys). Mixed-method studies investigating the perspectives on the roles and responsibilities of medical and nursing health professionals will also be included.	Not applicable

## Appendix 2: Data extraction (study 1)

Reference citation/ Country	Study Type/ Methods	Population	Outcome measures	Recommendation type	Sample size	Findings	Perceived Role of HP	Barriers/Facilitators	Summary of findings/ Conclusions	Themes	Quality
<b>Qualitative studies</b>											
Baker et al., 2015/ USA	Semi-structured interviews	Oncologists, surgeons, primary care providers, nurses, dietitians working with prostate, breast, or non-Hodgkin lymphoma cancer survivors.	Body size (BMI) and weight management.  Achieving a healthy weight.	Weight management	n=33	Most HPs focused on weight gain as opposed to weight loss.  Providers described lacking weight loss strategies to implement without referrals.  Some practitioners reported a hands-on approach in the office, using educational handouts, such as recipe books and portion guides, and graphs that help cancer survivors visualize information	Some providers reported reducing weight discussions as they do not feel it is appropriate for their clinical role or training.  However, PCPs reported frequent weight-related discussions, and cancer specialists also reported discussing weight management.	1. Perceived issues with training as established guidelines do not seem actionable to health professionals with limited experience in behavioural modification.  2. Lack of relevance to clinical roles.  3. Time constraints.	Health professionals can play an important role in providing weight management advice to cancer survivors. Given they are provided with sufficient resources and support.  Evidence-based clinical resources for weight management are required to provide appropriate advice to cancer survivors.	3 categories with 4 themes and 5 subthemes: benefits of diet/exercise, provision of dietary/physical activity advice, patient preferences, and barriers.  <ul style="list-style-type: none"> <li>Weight management</li> <li>Treatment-related concerns</li> <li>Cancer outcomes risk</li> <li>Timing</li> <li>Lack of relevance to clinical role</li> </ul>	QUAL=5 100%
						Variation in providers' reported exercise recommendations, with some questioning the utility of exercise for weight loss,					

Balneaves et al.,	Semi-structured interviews	Breast cancer survivors, and oncologists	Perceptions and experiences of providing	Aerobic and resistance training and	Breast cancer	Cancer survivors did not have	1. Time constraints	Cancer survivors require support during but also after completion of treatment to adopt healthy lifestyle	3 categories with 4 themes and 6 subthemes:	QUAL=5 100%
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2020/Canada			lifestyle advice to cancer survivors (i.e., barriers and facilitators, their role)	nutrition counselling session.	survivors: n=12  Oncologists: n=8	preferences to which specific health professional provided lifestyle advice, except that they had a trusting relationship with them.  Oncologists and nurses can play a role in discussing the importance and safety of lifestyle interventions during breast cancer treatment. As well as encouraging healthy lifestyle behaviours and providing referrals to other health professionals or community programs.	2.No streamlined process to support health professionals in referring cancer survivors to lifestyle interventions.	habits. Oncologists play an important role in encouraging participation in lifestyle interventions during breast cancer treatment.  Maintenance programs that transition cancer survivors into community settings and provide on-going information and follow-up are also required.	benefits of diet/exercise, challenges, patient preferences, provision of dietary/physical activity advice.  <ul style="list-style-type: none"> <li>• Motivation</li> <li>• Symptom management</li> <li>• Physical fitness</li> <li>• Social support</li> <li>• Trusting relationship</li> <li>• Dietary/exercise advice</li> </ul>	
Brandenburg et al., 2017/ Netherlands	Semi-structured interviews	Colorectal cancer survivors	Role of GP during treatment.  Role of GP during follow-up	Dietary and exercise advice	n=22	GPs are perceived to play a role of providing guidance on diet and lifestyle in the immediate post-treatment period.  Cancer survivors reported that clarification offered by the	Participants often feel uncertain regarding their lifestyles as it may have not been discussed in secondary care.	Participants prefer to receive guidance on diet and lifestyle in the immediate post-treatment period.  Participants value the involvement of GPs in monitoring directly after surgery.	4 categories with 2 themes and 3 subthemes: provision of dietary/physical activity advice, patient preferences.  <ul style="list-style-type: none"> <li>• Clarification</li> <li>• Psychosocial support</li> <li>• Support for families</li> </ul>	QUAL=5 100%



						GPs had a reassuring effect.				
Cheville et al., 2012/ USA	Semi-structured interviews	Cancer survivors with late-stage lung cancer.	Cancer survivors' views and preferences about exercise	Exercise guidance	n=20	<p>Participants stated that they would be comfortable discussing exercise with their oncologist; however, few had done so.</p> <p>Participants stated that receiving encouragement or an exercise prescription from their oncologist would give them the motivation to enhance their physical activity</p> <p>Participants only received general encouragement to "stay active" from their oncologist.</p> <p>Participants prefer exercise guidance from their oncologists as opposed to a physical therapist.</p> <p>Opinions around exercise guidance from</p>	<ol style="list-style-type: none"> <li>1. Symptoms affecting their activity.</li> <li>2. Past preferences and patterns</li> <li>3. Lack of equipment</li> <li>4. Differing views on being "exercise" or "non-exercise" people.</li> <li>5. Lack of awareness on the importance of exercise.</li> <li>6. Lack of encouragement from oncologists.</li> </ol>	<p>Exercise and physical activity can improve cancer-related symptoms (i.e., home programs that incorporate cancer survivors' daily activities).</p> <p>Participants require encouragement and support from their oncologist for positive outcomes.</p>	<p>3 themes with 4 subthemes: provision of dietary/physical activity advice, patient preferences, and barriers.</p> <ul style="list-style-type: none"> <li>• Motivation</li> <li>• Symptoms</li> <li>• Past preferences and patterns</li> <li>• Lack of awareness</li> </ul>	QUAL= 5 100%

						physical therapists varied with some participants believing that such assistance was for individuals with more functional disabilities and others viewing it as potentially beneficial.					
Coa et al., 2014/ USA	Interviews	Oncologists, surgeons, primary care providers, nurses, social workers, a registered dietitian, cancer survivors, navigator, and a survivorship coordinator who care for individuals diagnosed with breast cancer, prostate cancer, and non-Hodgkin's lymphoma.	Providers' roles and responsibilities in caring for long-term cancer survivors.  Perceived importance of behaviour changes and healthy diet for cancer survivors.  Barriers and facilitators.	Promote dietary changes	n=33	HPs generally agreed that making healthy dietary changes was good for the overall health of cancer survivors.  Variance among health professionals on the benefit of lifestyle changes - some believed the evidence to make lifestyle change recommendations was strong, others believed the evidence was not strong  Some HPs believed the evidence	Discussing healthy dietary behaviour changes with cancer survivors.	1. Strength of evidence was considered a priority to assess the importance of behaviour change among cancer survivors.  Health care providers were less likely to bring up diet if they perceived the evidence to be weak.	Health care providers can play an important role in promoting healthy diet among cancer survivors (i.e., incorporating behaviour changes into survivor care plans).	4 categories with 4 themes and 3 subthemes: benefits of diet, perceived role of HPs, patient preferences, and barriers.  <ul style="list-style-type: none"> <li>• Strength of evidence</li> <li>• Timing</li> <li>• Motivation</li> </ul>	QUAL=5 100%

						<p>between diet and recurrence was inconclusive.</p> <p>Specialist providers (e.g., oncologists, surgeons) expressed they were less likely to discuss health promotion than primary care providers, as they believed cancer survivors engaged with them for surveillance.</p>				
Haussman et al., 2018a/ Germany	Semi-structured interviews	GPs, specialised physicians, oncology nurses.	<p>Knowledge</p> <p>Perceived advantages and disadvantages of physical activity by cancer survivors.</p> <p>Barriers and facilitators for promoting physical activity.</p>	Physical activity promotion	n=30	<p>Most health professionals did not consider their role to involve encouraging sedentary cancer survivors to make behavioural changes.</p> <p>There was a preference to refer cancer survivors to physiotherapists, exercise counselling centres or recommend local exercise programs.</p>	<p>1. Health professionals valued a good relationship with their patient so preferred not to advise cancer survivors on how to spend their free time.</p> <p>2. Time constraints so physical activity was not considered a priority (e.g., increased workloads).</p> <p>3. Lack of knowledge in how to promote physical activity.</p> <p>4. Lack of informative</p>	<p>A patient's physical condition and assumed interest in physical activity is one of the main factors influencing if physical activity is addressed.</p> <p>Patient characteristics and structural conditions for health professionals can influence physical activity promotion. A broader perspective is needed to assess these factors.</p>	<p>3 themes with 5 subthemes: HP's concerns, patient preferences, and barriers.</p> <ul style="list-style-type: none"> <li>Physical overexertion</li> <li>Psychological stress</li> <li>Perceived interest in PA</li> <li>Current health behaviours</li> <li>HP's workload</li> </ul>	QUAL=5 100%

							resources (e.g., brochures for both HCPs and cancer survivors)  5. Fear of physical overexertion and psychological stress for cancer survivors.			
Koutoukidis et al., 2018/ UK	Semi-structured interviews	Surgeons, physicians, nurses and allied health workers caring for those with breast, prostate, or colorectal cancer.	Survivorship-centred barriers to provision.  HP-centred barriers to provision.  Optimal delivery of lifestyle advice.	Dietary/exercise advice	n=21	Some health professionals perceived their role to include empowering cancer survivors to follow a healthier lifestyle.  Others did not perceive it to be part of their role given their limited knowledge on the topic and other priorities during their short consultations.	1. Limited knowledge on the topic and limited knowledge of healthy lifestyle guidelines.  2. Socioeconomic barriers and ability to practise health behaviours.  3. Fear for potential loss of connection with cancer survivors.  4. Time constraints (i.e., other priorities during short consultations).	Health professionals believed that dietary/exercise advice should be tailored to each individual and delivered throughout the cancer journey.  They also believed they should focus on small and achievable changes and be cost-effective.  When developing training programmes for health professionals, barriers need to be incorporated.  This will ensure successful behavioural changes and improve outcomes for cancer survivors.	4 themes with 6 subthemes: patient preferences, provision of dietary/physical activity advice, barriers and facilitators. <ul style="list-style-type: none"> <li>• Current health behaviours</li> <li>• Physical inability</li> <li>• Loss of connection with patient</li> <li>• Socioeconomic barriers</li> <li>• Knowledge &amp; attitudes towards evidence and guidelines.</li> <li>• Cost-effectiveness</li> </ul>	QUAL=5 100%
Roberts et al., 2019/ UK	Semi-structured interview	Cancer nurse specialists (CNS) caring for breast, prostate, or colorectal cancer survivors	Current physical activity promotion practices  Role in promoting physical activity.	Physical activity promotion	n=19	CNSs stated that discussing and supporting PA with cancer survivors was an accepted and key part of their role.  CNSs felt they are in a good position to	Discussing physical activity with cancer survivors was a key part of their role.  1. Lack of accurate knowledge of the physical activity guidelines.  2. Time constraints  3. Lack of resources.	Cancer nurses play an important role in physical activity promotion in cancer care.	3 themes with 6 subthemes: provision of dietary and physical activity advice, barriers and facilitators. <ul style="list-style-type: none"> <li>• Relationships</li> <li>• Strength of evidence</li> <li>• Lack of knowledge</li> </ul>	QUAL=5 100%

			Challenges in physical activity promotion.			inform cancer survivors about PA, signpost and refer to further PA support and continue to promote and support PA throughout treatment and follow-up.  CNSs perceived that other HPs may be less likely to promote PA.				<ul style="list-style-type: none"> <li>• Safety concerns</li> <li>• Lack of referrals</li> <li>• Time constraints/resources</li> </ul>	
Waterland et al., 2020/ Australia	Semi-structured interviews	GPs	Views on diet and exercise recommendations.  Experiences of providing dietary and exercise advice.  Experiences of referring cancer survivors for dietary and exercise services.	Dietary and exercise advice	n=23	Most participants acknowledged importance of exercise and nutrition recommendations for cancer survivors.  Discussing exercise and nutrition was rarely the reason for a cancer survivor's GP visit so difficult to weave in. GPs perceived the provision of nutrition and exercise advice was part of their role.	<ol style="list-style-type: none"> <li>1. Time constraints in general practice setting.</li> <li>2. Lack of knowledge or experience.</li> <li>3. Lack of access to cancer survivors during treatment.</li> <li>4. Lack of communication between the tertiary and primary care settings.</li> <li>5. Lack of GP-specific resources and programs</li> </ol>	GPs value their involvement in supporting healthy behaviours of cancer survivors.  Future research should tailor exercise and nutrition resources for use within the primary care setting, enhance communication pathways between tertiary and primary care settings and improving access to dietary and exercise professionals.	<p>5 themes with 5 subthemes: benefits of diet and exercise, provision of dietary/physical activity advice, patient preferences, barriers and facilitators.</p> <ul style="list-style-type: none"> <li>• Lack of GP-specific resources</li> <li>• Lack of knowledge</li> <li>• Time constraints</li> <li>• Lack of communication</li> <li>• Referrals</li> </ul>	QUAL=5 100%	
<b>Quantitative studies</b>											
Alderman et al., 2020/ Australia	Cross-sectional study	GPs	Knowledge, attitudes, perceived behaviours regarding	Physical activity promotion	n=111	GPs agreed PA can improve QOL (92.8%), reduce negative cancer side	GPs are aware that physical activity is safe for people living with cancer and	1.Few GPs had received training regarding physical activity, so they	GPs reported positive attitudes and perceptions towards	3 themes: provision of physical activity advice, barriers, and facilitators.	QUAL=4 80%

			<p>physical activity.</p> <p>GP recommendation and referral rates of physical activity.</p>		<p>effects (89.2%) and saw PA as important and beneficial (91%) to a cancer survivor's journey.</p> <p>64% of GPs thought cancer survivors would follow PA advice they provided and 27% of participants reported that cancer survivors asked them about PA.</p> <p>Most GPs thought providing PA recommendations was easy (67%), were confident in providing PA recommendations (77.5%). 53.2% believed it was their role to discuss PA cancer survivors.</p>	<p>that believe they play a role in encouraging physical activity.</p> <p>GPs prefer exercise physiologists and physiotherapists to deliver physical activity guidance and services.</p>	<p>had to complete additional training.</p> <p>2. Not all GPs were aware of the COSA guidelines and had limited access to resources.</p> <p>3. GPs had limited awareness regarding physical activity services for people living with cancer.</p>	<p>promoting physical activity for people living with cancer.</p> <p>GPs are willing to promote and refer cancer survivors for physical activity.</p>		
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Chan et al., 2018/ Australia	Cross-sectional survey	Cancer nurses caring for haematological cancer survivors.	<p><b>Perception of responsibility</b> (5-point Likert; 1=total disagree, 5=total agree)</p> <p><b>Confidence in delivering care</b> (0=cannot do, 10=highly certain can do)</p> <p><b>Frequency of care provision</b> (5-point Likert; 1=never, 5= all the time)</p> <p>Barriers for quality survivorship care provision to cancer survivors and for caregivers and/or family members.</p>	Survivorship advice	n=310	<p><b>Responsibility</b> Participants agreed that discussing exercise and physical activity (M=4.48, SD=0.80); health diet recommendations (M=4.40, SD=0.83); and information on health behaviours (M=4.42, SD=0.84), were part of their role.</p> <p><b>Confidence</b> Participants were relatively confident they could discuss exercise and physical activity (M=7.69, SD=2.18); diet (M=7.79, SD=2.09); and information of healthy behaviours (M=7.76, SD=2.13) with cancer survivors.</p> <p><b>Frequency</b> Participants often discussed exercise and physical activity (M=3.31, SD=1.12); diet (M=3.24, SD=1.15); and</p>	Nurses perceived their roles to involve discussing exercise and physical activity, healthy diet and healthy behaviours.	1. Time constraints	There are variations in practice and confidence with respect to implementation of survivorship care practices.	3 themes: provision of physical activity advice, barriers, and facilitators.	QUAL= 4 80%
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						healthy behaviour (M=3.05, SD=1.16) recommendations with cancer survivors.					
Hausmann et al., 2018b/ Germany	Cross sectional study	Physicians (GPs, oncologists, surgeons, gynaecologist, urologist, gastroenterologist) & oncology nurses in outpatient and inpatient care.	Demographic information.  Physical activity promotion behaviour.  Structural barriers.  Interest in information resources about physical activity.	Physical activity promotion	n=917	PA was recommended often or routinely in 88.5% of physicians working in outpatient care, 78.1% of physicians working in inpatient care, and 73.1% of oncology nurses.  Only three HPs indicated that they advised against doing PA.	Health professionals are likely to recommend physical activity to cancer survivors.	1. Time constraints  2. Physicians in inpatient care who were unable to consult an expert contact person were less likely to promote physical activity to cancer survivors.  3. Structural barriers (i.e., lack of therapeutic programs; information for cancer survivors and medical staff; specific guidelines; reimbursement for PA counselling, expert contact person).	Most health professionals promoted physical activity to cancer survivors.  Oncology nurses faced more barriers in promoting physical activity than physicians.  Most participants, including physicians in outpatient care highlighted the need for information resources.	3 themes: provision of physical activity advice, barriers, and facilitators.	QUAL= 4 80%



									Most health professionals frequently promoted physical activity, but structural barriers still exist and differ between professional groups.		
Keogh et al., 2017/ Australia & New Zealand	Cross-sectional survey	Oncology nurses	Physical activity promotion practices.  Physical activity beliefs.	Physical activity promotion	n=119	Most oncology nurses considered themselves the primary professional group for promoting PA to cancer survivors (n=52/97; 54%) as opposed to a physiotherapist, oncologist, exercise physiologist, other, or “I don’t know”.  76% of oncology nurses believed the level of evidence supporting the benefits of PA promotion to cancer survivors was strong.  Most oncology nurses believed that PA had many benefits for cancer	Oncology nurses perceived their role to involve providing physical activity advice to cancer survivors.	<ol style="list-style-type: none"> <li>1. Lack of time</li> <li>2. Lack of adequate support structures</li> <li>3. Lack of expertise and knowledge, and risk to cancer survivors.</li> <li>4. Nurses have more frequent opportunities to interact with cancer survivors than oncologists or exercise professionals.</li> </ol>	<p>Despite numerous barriers, oncology nurses prefer to promote physical activity across multiple treatment stages because they believe physical activity is beneficial for cancer survivors.</p> <p>Hospitals need to provide better support to oncology nurses in promoting PA to cancer survivors.</p> <p>There also needs to be better referral pathways to exercise physiologists and physiotherapists.</p>	3 themes: provision of physical activity advice, barriers, and facilitators.	QUAL= 4 80%

						<p>survivors. Nurses agreed or strongly agreed that PA could improve cancer survivors' QOL (n = 107, 90%), mental health (n = 106, 89%), activities of daily living (n = 106, 89%), and reduce risk of developing other chronic diseases (n = 101, 85%).</p>					
Kiss et al., 2020/ Australia	Cross-sectional survey	Dietitian, exercise physiologist, nurses, nutrition/allied health assistant, medical team, physiotherapist, other allied health professionals.	<p>Awareness and understanding of malnutrition and sarcopenia</p> <p>Perception of responsibility</p> <p>Confidence in malnutrition identification and appropriate management</p> <p>Barriers and enablers to identification and appropriate management.</p>	Dietary advice	n=111	<p>84% of participants agreed or strongly agreed it was part of their role to recognise if a cancer survivor was malnourished or sarcopenic and initiate appropriate management.</p> <p>Most cancer survivors believed the responsibility for identifying cancer survivors with malnutrition or sarcopenia lay with all health professionals (60%), followed by the medical team (40%) and dietitians</p>	Most health professionals perceived the identification of malnutrition and sarcopenia to be a part of their role.	<ol style="list-style-type: none"> <li>1. Access to resources</li> <li>2. Lack of confidence</li> <li>3. Time constraints</li> <li>4. Protocols available to support practice and training.</li> </ol>	<p>Most health professionals had a good understanding of malnutrition and sarcopenia, as well as their significance in cancer care.</p> <p>There were many barriers to delivering optimal nutrition care.</p>	3 themes: provision of diet advice, barriers, and facilitators.	QUAL= 4 80%

						(37%). 90% of participants reported discussing nutrition with cancer survivors.					
Ligibel et al., 2019/ USA	Cross-sectional study	Oncologists, physicians, nurses, physician assistants	Oncology provider practice patterns.  Perceptions of obesity and weight management during and after active cancer treatment.	Weight management, physical activity, and diet	n=971	89% of participants agreed or strongly agreed that addressing a cancer survivor's weight if overweight or obese should be a standard part of cancer treatment.  79% believed that the treating physician is responsible for recommending weight loss, increased physical activity, and improved nutrition.  84% believed that interventions to implement changes in weight, diet, or activity should be conducted by other clinical staff with relevant expertise.	Most health professionals reported advising cancer survivors to maintain a healthy weight/lose weight if overweight, increase physical activity; and eat a healthy, balanced diet during active treatment.	1.Lack of awareness of lifestyle guidelines for cancer survivors.  2.Lack of training on obesity-related topics.  3. Time constraint during clinic visits.  3.Lack of referral programs or specialists.	Most health professionals believed that there was strong evidence linking obesity to cancer outcomes.  Referrals to providers and programs/services occurred less frequently.  Further research is needed to support education and training of health professionals to facilitate referrals and overcome barriers.	2 themes: provision of diet and physical activity advice, barriers.	QUAL=4 80%
Puhringer et al.,	Cross-sectional	RNs	Nurses' healthy eating	Nutrition promotion	n=123	Most cancer nurses	Most (35.9%) cancer nurses	1.Time constraints	Most RNs promoted	2 themes:	QUAL=4

2015/ Australia & New Zealand			promotion habits and beliefs on health eating.			agreed or strongly agreed that healthy eating improved QOL (85.4%), weight management (82.9%), mental health (80.5%), activities of daily living (79.7%) and reduces the risk of other chronic diseases (79.7%) for cancer survivors.  52.8% promoted healthy eating to cancer survivors during all cancer stages (pre-, during, and post-treatment)	considered the dietitian/nutritionist, the primary person responsible for providing healthy eating advice to cancer survivors.  However, some (32.5%) nurses considered themselves the main person responsible for addressing cancer survivors' nutrition concerns.	2. Lack of adequate support structures.  3. Lack of nutrition expertise.	healthy eating prior, during and post treatment, as they felt healthy eating has many benefits for cancer survivors.  Despite favourable attitudes towards promoting healthy eating to cancer survivors across multiple treatment stages, several barriers to healthy eating promotion were reported.	provision of diet advice, barriers.	80%
Spellmann et al., 2014/ Australia	Cross-sectional study	Radiation oncologists, urologists, nurses, medical oncologists caring for prostate cancer survivors	Clinicians' knowledge, attitudes, and practices towards promoting physical activity to prostate cancer survivors.	Physical activity promotion	n=31	54.9% of participants felt that discussing physical activity was part of their role.  <b>Knowledge:</b> Most clinicians (93.6%) strongly agreed or agreed that regular physical activity can improve the	Many medical and nursing professionals reported that advising cancer survivors on physical activity was not part of their role.	1. Lack of confidence  2. Lack of resources  3. Lack of formal training.  4. Lack of referrals to an exercise professional due to health professionals being unaware of	Despite having a good understanding on the importance of physical activity, few health professionals provided physical activity advice (e.g., was always verbal).  No health professionals	2 themes: provision of physical activity advice, barriers.	QUAL= 4 80%

						<p>quality of life of cancer survivors. 50% strongly agreed or agreed that regular physical activity was associated with reduced side effects of treatment.</p> <p><b>Confidence:</b> 83.9% agreed and strongly agreed they were confident to provide physical activity advice.</p> <p><b>Practices (advice regarding physical activity):</b> Only 3.2% of participants always gave this advice; 36% often gave advice, 45.2% sometimes gave advice and 16% rarely gave advice</p>	exercise professionals.	<p>reported that they referred cancer survivors to an exercise professional.</p> <p>Physical activity advice may not be provided frequently. Further research should address this issue.</p>		
Wallace et al., 2015/ Australia	Cross-sectional study	Oncology nurses caring for cancer survivors with haematological cancer	<p>Perspectives, confidence levels, and delivery of survivorship practices</p> <p>Barriers influencing survivorship practices</p>	Survivorship advice	n=119	<p>Most oncology nurses agreed discussing exercise and physical activity (85%), healthy diet recommendations (82%), and health behaviours (80%) was part of the nursing role.</p> <p>Most nurses believed that discussing exercise, physical activity and healthy diet was a nursing role.</p>	<ol style="list-style-type: none"> <li>1. Lack of time</li> <li>2. Limited educational resources.</li> <li>3. Lack of dedicated end-of-treatment consultation and insufficient skills/knowledge.</li> </ol>	<p>Cancer centres should implement an appropriate model of survivorship care and provide improved training and educational resources for nurses to</p>	2 themes: provision of diet and physical activity advice, barriers.	QUAL= 4 80%

									enable them to deliver quality survivorship care and meet the needs of haematological cancer survivors.		
Williams et al., 2013/ UK	Cross sectional study	Cancer survivors & individuals in a cancer survivor's social network.	Attitudes towards advice on diet and physical activity.	Health behaviour advice (physical activity, healthy eating, weight loss)	n=222	Most cancer survivors (87–93%) agreed that advice on diet, activity and weight would be ‘beneficial’, ‘helpful’ and ‘encouraging’,  Most cancer survivors (84–87%) thought it was ‘the doctor’s duty’ to provide advice on physical activity, diet, and weight loss.	Most cancer survivors found lifestyle advice helpful and believed that doctors had a duty to provide it.	1. Cancer survivors believe health behaviour advice to be beneficial so are more likely to adopt these behaviours.	Not only do most cancer survivors welcome advice on diet, activity and weight, but their family and friends are also likely to be supportive.		QUAL=4 80%
<b>Mixed methods studies</b>											
Anderson et al., 2013/ UK	Mixed methods (questionnaire & telephone interviews)	Doctors and nurses working in colorectal cancer (consultant surgeons & oncologists, surgical registrars, nursing staff)	Familiarity with providing lifestyle advice. Body weight-recording, recognition. Access to support services. Perceived importance of lifestyle changes.	Weight management	n=323	53% of participants were familiar with lifestyle advice guidance for cancer survivors.  89% indicated weight management was important for improving cancer survivor health.	Discussing weight management was perceived to be the role of the GP, multidisciplinary team, clinical nurse specialist, consultant, and physiotherapist.	1. There is limited evidence on the impact of weight management.  2. Doctors did not want to affect the patient-doctor/nurse relationship by raising difficult topics (i.e., weight management).  3. Time constraints	Lifestyle changes in obese colorectal cancer survivors are perceived to be beneficial.  Written advice tailored to colorectal cancer survivors may encourage them to follow healthier lifestyles.	3 main themes with 3 subthemes: benefits of diet and exercise, HP’s concerns, and barriers.  <ul style="list-style-type: none"> <li>Relationships</li> <li>Time constraints</li> <li>Lack of training</li> </ul>	MM=4 80%

						<p>26% said they were 'always aware' and 36% said they were 'often aware' of BMI.</p> <p>47% had referred some overweight cancer survivors to other service providers for weight management during the previous month.</p> <p>Qualitative data suggested body weight was not routinely measured at follow-up clinics and that clinicians' concerns about body weight were principally related to identifying weight loss as an indicator of recurrence.</p>		<p>4. Lack of training on weight management.</p> <p>Health professionals consider weight management important in colorectal cancer survivors.</p> <p>However, current perceptions, knowledge and skills suggest further training is required.</p>			
Kassianos et al., 2017/ UK	Mixed methods (cross sectional survey and open-ended questions)	GPs caring for prostate cancer survivors	<p><b>Primary outcomes:</b></p> <p>Dietary behaviour change (general)</p> <p>Dietary behaviour change (specific)</p>	Promote dietary changes	n=95	<p>GPs felt that they were the medical speciality mainly responsible for providing dietary-related information</p> <p>GPs sceptical on the benefits</p>	<p>GPs are considered to have a role in providing dietary-related information to cancer survivors.</p>	<p>1. Lack of knowledge about diet in relation to cancer.</p> <p>2. Lack of confidence.</p> <p>3. Lack of information/resources is needed regarding cancer</p>	<p>GPs are interested in promoting dietary changes but do not have the relevant knowledge and confidence.</p> <p>Dietary interventions should consider</p>	<p>3 main themes with 3 subthemes: benefits of diet and exercise, provision of dietary/physical activity advice, and barriers.</p> <ul style="list-style-type: none"> <li>Evidence</li> <li>Lack of knowledge &amp; confidence</li> </ul>	MM=4 80%

			<p><b>Secondary outcome:</b></p> <p>Dietary behaviour change (specific)</p>			<p>of dietary changes post-diagnosis and did not want to provide information post-diagnosis to avoid raising false hopes.</p> <p>GPs reported lack of confidence in recommending dietary changes. Visual aids (i.e., leaflets) were recommended to help inform cancer survivors.</p>		<p>survivors' awareness, self-care, and diet information.</p>	<p>cancer survivors' cognitive ability, relationship with their health professionals and wellbeing.</p>	<ul style="list-style-type: none"> <li>Lack of information</li> </ul>	
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**List of acronyms:** BMI=body mass index, GP= general practitioner, HP= health professional, PA= physical activity, PCP= primary care physician, QOL=quality of life



### Appendix 3: Thematic analysis (study 1)

<b>Subgroups</b>	<b>Themes</b>
Role of medical and nursing health professionals	<ul style="list-style-type: none"><li>• Favourable /Unfavourable attitudes of medical and nursing health professionals and consumers.</li></ul>
Barriers	<ul style="list-style-type: none"><li>• Knowledge &amp; confidence levels</li><li>• Time constraints</li><li>• Role clarity</li><li>• Referral pathways</li></ul>
Facilitators	<ul style="list-style-type: none"><li>• Clinician-patient interactions</li></ul>

## Appendix 4: Mixed methods appraisal tool (study 2)

Types of mixed methods study components or primary studies	Methodological quality criteria (see tutorial for definitions and examples)	Responses			
		Yes	No	Can't tell	Comments
<b>Screening questions (for all types)</b>	<ul style="list-style-type: none"> <li>Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?</li> <li>Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).</li> </ul>				
	<i>Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>				
<b>1. Qualitative</b>	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
<b>2. Quantitative randomized controlled (trials)</b>	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
<b>3. Quantitative non-randomized</b>	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
<b>4. Quantitative descriptive</b>	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				
	4.4. Is there an acceptable response rate (60% or above)?				
<b>5. Mixed methods</b>	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?				
<i>Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.</i>					

\*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

## Appendix 5: Participant information form (study 2)



### PARTICIPANT INFORMATION FOR QUT RESEARCH STUDY – WORKSHOP–

#### Co-designing Elements of Care for Optimal Dietary and Exercise Referral Practices for Cancer Survivors: A Delphi Study

QUT Ethics Approval Number 2000000940

#### Research team

Professor Raymond Chan	<a href="mailto:raymond.chan@qut.edu.au">raymond.chan@qut.edu.au</a>
Dr Nicolas Hart	<a href="mailto:nicolas.hart@qut.edu.au">nicolas.hart@qut.edu.au</a>
Mrs Elizabeth Pinkham	<a href="mailto:elizabeth.pinkham@health.qld.gov.au">elizabeth.pinkham@health.qld.gov.au</a>
Ms Ria Joseph	<a href="mailto:ria.joseph@qut.edu.au">ria.joseph@qut.edu.au</a>

#### Why is the study being conducted?

The purpose of this Delphi study is to achieve consensus on elements of care relevant to referral practices for dietary and exercise interventions with considerations for (i) referrers (ii) service providers (iii) consumers; and (iv) resources, practice environments and funding models, which can ultimately inform local implementation efforts and improve patient outcomes.

#### What does participation involve?

The Brisbane Cancer Conference discussion workshop (26<sup>th</sup> November 2020) aimed to co-design elements of care for optimal dietary and exercise referral practices with considerations for (i) referrers; (ii) service providers; (iii) consumers; and (iv) resources, practice environments and funding models. Based on the results from this workshop, the final elements of care will be drafted by the workshop research team. Drafted consensus statements will undergo a three-step Delphi process with a group of experts. The Delphi process will involve two online survey rounds and one face-to face meeting. For the online survey rounds, participants will be asked to rate the importance of each of the drafted elements of care statements through a survey-based platform (Google Forms). The third round will involve a face-to-face meeting (which may be through Zoom or in-person) with the experts to clarify and finalise the elements of care statements through discussion.

Your participation in this research study is entirely voluntary. If you do agree to participate you can withdraw from the research study without comment, penalty or loss of benefits to which you are entitled. You can withdraw anytime during the Delphi consensus process. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT.

#### What are the possible benefits for me if I take part?

It is expected that this research study will not benefit you directly. The outcomes of the research, however, will provide insights that will inform the development of a state-wide

framework to guide policy, planning and health system responses to cancer survivorship, focusing on the health and wellbeing of people living with and beyond cancer.

#### **What are the possible risks for me if I take part?**

There are no foreseeable risks beyond the inconvenience of giving up time to participate and the low risk of anxiety induced by participating in the Delphi consensus process. If participants do feel anxious or overwhelmed by issues raised, they will be referred to their GPs.

#### **What about privacy and confidentiality?**

All input during the workshop and Delphi consensus process will not be linked to any individuals and will not relate to any professional or demographic characteristics of the workshop participants. Any data collected as part of this research study will be stored securely as per QUT's Management of research data policy. Data will be stored for a minimum of 5 years and can be disclosed if it is to protect you or others from harm, if specifically required by law, or if a regulatory or monitoring body such as the ethics committee requests it.

#### **Will I be reimbursed for taking part?**

There are no expected costs for enrolling in this study.

#### **How do I give my consent to participate?**

Participants will be emailed to obtain informed consent to participate in the Delphi consensus process. Participation in the consensus process, to rate the importance of drafted elements of care statements, will be accepted as an indication of your consent to participate in this study.

#### **What if I have questions about the research study?**

If you have any questions or require further information, please contact one of the listed researchers:

Professor Raymond Chan      raymond.chan@qut.edu.au

Dr Nicolas Hart                nicolas.hart@qut.edu.au

Ms Ria Joseph                 ria.joseph@qut.edu.au

#### **What if I have a concern or complaint regarding the conduct of the research study?**

QUT is committed to research integrity and the ethical conduct of research projects. If you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the QUT Research Ethics Advisory Team on +61 7 3138 5123 or email [humanethics@qut.edu.au](mailto:humanethics@qut.edu.au).

**Thank you for helping with this research study. Please keep this sheet for your information.**

## **Appendix 6: Draft invitation email (study 2)**

Dear Mr/Ms/Dr/Prof,

On behalf of Professor Raymond Chan, Associate Professor Nicolas Hart, and Professor Natalie Bradford, I would like to thank you all for bringing your valuable expertise and

experience and engaging in such constructive discussions at the Brisbane Cancer Conference (2020) in November last year.

I would like to invite you to join the expert stakeholder group to participate in a modified Delphi process. The aim of the study is to explore expert opinion and reach a consensus on the importance of essential elements of care statements for use by health professionals. Initial statements were informed by (1) Cancer Australia's principles for cancer survivorship; and (2) input from stakeholders through the workshop at the Brisbane Cancer Conference (2020) conducted by the research group. This Delphi process will identify essential elements of care that health professionals can implement to provide optimal dietary and exercise care to cancer survivors, and referrals to dietitians and exercise specialists.

The Delphi process will involve two online survey rounds and potentially one face-to-face meeting (if required). For the online survey rounds, participants will be asked to rate the importance of each of the drafted essential elements of care statements through a survey-based platform, and any other opinion they would like to express.

Please let us know if you are willing to participate in this study.

If you would like to discuss this study further, please contact Project Officer: Ria Joseph via email: [ria.joseph@qut.edu.au](mailto:ria.joseph@qut.edu.au).

We look forward to hearing from you, and we thank you for your consideration.

Yours sincerely,  
Ria

**Ms Ria Joseph**

PhD Candidate/Project Officer

Cancer and Palliative Care Outcomes Centre and School of Nursing, Queensland University of Technology

**Professor Raymond Chan**

Professor of Cancer Nursing

Division of Cancer Services, Princess Alexandra Hospital

Cancer and Palliative Care Outcomes Centre and School of Nursing, Queensland University of Technology

**Associate Professor Nicolas Hart**

Senior Research Fellow in Cancer Survivorship

Division of Cancer Services, Princess Alexandra Hospital

Cancer and Palliative Care Outcomes Centre, School of Nursing, Queensland University of Technology

**Professor Natalie Bradford**

Principal Research Fellow

Cancer and Palliative Care Outcomes Centre and School of Nursing, Queensland University  
of Technology

## Appendix 7: Summary of feedback from Delphi rounds 2 and 3 (study 2)

### Principle 1: Consumer involvement in person-centred care

#### Outcome

People affected by cancer are empowered to participate in shared decision-making and supported toward self-management according to their preferences. Informed and engaged consumers lead to better health outcomes and improved safety.

Essential Elements		Panel Feedback	R2 + R3 Consensus (≥75% of panel rated a score of 3 or more)	R4 Agreement (% agreement of consumers)
<b>Element 1</b>	People affected by cancer are provided with information on dietary and exercise services available to support healthy lifestyles.	<ol style="list-style-type: none"> <li>1. Exercise has an established evidence-based role in cancer treatment and support. Patients need to be provided with the tools and resources to make informed decisions on the inclusion of exercise into their treatment plan. Subsequently to this there is an important link that needs to be filled that transfers this information into action with encouragement from treating oncologists, family, GPs, and allied health. Most importantly it needs to be right for the patient, patients can be encouraged but shouldn't overburden them that they then perceive exercise in a negative light.</li> <li>2. Given that diet and exercise are highly modifiable risk factors for cancer, it is absolutely essential to ensure people affected by cancer are provided with timely, evidence-based diet and exercise-related information to improve their health and quality of life. Information is only one part of this though, equally important is the ability to empower people affected by cancer in relation to their ability to access information and services.</li> <li>3. I believe the most important and first point of call is they receive access to cancer specific professionals and information before they access general information however, the general info is better than nothing.</li> <li>4. I believe it is extremely important that people affected by cancer are informed of, and assisted with referral, to dietary and exercise support services during and following their treatment. In my experience, people affected by cancer are not usually aware of such services being available. This is especially true if these services are offered outside their usual treating service provider.</li> </ol>	Reached consensus with no changes	Reached consensus
<b>Element 2</b>	People affected by cancer are recommended to access existing dietary and exercise services available to support healthy lifestyles.	<ol style="list-style-type: none"> <li>1. Patients, across all diseases and settings, have the right to access to appropriate healthcare services to manage their condition and beyond, they also should be made adequately aware of the availability of these services, how they are able to engage at a level that suits them and their needs. As well as if they see fit should be encouraged to seek referrals to professionals that could provide input in their management. This encouragement and empowerment provide some control back to the</li> </ol>	Reached consensus with no changes	Did not reach consensus

		<p>individual, where in many cases patients with cancer lack confidence as the illness is highly debilitating.</p> <ol style="list-style-type: none"> <li>2. I think we could use proactive language that is more definitive. I think people should be more than simply encouraged - it's very passive language. It's quite well-established that exercise (as an example) has a plethora of benefits to people affected by cancer - including the capacity to improve treatment tolerance and completion. Oncologists in Western Australia) literally tell their patients that exercise is PART of their treatment. That is, "I will give you XYZ radiation to treat your prostate cancer, and you will attend supervised exercise with an exercise physiologist". I think we need to capture that the need for people to access diet/exercise isn't some casual optional extra. It's far more than that. The literature is clear. The problem is implementation (not efficacy). This would be my preference.</li> <li>3. An important part of empowering people is ensuring they have up to date information and advice. Encouragement to access dietary and exercise support would be more of a case-by-case consideration depending on the individual and their circumstances</li> <li>4. Encouragement is not enough for people to change. Medical professionals need to tell them that they need to change their diet and introduce exercise as well as make them responsible for those changes.</li> <li>5. I strongly suggest you change this wording. You should do MORE than just "encourage" people to access diet and exercise services. You should use a stronger word and more active word. Use of words and language matters so I ask the Delphi team to please consider more "active" and "engaging" language. You could say: "People affected by cancer are recommended to access...." or "People affected by cancer should access..." or "People affected by cancer are requested to access." - I don't know what the best, active, engaging, and proactive words are - though I believe you should ensure they know it is not just some optional extra. In medicine, and oncologists, often consider it as part of treatment. It should be treated with the same level of emphasis.</li> <li>6. People affected by cancer may not be aware of the benefits of appropriately prescribed dietary and exercise interventions to assist their intra- and post-treatment cancer care. In my experience, sometimes referrers are also not aware of the known and potential benefits of such lifestyle services. This is where educating both the oncologists/haematologist/GP and people affected by cancer, is extremely important to promote uptake into these services. In my team, we have also found that a person is more likely to join one of these services if their oncologists/haematologist/GP encourages them to participate.</li> </ol>		
<b>Element 3</b>	People affected by cancer are empowered to take control of their health.	<ol style="list-style-type: none"> <li>1. By empowering people to take control of their care, we are encouraging them to undertake self-responsibility. I believe this is likely from my experience to have the most successful long-term outcome.</li> </ol>	Reached consensus with minor changes	Reached consensus



<b>Element 4</b>	People affected by cancer are provided with referrals to dietitians and exercise professionals when required.	<p>2. I don't think that people would be empowered by having to seek their own referrals - I think they should be empowered to take control for their own health behaviours and also given referrals which they may or may not use. So perhaps it is a wording issue for this item?</p> <p>3. I believe that it is important people affected by cancer are empowered to seek referrals. However, it is likely that most individuals may not be aware of the potential benefits, so I believe the onus is more on the oncologists/haematologist/GP (or an appropriately trained nurse or allied health professional) to provide this education. Then they should be assisted in getting referrals to these services. If the person is left to their own devices to seek a referral, it may only be that the "highly motivated" individuals will do so. This may reduce the likelihood of less-motivated individuals to seek referrals.</p>	Reached consensus with minor changes	Did not reach consensus
<b>Element 5</b> (new element)	People affected by cancer are informed about the benefits of diet and exercise for the management of cancer.	<p>One aspect of Consumer Involvement in Patient-Centred Care may be education. Above, we state 'information' is provided; 'accessing referrals' is encouraged; and people are 'empowered to take control'. Perhaps education is inherent in empowering people to take self-control - but for consumers to be understand information on dietary/exercise services; and for people to seek access to diet/exercise referrals; and for people to feel empowered to take action - presumably their health literacy and education/knowledge of the health/clinical/other benefits of exercise for cancer, and dietary changes in cancer. That is, it's not just about 'what services are available and how do we reach them?' but also 'why is exercise and diet for the management of my cancer important?' because consumers who value exercise and diet to help them move through cancer, will be highly motivated to engage with services as per the above three elements.</p> <p>RECOMMENDATION: We add a 4th statement around education? Open for discussion. Just think this is an aspect missing.</p>	Development of new element based on panel feedback	Reached consensus

**Principle 2: Support for living well**

**Outcome**

Supportive care needs\* of people affected by cancer are assessed to determine appropriateness of referrals to dietary and exercise services. People affected by cancer are supported to make informed lifestyle choices to promote wellness, manage treatment related side effects and co-morbidities, and reduce risk of second and recurrent cancers. \*Includes physical, psychological, social (including educational, financial and occupational issues), cultural, information and spiritual needs.

Essential Elements	Panel Feedback	R2 + R3 Consensus (≥75% of panel rated a score of 3 or more)	R4 Agreement (% agreement of consumers)
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<b>Element 6</b>	People affected by cancer are best supported when their needs for referrals to dietitians and exercise professionals are evaluated at key transition phases (at diagnosis or end of treatment).	<ol style="list-style-type: none"> <li>1. The transitions phases of care can be confusing and support of their diet and exercise across these is important to enable smoother transitions. It is well known that support groups are key in providing psychosocial support to people with chronic illness. The ability to speak and engage with people who share similar lived experience can facilitate a sense of "I'm not the only one".</li> <li>2. These key transition phases are different for each cancer type. For example, I don't feel people with breast and prostate cancer need this advice during the early diagnosis period as they are often overwhelmed with information regarding treatment and prognosis, however for the head and neck population dietary advice at diagnosis is essential to them making it through treatment. Agree for all cancer types the transition period at the end of treatment might be an ideal time)</li> <li>3. "When dietitians and exercise provide personalised interventions or advice"? Are they just providing support, in what way? Do we need to be clearer, or deliberately vague? Key transition phases are essential to tailor the appropriate management as a one size fits all for diet and exercise will not be effective even for the same patient at different phases of their cancer.</li> <li>4. In my opinion Element 5 is not necessary. As someone who trains student AEPs, I believe AEPs and dietitians are appropriately trained to provide support to people affected by cancer, so this is redundant.</li> </ol>	Reached consensus with minor changes	Reached consensus
<b>Element 7</b> (new element)	People affected by cancer are supported when referrers are informed about the benefits of diet and exercise for the management of cancer.	OTHER - what about education? Educating referrers AND people affected by cancer to the benefits of diet and exercise for cancer survivors will help FACILITATE a lot of these elements too. I think education needs to be captured. Education is empowerment so education could also fit under Principle 1 too.	Reached consensus with no changes	Reached consensus
<b>Element 8</b>	Referrers are informed about the available dietary and exercise community programs, support groups and other services, and how to refer to these services.	<ol style="list-style-type: none"> <li>1. Providing support for people affected by cancer to live well is critical to maintaining and improving quality of life. It is also essential for creating a sense of empowerment and agency for individuals.</li> <li>2. ELEMENT 5 - should we suggest something more than "made aware of" for support groups, and services? Again, more proactive language. This is about referrals so do we need to say, "referrers are made aware of, and facilitated to refer to dietary- and exercise-related support groups and services"?</li> <li>3. Referrers should be aware of the services available, but possibly support groups are not as critical as actual service provision. Biggest barrier to this is not having a centralised database/website where all services are listed with inclusion/exclusion criteria.</li> <li>4. Again, being made aware is not enough for people to take responsibility. They need to be sent places and giving directions backed up by research that shows if they go that they might have a better chance of survival.</li> </ol>	Reached consensus with minor changes	Reached consensus

		5. Just "made aware" of existing services? What about educating referrers on "how" to refer to these services. They need to have more than just awareness of what is available, but education on how to operationalise systems to get patients there.		
<b>Element 9</b>	People affected by cancer are supported when general practitioners develop and review relevant Chronic Disease Management plans and incorporate dietary and exercise referrals for optimal care.	<ol style="list-style-type: none"> <li>1. GPs are the gatekeeper in primary care to effective care - they hold a lot of responsibility for individual health across all life stages. typically, a GP would be a first point of call, and also the HP someone sees for their ongoing care in the community (post-discharge from any hospital services). Thus, ensuring these plans are available to cancer survivors is important to ensure the person is supported post-treatment and to prevent recurrent cancer.</li> <li>2. Community models that promote and support optimal healthy lifestyles are a key public health initiative for overall general population, and particularly for patients with cancer or at risk or those who are in remission.</li> <li>3. I think GPs' involvement is essential, especially in TCA etc. It's a really good way to offer pts subsidized allied health access.</li> <li>4. CDM plans help clarify long term care with the aid of GPs and the multidisciplinary team, and are essential as even metastatic cancers e.g. breast are moving to chronic disease model of care in many instances now. These models of care are appropriately community based.</li> <li>5. Current CDM plans should be expanded to 10 sessions, not 5, similar to mental health plans, to allow for sufficient support to be provided by dietitian / exercise specialist.</li> </ol>	Reached consensus with no changes	Reached consensus
<b>Element 10</b>	People affected by cancer are supported when models of care in the community are adapted to optimally support healthy lifestyles and sustainable lifestyle change.		Reached consensus with minor changes	Reached consensus

**Principle 3: Evidence-based care pathways**

**Outcome**

People affected by cancer receive consistent, safe, high-quality evidence-based dietary and exercise cancer care in line with Optimal Cancer Care Pathways,<sup>7</sup> according to their individual circumstances and needs.

Essential Elements	Panel Feedback	R2 + R3 Consensus (≥75% of panel rated a score of 3 or more)	R4 Agreement (% agreement of consumers)
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<b>Element 11</b>	Referrals to dietitians and exercise professionals are based on grading systems or validated screening tools where possible to assist in identifying individual needs.	<ol style="list-style-type: none"> <li>1. I feel this is important, but I have rated this lower as it should not be considered in isolation from other methods or forms of assessment, but rather as a suite of approaches used to assist in identifying individual needs.</li> <li>2. I think everyone with a cancer diagnosis would benefit from attending at least one session with an AEP and dietitian to enhance their knowledge and self-efficacy around these important adjuvant therapies. The grading systems or validated screening tools to identify individual needs should then be utilised by the AEP/dietitian to identify subsequent referrals (e.g., social worker) or guide further treatment, or not, as indicated.</li> </ol>	Reached consensus with minor changes	Did not reach consensus
<b>Element 12</b>	Referrals to dietitians and exercise professionals are based on individualised needs in accordance with evidence-based dietary and exercise guidelines.	<ol style="list-style-type: none"> <li>1. It is not uncommon for individual needs to be missed by the referring partner. Every consumer would benefit from exercise referral so no one should be excluded.</li> <li>2. I don't think it's so much that the referral needs to be individualised, but rather that the prescription needs to be individualised.</li> </ol>	Reached consensus with minor changes	Reached consensus
<b>Element 13</b>	Referrals to dietitians and exercise professionals are based on regular screening of individual needs at key transition phases to facilitate timely referrals to appropriate services.	<ol style="list-style-type: none"> <li>1. I'm not sure if regular screening means routine screening. I don't think that screening for diet and exercise referral needs to happen regularly at set intervals but there are key transition moments as mentioned above when it should be screened for again - this may be what is meant by regular.</li> <li>2. Specialists treating people with cancer should be regularly screening for the development of disease- and treatment-related side effects (e.g., sarcopenia, cachexia, malnutrition, low fitness) to prevent and/or detect early signs of these symptoms that could be addressed by adjuvant therapy.</li> </ol>	Reached consensus with minor changes	Reached consensus
<b>Element 14</b>	Dietary and exercise referrals are prioritised for Indigenous people, culturally and linguistically diverse (CALD) populations, and other vulnerable populations.	<ol style="list-style-type: none"> <li>1. I want to highlight that focusing on vulnerable populations including Indigenous and CALD - are well-known groups that are at risk of not seeking treatment, not receiving adequate treatment that is adapted to personal and cultural requirements, and also increased risk of stigma in our privilege-enabling healthcare system.</li> <li>2. Very large gap in service provision and information resources with First Nation people and CALD populations.</li> <li>3. Separately, I agree we need to prioritise First Nation and CALD people but - how do we prioritise them above other people affected by cancer? Is this meaning that if resources are limited (which, in the health system, we know it is resource-constrained), that resources be prioritised for them? If- so this is OK I presume, but I wanted to just be clear with what we mean by these.</li> <li>4. Barlow et al. 2021 (Aust J Health Prom) identified this is an area of need in Australia</li> <li>5. It is important that referrals and services are prioritised for people with most need. People with intersecting barriers to healthcare (marginalisation, linguistic barriers) should ideally be matched with services that are flexible around meeting their needs.</li> </ol>	Reached consensus with minor changes	Did not reach consensus

		<p>6. I think it is not necessarily completely fair to expect vulnerable groups to go looking for referrals even though empowerment is a good thing, the reality is that certain groups will be disadvantaged by this approach alone. Information is very important and starting with the appropriate use of available services is also very important.</p>		
<b>Element 15</b>	<p>Referrals are directed to dietitians and exercise professionals with experience in cancer care (where possible) with consideration of risks.</p>	<ol style="list-style-type: none"> <li>1. Dietitians and exercise specialists with experience in cancer care would enable the specific needs of people affected by cancer to be met. Specialist clinicians in cancer care that extend to diet, and exercise is a must!!</li> <li>2. Element 14 is the most important to assure quality</li> <li>3. Not sure where this sits - but it is my view the most - if not ALL - people affected by cancer should be referred to an exercise specialist for a consult and needs assessment (regardless of what their exercise program looks like thereafter). The exercise specialist has the ability to determine risk and benefit. The exercise specialist (most importantly) has the ability to determine patient wants versus patient needs (that is, patient wants are not always what they need - and this needs to be acknowledged and navigated). Exercise specialists can then design a program for this. I presume the same is for dietetics. So, we need to ensure this is captured, or a way to adjust wording to add a stronger position here. As noted earlier. The evidence of benefit is clear. The right people with the right knowledge and the right skillsets need to be the ones advising these people affected by cancer. Hence the need for referral as mandatory in my view.</li> <li>4. You could argue that all dietitians (not sure about EPs so won't comment on them) have been trained to have some experience and expertise in cancer care. In an ideal world it would be great for all cancer patients to see a dietitian with cancer experience, but may not be feasible... I guess this is why you are doing this work though to help change current practice (yay!). And I also love the idea of doing risk assessments to stratify patients to dietitians with differing levels of cancer experience depending on patient needs.</li> <li>5. People with extensive experience working in cancer care is important, however working with numerous people with cancer does not necessarily mean that the treatment being provided is optimal and evidence based. I would be more interested in seeing those who have sought further evidence-based knowledge accrual e.g., honours/MPhil/PhD, ExMed, ECU grad program, ACSM/ESSA training module being preferentially referred to.</li> </ol>	<p>Reached consensus with minor changes</p>	<p>Reached consensus</p>

**Principle 4: Coordinated and integrated care**  
**Outcome**

People affected by cancer receive holistic patient-centred dietary and exercise services coordinated and integrated across treatment modalities, providers, and health settings. This includes public and private sectors, as well as specialist, primary, community-based and not-for-profit services. Dietary and exercise care is delivered in a logical, connected, and timely manner for optimal continuity and to meet the individual needs of people affected by cancer.

Essential Elements		Panel Feedback	R2 + R3 Consensus (≥75% of panel rated a score of 3 or more)	R4 Agreement (% agreement of consumers)
<b>Element 16</b>	Between people affected by cancer, referrers, and service providers, care is coordinated and integrated to develop and implement dietary and exercise referral pathways.	<ol style="list-style-type: none"> <li>All elements are absolutely essential, unfortunately I feel that integrating and coordinating a model of care around diet and exercise service delivery for people affected by cancer would be particularly problematic and difficult to achieve.</li> <li>I like this very much. Care co-ordination is KEY. How do we make it work? I guess is a level beyond these elements for now.</li> <li>The coordination of these care models are important considerations so to maximise the outcomes while minimising time and cost for people living with cancer, health professionals and cancer support workers.</li> <li>Elements 15 and 16: the more streamline, timely and easy it is to refer people with cancer to exercise and nutrition professionals the better. What that looks like and if there is a 'gold standard' model of referral requires further consideration.</li> <li>The care coordinator plays an essential role in offering all relevant info for the patients.</li> </ol>	Reached consensus with no changes	Did not reach consensus
<b>Element 17</b>	Between people affected by cancer, referrers, and service providers; there are clear, timely and effective bilateral communication processes adopted.	<ol style="list-style-type: none"> <li>ELEMENT 16 isn't written correctly. I presume it's meant to say: "Between people affected by cancer, referrers, and service providers; there are clear, timely and effective two-way communication processes adopted." - I added two-way, but you can use bilateral or other. We need something to show that communication is not in one direction.</li> <li>ELEMENT 16 - Has a typing error of sorts. I assume this is to deliver "clear, timely, and effective BILATERAL communication processes" - not unilateral. There needs to be a word added between "services, clear" too.</li> </ol>	Reached consensus with minor changes	Did not reach consensus
<b>Element 18</b>	People affected by cancer have dietary and exercise care plans, assessments, and updates on progress and outcomes which service providers feedback to referrers.	<ol style="list-style-type: none"> <li>Assessments and reports are integral to progress and care of a person affected by cancer. My concern here is that without appropriate funding and resourcing dietitians and exercise physiologists will struggle to write timely reports unless a funded model of care was implemented that paid for the report writing.</li> <li>Consensus and standardisation of assessments/outcomes is needed</li> <li>For element 17, not sure if all care plans and progress would need to be fed back to referrer - depends on the provider type of the referrer and the timing in the cancer pathway. I think communication between providers is more important than this step.</li> </ol>	Reached consensus with no changes	Did not reach consensus

		4. Element 17: the more specialists and GPs are made aware of the benefits AEPs/dietitians are making to the health of their patients, the more likely they are to continue referring patients.		
<b>Element 19</b>	People affected by cancer have routine evaluations of their dietary and exercise plans to improve quality of care.	Elements 18 and 19: whilst important, these should be standard components of AEP/dietitian practise	Reached consensus with no changes	Did not reach consensus
<b>Element 20</b>	People affected by cancer can access various modes of dietary and exercise service delivery (e.g., using telehealth) based on their individual needs and preferences.	I can see Telehealth being a huge facilitator here!	Reached consensus with no changes	Did not reach consensus

## Principle 5: Data-driven improvements and investment in research

### Outcome

National collection and reporting of key cancer data, including consumer experience and outcome data, provides an indicator for high quality care, influences health service improvements and informs investment in research. Published research in cancer survivorship enriches the evidence base and informs improvements to enhance the care and outcomes of people affected by cancer.

Essential Elements		Panel Feedback	R2 + R3 Consensus (≥75% of panel rated a score of 3 or more)	R4 Agreement (% agreement of consumers)
<b>Element 21</b>	Dietary and exercise referrals can be optimised by collecting and evaluating quality data on the referral process and care outcomes using validated	<ol style="list-style-type: none"> <li>Ongoing evaluation and monitoring of these systems are key in identifying areas of improvement as well as key strengths that can be reported in the body of growing evidence to facilitate systemic changes.</li> <li>Element 20 and 21: Although I'm biased given this is the course, I teach to undergraduate AEPs, valid and accurate assessments and evidence-based practice are essential to optimise the health and wellbeing of people with</li> </ol>	Reached consensus with no changes	Reached consensus

	instruments and standardised protocols, where appropriate.	cancer. It simply is inappropriate given the current evidence to simply recommend walking or general physical activity, knowing the specific exercise prescriptions required to alleviate many disease- and treatment-related side effects. 3. Diet and exercise research/evaluation for people affected by cancer is so important, as well as the translation of that evidence into practice/service improvement!		
<b>Element 22</b>	Dietary and exercise referrals can be optimised by translating research into practice, innovation, and improvements in cancer care.		Reached consensus with no changes	Reached consensus
<b>Element 23</b> (new element)	Research for dietary and exercise referral practices should be continually invested in, and strengthened, to optimise outcomes for people affected by cancer.	1. This Principle has, in its title, "Investment in Research" - but I do not see any elements addressing this component. Shouldn't we have an element that canvasses the need to continually invest in, and strengthen, research efforts to optimise outcomes for people affected by cancer? We should work through this to add one (or two) elements for this in my view. 2. Yes, but this needs to take into consideration things like the "blue zones" research (longest living people who are healthy on the planet), radical remission (people who were dying from cancer but recovered by taking responsibility through diet and exercise). A holistic approach that is inclusive needs to be taken into consideration and not one that supports the food companies, convenience, and sickness.	Reached consensus with no changes	Reached consensus
<b>Element 24</b> (new element)	Investment in research for dietary and exercise referral practices should be produced in partnership with public and private sectors together with governing bodies and industry.		Reached consensus with no changes	Reached consensus



## Appendix 8: Summary of feedback from Delphi round 4 (study 2)

### Principle 1: Consumer involvement in person-centred care

#### Outcome

People affected by cancer are empowered to participate in shared decision-making and supported toward self-management according to their preferences. Informed and engaged consumers lead to better health outcomes and improved safety.

Essential Elements of Care		Consumer Feedback	Consensus (% agreement)
<b>Element 1</b>	People affected by cancer are informed about the benefits of diet and exercise for the management of cancer.	<ol style="list-style-type: none"> <li>1. At the QCH children &amp; their families are advised to eat &amp; drink crap, &amp; indeed provided with said crap when an inpatient. Exercise &amp; the evidence-based value of exercise is never mentioned. The uptake of Exercise Medicine in the children's oncology services (day clinic &amp; ward) is no existent, &amp; criminal.</li> <li>2. Was told to let my son rest. If he wanted to sit on couch all day let him. He lost 14kg most of that was muscle.</li> <li>3. When going through treatment you are wanting your child to eat anything. Her diet was full of fruit and veggies prior to treatment. While treatment she did not want that. Exercise - that's general walking and dancing. It was discussed briefly with us.</li> <li>4. Generally, a vague answer to activities that okay, apart from looking after central line. Best done by oncology nurse that has time, especially in regional hospitals.</li> <li>5. Not in-depth though.</li> <li>6. With Paeds this seems to be absent - even with the food served in the wards.</li> </ol>	52%
<b>Element 2</b>	People affected by cancer are provided with information on dietary and exercise services available to support healthy lifestyles.	<ol style="list-style-type: none"> <li>1. In 27 months of active treatment, we were not offered the services of a dietitian or an EP once. They simply do not care about our children or families. They are also incredibly reluctant to investigate any of the evidence-based fallout from the lack of dietary &amp; exercise, as a result of treatment. Additionally, there is currently no survivorship clinic for our children. Parents &amp; carers are abandoned once 'treatment' is over. Cruel &amp; negligent.</li> <li>2. I feel at that stage you are focusing on getting through the challenges you are faced with at the time. I work in the health and wellbeing industry and I wasn't my concern as I knew after treatment our lifestyle would revert to before treatment. we are an active family and eat over 10 serves of fruit and veg daily.</li> <li>3. Dietitian helps with weight loss once weight falls down to having a feeding tube.</li> <li>4. Not in-depth</li> <li>5. Paediatric cancers are rarely caused by diet, so this is overlooked. Wonder if it is considered invalid and not necessary.</li> </ol>	68%

<b>Element 3</b>	People affected by cancer are advised to access existing dietary and exercise services available to support healthy lifestyles.	<ol style="list-style-type: none"> <li>1. Nope, nada, zip, nothing...</li> <li>2. We weren't informed about anything. Left completely in the dark</li> <li>3. Only when an in potential at the hospital is when diet was discussed. exercise was never talked about.</li> <li>4. Once again this applies to adult cancers and not paed.</li> </ol>	60%
<b>Element 4</b>	People affected by cancer are empowered to take control of their health.	<ol style="list-style-type: none"> <li>1. Encouraged to follow the advice/orders from the 'experts' at the hospital. Parents are excluded &amp; discouraged from collaborating in the care of their precious children. If you dare to ask questions, you are labelled "one of 'those' parents".</li> <li>2. I feel this is an area of improvement to provide the information</li> <li>3. Much better in the adults. But no information in pediatrics.</li> <li>4. We were Always Encouraged to ask questions</li> <li>5. Maybe in the Adult cancer world but not in the paed world</li> </ol>	76%
<b>Element 5</b>	People affected by cancer are provided with referrals to dietitians and exercise specialists (i.e., exercise physiologists, physiotherapists).	<ol style="list-style-type: none"> <li>1. zero care is offered or shown.</li> <li>2. I had to ask them about a physiotherapist then for them to organise it. Not once was it mentioned to me very disappointing and life changing.</li> <li>3. While these specialist areas are discussed i don't think that enough is done to connect individuals with services in the longer term of survivorship.</li> <li>4. This is fine; however, I think there needs to be an increased importance on the message of diet and exercise to encourage survivors to utilise these services. The main message in paediatrics is maintain weight by whatever means possible and we were directed to a physio who added absolutely no value to recovery. We set up a home gym that was much more useful and targeted.</li> <li>5. only when required. My daughter could not walk due to the chemo, that's when we engaged the physio.</li> <li>6. Dietitian only. Physio for drop foot, and to assess function. No exercise physiologists.</li> <li>7. When we were in hospital for admissions, we saw the dietician intermittently.</li> <li>8. This is only offered in extreme cases for kids/teens and then restricted to the hospital service which is very limited, and they seem to have limited understanding on impacts of cancer treatments and impacts.</li> </ol>	56%

## Principle 2: Support for living well

### Outcome

Supportive care needs\* of people affected by cancer are assessed to determine appropriateness of referrals to dietary and exercise services. People affected by cancer are supported to make informed lifestyle choices to promote wellness, manage treatment related side effects and co-morbidities, and reduce risk of second and recurrent cancers. \*Includes physical, psychological, social (including educational, financial and occupational issues), cultural, information and spiritual needs.

Essential Elements of Care	Consumer Feedback	Consensus (% agreement)
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<b>Element 6</b>	People affected by cancer are best supported when their needs for referrals to dietitians and exercise specialists (i.e., exercise physiologists, physiotherapists) are evaluated at key transition phases (at diagnosis or end of treatment).	<ol style="list-style-type: none"> <li>1. Exercise Medicine should be offered from diagnosis. This is what the evidence advises.</li> <li>2. Not enough is done or focussed on beyond 'end of treatment'</li> <li>3. Practitioners need to be specialised in order to assess pre-diagnosis capability vs current capability vs goal capability as each of these levels and motivations would be different for every patient. This is extremely important for patient mental health because if you get this wrong, there is nothing realistic to work towards.</li> <li>4. My son was an adolescent inpatient at QCH and it might have been useful to have some sort of exercise area in the ward. I don't know if he would have been well enough to use an exercise bike or raise dumbbells (in the arm which didn't have a central line in!) but I he was a very active person before diagnosis.</li> <li>5. This is a very expensive exercise - private practice is hard to access and is out of the range of many.</li> </ol>	96%
<b>Element 7</b>	People affected by cancer are best supported when referrers are informed about the benefits of diet and exercise for the management of cancer.	<ol style="list-style-type: none"> <li>1. Though you are hard placed to find any providers who are informed &amp; educated about such opportunities in the world of childhood cancer.</li> <li>2. Definitely. Exercise helps mental health.</li> <li>3. After completing all treatment (4 major surgeries plus chemotherapy) my son found it difficult to get moving again physically. We got a referral from our GP for an exercise physiologist, but my son did not like the approach, so he ended up joining a gym and setting up his own programme. Diet during chemotherapy is about 2 things - what the person feels like and then what they can keep down. For my son he seemed to cope better with foods like Subway and otherwise items like toast with avocado or the old standby vegemite toast! He also used to enjoy the special menu you could order like mini pizzas that he could get when he felt like he could eat something. Like most cancer patients it's about trying to eat something to minimize the weight loss.</li> <li>4. I feel this survey is aimed solely at the adult cancer world. The wording reads as though diet can be the cause of cancer which is not part of the majority of childhood cancers.</li> </ol>	100%
<b>Element 8</b>	Referrers are informed about the available dietary and exercise community programs, support groups and other services, and how to refer to these services.	<ol style="list-style-type: none"> <li>1. The CNC's were useless. The SW'ers were crap. We had one super awesome OT who cared &amp; was competent. The QCH repeatedly send oncology families pout into the community, or in the direction of charities, all the while knowing that the services simply do not exist. Again, there is zero care.</li> <li>2. Up to GP, and parents and family to seek out.</li> <li>3. This may be due to the fact we were not from a metropolitan community. We liaised with our GP who did a Health Care Plan with us and referred us to local services.</li> <li>4. This in my experience does not apply to kids/teens. There are no community programs, support groups or other services that support this age group.</li> </ol>	64%
<b>Element 9</b>	People affected by cancer are best supported when general practitioners develop and review relevant Chronic Disease Management plans and incorporate dietary and exercise referrals for optimal care.	<ol style="list-style-type: none"> <li>1. The QCH repeatedly fails to share treatment notes with our GP's (over months &amp; years), &amp; therefore once you are kicked out of the 'service' post treatment, the GP's do not feel competent, informed, supported or educated to help the young folk they are now being charged to care for.</li> <li>2. By the time GP's become involved with a CDM, the dietary and exercise habits should be well and truly formed.</li> <li>3. If that happens. This did not occur for my daughter.</li> <li>4. Very regular check-ups with GP -- now by telehealth are essential. Oncology needs to share progress of the patient's condition. Transparency to GP would be helpful.</li> </ol>	92%

		<ol style="list-style-type: none"> <li>5. This is probably true because GP's know the patient and the services available in their community.</li> <li>6. I feel in a perfect world this would work. Sadly, very few paed patients are given a CDM. Sounds like a great argument for a survivorship clinic.</li> </ol>	
<b>Element 10</b>	People affected by cancer are best supported when models of care in the community are adapted to optimally support healthy lifestyles and sustainable lifestyle change, if required.	<ol style="list-style-type: none"> <li>1. engaging the people affected into local support services where they live. That ensures connect and accountability to engage in that lifestyle choice and service.</li> <li>2. With a very serious, life changing medical condition ways to support everyone (carer and patient) absolutely valuable at the beginning of treatment. Western Australian and breast cancer evidence of the benefits of movement for mental health and metabolizing chemotherapy.</li> <li>3. While this is a goal statement supporting people with cancer requires diverse and supports, including psychology and practical supports. It can take people six months or longer to recover from cancer treatment and lifestyle changes is not always on the top of their list.</li> <li>4. I hope the outcome of this survey results in QUT helping set up and run a survivorship clinic so diet, exercise and healthy lifestyles education can be included.</li> </ol>	88%

### Principle 3: Evidence-based care pathways

#### Outcome

People affected by cancer receive consistent, safe, high-quality evidence-based dietary and exercise cancer care in line with Optimal Cancer Care Pathways, according to their individual circumstances and needs.

Essential Elements of Care		Consumer Feedback	Consensus (% agreement)
<b>Element 11</b>	Referrals to dietitians and exercise specialists (i.e., exercise physiologists, physiotherapists) are based on grading systems or validated screening tools where possible to assist in identifying individual needs.	<ol style="list-style-type: none"> <li>1. These grading systems do not currently exist in paediatric oncology.</li> <li>2. All patients should be explained the possible benefits of working with these practitioners and if the grading system precludes the patient (presumably a way of maximising limited funding), they should be offered services at a cost if it improves outcomes. They should have a choice.</li> <li>3. Needs to be up front. Most patients will not go if everything is physically normal.</li> <li>4. Particularly children who are diagnosed as toddlers. An overall check with dieticians and Physio is to ensure they are developing and meeting milestones.</li> <li>5. While these tools may be useful, should not all clients who have experienced cancer be offered this? What happens if they don't meet the validated screening tools magic no. to get a referral but really want one?</li> <li>6. And sadly, the majority of paed's don't qualify.</li> </ol>	60%

<b>Element 12</b>	Referrals to dietitians and exercise specialists (i.e., exercise physiologists, physiotherapists) are based on individualised needs in accordance with evidence-based dietary and exercise guidelines.	<ol style="list-style-type: none"> <li>1. It is a great goal to be working towards... but atm, nope, this simply does not happen. There is no personalised 'care'.... everything is dictated by a protocol that does not take into account the individual needs of the child or YA.</li> <li>2. We told them what we needed no help at all.</li> <li>3. All patients should be asked and offered services if it improves outcomes. Don't assume a patient's situation.</li> <li>4. Never happened for us.</li> <li>5. Not always. For many things are simply left to the parent. Many of these parents requests for help are ignored.</li> </ol>	60%
<b>Element 13</b>	Referrals to dietitians and exercise specialists are based on regular screening of individual needs at key transition phases to facilitate timely referrals to appropriate services.	<ol style="list-style-type: none"> <li>1. Zero care. Zero action. Zero referrals. I know of one family who had a child wheelchair bound for 7 months. Zero offer of any rehab... referrals in house or external. The child (12 years old at the time) was routinely bullied &amp; mocked by the most senior physio there. The child once stated: 'when I am swinging from a bridge, will they take my pain &amp; not being able to walk seriously'. How utterly disgusting is the 'care' that leads to a cancer warrior feeling the need to make such a statement.</li> <li>2. Did not occur but I did not ask. I'm sure if I had concerns, I would have got assistance. I got great help when we were an inpatient.</li> <li>3. Welcome to the world of paed cancer. Nothing of the sort is offered. We are madly trying to set up a much-needed survivorship clinic to cover this and many other things.</li> </ol>	80%
<b>Element 14</b>	Dietary and exercise referrals are culturally tailored for Indigenous people, culturally and linguistically diverse (CALD) populations, and other vulnerable populations.	<ol style="list-style-type: none"> <li>1. The folk in the belly of the bell curve struggle... minority groups even more so.</li> <li>2. This is great when required however it should not be a political priority above other populations. Cancer does not discriminate. All patients to be equal.</li> <li>3. I doubt this very much if related to paed cancer patients - they are failing for mainstream so can't see it happening for CALD.</li> </ol>	64%
<b>Element 15</b>	Referrals are directed to dietitians and exercise specialists (i.e., exercise physiologists, physiotherapists) with experience in cancer care (where possible) with consideration of risks.	<ol style="list-style-type: none"> <li>1. I don't believe there are enough experienced specialists in rural areas to support this practice or statement.</li> <li>2. Absolutely. This being ignored would potentially work adversely for patient recovery.</li> <li>3. If these people exist, they certainly do not deal with paed - 0 -18yrs or are so hard to locate and book into people give up.</li> </ol>	76%

#### Principle 4: Coordinated and integrated care

##### Outcome

People affected by cancer receive holistic patient-centred dietary and exercise services coordinated and integrated across treatment modalities, providers, and health settings. This includes public and private sectors, as well as specialist, primary, community-based and not-for-profit services. Dietary and exercise care is delivered in a logical, connected, and timely manner for optimal continuity and to meet the individual needs of people affected by cancer.

Essential Elements of Care		Consumer Feedback	Consensus (% agreement)
<b>Element 16</b>	Between people affected by cancer, referrers, and service providers, care is coordinated and integrated to develop and implement dietary and exercise referral pathways.	<ol style="list-style-type: none"> <li>1. We got no help</li> <li>2. Not till the patient has a problem - dramatic weightloss, foot drop</li> <li>3. Once again, I will mention the dire need for a survivorship clinic to help in the area for our children (or in fact 0-30yr olds).</li> </ol>	60%

<b>Element 17</b>	Between people affected by cancer, referrers, and service providers, there are clear, timely and effective bilateral communication processes adopted by various methods (e.g., email, telephone, shared medical records).	<ol style="list-style-type: none"> <li>1. Health care worker attached to your patient</li> <li>2. Physio and dietitian always let the treating team know of their findings.</li> <li>3. Something all parents would like to see. Currently depends on who demanding a parent is. Often, they simply give up.</li> </ol>	64%
<b>Element 18</b>	People affected by cancer have dietary and exercise care plans, assessments, and updates on progress and outcomes which service providers feedback to referrers.	<ol style="list-style-type: none"> <li>1. There is currently a three-year waitlist to access any survivorship services at the QCH. Even to access the pain clinic, for daily, chronic, quality of life reducing pain is a yearlong wait. Disgraceful &amp; cruel.</li> <li>2. Well before treatment you have a weigh in to see your weight. I'm sure there are red flags with this process but don't know.</li> <li>3. Dietary and exercise care plans, assessments and updates in paedics are so rare I doubt feedback happens.</li> </ol>	68%
<b>Element 19</b>	People affected by cancer have routine evaluations of their dietary and exercise plans to improve quality of care.	<ol style="list-style-type: none"> <li>1. Not once in over five years. Zero care or expertise at the QCH.</li> <li>2. sometimes - if you ask for a dietitian or physio</li> <li>3. Only if the parent is able to do this - thankfully diet is not a general cause on paediatric cancers.</li> </ol>	60%
<b>Element 20</b>	People affected by cancer can access various modes of dietary and exercise service delivery (e.g., using telehealth) based on their individual needs and preferences.	<ol style="list-style-type: none"> <li>1. They may have access but not all long-term survivor patients have this prioritised to them.</li> <li>2. Rarely</li> </ol>	60%

## Principle 5: Data-driven improvements and investment in research

### Outcome

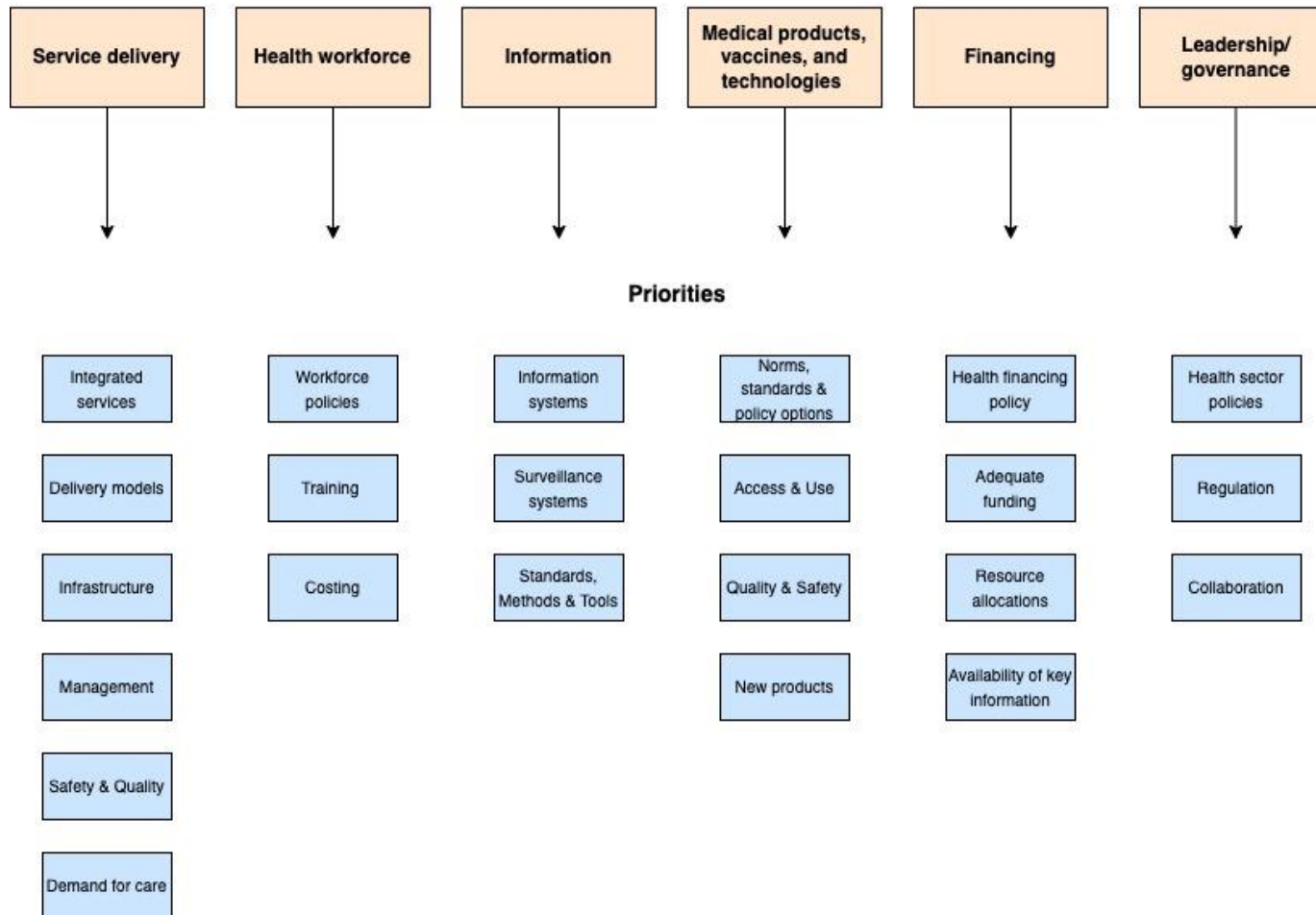
National collection and reporting of key cancer data, including consumer experience and outcome data, provides an indicator for high quality care, influences health service improvements and informs investment in research. Published research in cancer survivorship enriches the evidence base and informs improvements to enhance the care and outcomes of people affected by cancer.

Essential Elements of Care		Consumer Feedback	Consensus (% agreement)
<b>Element 21</b>	Dietary and exercise referrals can be optimised by collecting and evaluating quality data on the referral process and care outcomes using validated instruments and standardised protocols, where appropriate.	<ol style="list-style-type: none"> <li>1. But also, each patient has different needs so needs to be flexible. Tailored.</li> <li>2. I agree. However, if the patient is not particularly motivated about diet and exercise, collecting reliable data (i.e., diet quality from a questionnaire) may be a challenge, even with validated instruments.</li> </ol>	83.33%

<b>Element 22</b>	Dietary and exercise referrals can be optimised by translating research into practice, innovation, and improvements in cancer care.	<ol style="list-style-type: none"> <li>1. A part of the solution but must be done in conjunction with other markers.</li> <li>2. Changing practice with new knowledge is great. However, my concern is that diet and exercise often place great responsibility on the individual, and particularly for cancer patients, this may be hard to achieve.</li> <li>3. Only if they happen</li> </ol>	91.67%
<b>Element 23</b>	Research for dietary and exercise referral pathways should be continually invested in, and strengthened, to optimise outcomes for people affected by cancer.	<ol style="list-style-type: none"> <li>1. And children &amp; YA's need to be included. Additionally, when public funds are being accessed to fund the research &amp; CT's, the results must be translated, otherwise nothing is gained for the end users/funders.</li> <li>2. Only a positive impact in challenging times</li> <li>3. Depends on the frequency at which it is updated, however, it is always good to update knowledge with changing treatments and environments.</li> <li>4. Diet and exercise are two facets of cancer recovery. While research on best practice approaches can be helpful the approach should be holistic and not just focus on diet and exercise. Supporting the individual's mental health is probably most important because that will have a direct impact on their ability to implement any diet and exercise recommendations.</li> <li>5. But rarely occurs in the paed cancer world</li> </ol>	95.83%
<b>Element 24</b>	Investment in research for dietary and exercise referral practices should be produced in partnership with public and private sectors and organisations representing people affected by cancer together with governing bodies and industry.	<ol style="list-style-type: none"> <li>1. Vital as not all government services are located throughout QLD. Also, the waiting list can impact service deliver and time. Need to create a preferred list of supplies. they need to provide the service at No Gap - community minded. Or the QLD Gov pays for the service or influence the Medicare system to add various cost items for cancer patients. or the health care card cancer patient's referral system.</li> <li>2. Conflicts of interest and (at times) differing agendas may make that difficult.</li> <li>3. Doctors are good at ensuring the best chemotherapy/dose/radiation treatment. Nurses, teacher, physios, dietitians and (never seen) exercise physiologists are great for making a connection with the patient and family. Helping them get through the changes and treatment, both mentally and physically. Childhood Cancer Service Accommodation had gym equipment that was used by the patients, but mostly by carers who need to maintain their health to be the best advocate for their child. Why is there no light gym equipment (stretch fabrics etc) for families of patients to bring exercise, laughter and health of the carer and therefore the child. How about in the ward?</li> </ol>	92%

### Appendix 9: WHO building blocks and priorities (study 3)

## WHO building blocks





## Appendix 10: Participant information form (study 3)

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### PARTICIPANT INFORMATION SHEET AND CONSENT FORM

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**Title: A systems-thinking mapping workshop to implement essential elements of diet and exercise referral practices for people with cancer**

#### **Chief Investigator**

Ms Ria Joseph/ PhD Candidate  
Cancer Survivorship Program, Caring Futures Institute  
College of Nursing and Health Sciences, Flinders University  
Adelaide, South Australia  
Tel: +61 406437648

#### **Co-Investigator**

Professor Raymond Chan  
Director and Matthew Flinders Professor of Cancer Nursing  
Caring Futures Institute  
College of Nursing and Health Sciences, Flinders University  
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#### **Co-Investigator**

Associate Professor Nicolas Hart  
Deputy Lead (Cancer Survivorship Program) and Matthews Flinders Senior Research Fellow  
Caring Futures Institute  
College of Nursing and Health Sciences, Flinders University  
Adelaide, South Australia

#### **Co-Investigator**

Professor Natalie Bradford  
Principal Research Fellow  
Cancer and Palliative Care Outcomes Centre  
School of Nursing, Queensland University of Technology  
Brisbane, Queensland

#### **Description of the study**

Optimal dietary and exercise care for cancer survivors requires effective strategies that address different processes at individual, interpersonal, organisational, community and policy levels. At the individual level, diet and exercise play an important role in addressing the physical and psychosocial effects experienced by cancer survivors. Therefore, a multidisciplinary team approach is critical to support cancer survivors in achieving optimal wellbeing, including medical, nursing, and allied health professionals (such as dietitians, exercise physiologists, or physiotherapists).

Although medical and nursing health professionals understand that referrals to allied health professionals form part of their role, there is limited standardised guidance regarding the use of appropriate referral processes, to effectively provide dietary and exercise support to cancer survivors, including Aboriginal and Torres Strait Islander people and culturally and

linguistically diverse communities. Better guidance is required for medical and nursing health professionals, in terms of what advice they should provide, when to provide the advice, as well as how and when to refer cancer survivors to dietitians and exercise professionals (i.e., exercise physiologists and physiotherapists).

Therefore, *essential elements of diet and exercise referral practices* were developed through a modified Delphi consensus process, and underpinned by Cancer Australia's Principles of Cancer Survivorship. Prior to the implementation of these essential elements, factors in the health system which can influence implementation; and potential strategies to address these barriers need to be identified. Given the World Health Organisation (WHO) building blocks is a widely used framework applied to a range of health system related studies, it can be used to facilitate key stakeholders' preferences and context-specific needs. Thus, the WHO building blocks can be used to identify factors that may influence the implementation of essential elements of diet and exercise referral practices in a cancer setting.

This project is supported by Caring Futures Institute, College of Nursing and Health Sciences, Flinders University.

### **Purpose of the study**

This study aims to understand and identify factors in the healthcare system which can influence the implementation of essential elements in practice. The overarching research question is "From the perspectives of key stakeholders, what factors in a health system can impact the implementation of essential elements in practice?"

### **Benefits of the study**

It is expected that this research study will not benefit you directly. The outcomes of the research, however, will provide a visual representation of the factors that can impact the implementation of essential elements for cancer survivorship. In summary, this model will inform the development of a state-wide framework to guide policy, planning and health system responses to cancer survivorship, focusing on the health and wellbeing of people living with and beyond cancer.

### **Participant involvement and potential risks**

Your participation in this study is entirely voluntary. If you agree to participate in the research study, you will be asked to attend a full day workshop (split into sessions):

*Session 1:* You will receive an overview of the study and an explanation of the systems-thinking approach to this study. You will be asked to: 1.) discuss barriers and facilitators that may affect the implementation of essential elements; and 2.) identify relationships between the factors.

*Session 2:* You will be asked to: 1.) present your diagram with identified barriers and facilitators to the whole group for discussion and refining; and 2.) brainstorm potential strategies to address the identified barriers.

### **Reimbursement**

You will be reimbursed for any reasonable travel, accommodation, car parking fees, taxi fares, and meals associated with the study visit. If travelling from interstate, Flinders

University will purchase your flight tickets and accommodation. Consumers will also be compensated for their time with \$200 gift cards in addition to any travelling costs.

### **Risks of the study**

There are no foreseeable risks beyond the inconvenience of giving up time to participate and the low risk of anxiety induced by participating in workshops. However, consumer representatives may experience feelings of distress due to discussing their own experiences as cancer survivors. If you experience feelings of distress as a result of participation in this study, please let the research team know immediately. You can also contact the following services for support:

- Lifeline – 13 11 14, [www.lifeline.org.au](http://www.lifeline.org.au)
- Beyond Blue – 1300 22 4636, [www.beyondblue.org.au](http://www.beyondblue.org.au)

### **Withdrawal Rights**

You may, without any penalty, decline to take part in this research study. If you decide to take part and later change your mind, you may, without any penalty, withdraw at any time without providing an explanation. To withdraw, please contact the Chief Investigator or you may just not participate in workshops at any time. The audio recording and transcriptions will be re-identifiable. Should you choose to withdraw, it will not be possible to identify and remove any comments you have made prior to withdrawing due to the workshop format.

### **Confidentiality and Privacy**

Only researchers listed on this form have access to the individual information provided by you. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected at all times. You will not be named, and your individual information will not be identifiable in any research products without your explicit consent. De-identified datasets may be used in future research projects.

### **Data Storage**

The information collected will be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for ten years after publication of the results. The stored data generated by this research project may be used in future research projects for no more than ten years after publication of the results of this study. Following the required data storage period, all data will be securely destroyed according to university protocols.

### **How will I receive feedback?**

On project completion, a short summary of the outcomes will be provided to all participants via email or published on Flinders University's website.

### **Ethics Committee Approval**

The project has been approved by Flinders University's Human Research Ethics Committee (HREC application number: 5566).

### **Queries and Concerns**

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 2543 or email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).

Thank you for taking the time to read this information sheet which is yours to keep. If you accept our invitation to be involved, please sign the enclosed Consent Form.

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## CONSENT FORM

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### Consent Statement

- I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.
- I am not aware of any condition that would prevent my participation, and I agree to participate in this project.
- I understand that I am free to withdraw at any time during the study.
- I understand it will not be possible to identify and remove any comments I have made prior to withdrawing due to the workshop format.
- I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.
- I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

- taking part in a full day workshop (split into sessions)
- having my information audio recorded
- my de-identified data and information being used in this project and other related projects for an extended period of time (no more than 10 years after publication of the data)

**Signed:**

**Name:**

**Date:**

### **Appendix 11: Draft invitation email (study 3)**

Dear Mr/Ms/Dr/Prof,

On behalf of Professor Raymond Chan, Dr Nicolas Hart, and Associate Professor Natalie Bradford, I would like to invite you to join our stakeholder group and take part in a **full day workshop** at Flinders University, Adelaide, Australia, **on 11<sup>th</sup> November 2022**. If you live interstate, you will be reimbursed for interstate travel and accommodation costs for participating in this workshop.

Your expertise and insights are invaluable to our systems-thinking needs in this workshop pertaining to diet and exercise referral practices for people with cancer.

We are holding this workshop to understand, from a complex systems perspective, the interactions of the healthcare system that may influence the implementation of essential elements of dietary and exercise referral in a cancer setting. These essential elements underpinned by Cancer Australia's principles of cancer survivorship are aspirational, governing statements that can help medical and nursing health professionals implement and evaluate optimal dietary and exercise referral practices to achieve high-quality survivorship care for cancer survivors. Our research group would like to talk to key stakeholders from

different healthcare settings to establish (1) how the healthcare systems influence referral practices; (2) identify barriers and facilitators relating to referral practices for cancer survivors; and to (3) identify innovative strategies to address these system factors.

Please find attached a participant information sheet/consent form to gain a better understanding of what the study is about and what you would be expected to do before you decide whether you wish to participate in this study.

If you decide to take part in the study, you will be asked to take part in a full day workshop (split into sessions), held at Victoria Square, Flinders University. Reminder: if you live interstate, you will be reimbursed for interstate travel and accommodation costs.

If you are unable to take part, we would appreciate it if you could nominate a potential member of your team or network to act as a proxy to represent you, or decline participation, with an email reply.

However, if you are willing to participate in this study, or if you would like to discuss this study further, please contact Project Officer: Ria Joseph via email: [ria.joseph@flinders.edu.au](mailto:ria.joseph@flinders.edu.au)

We look forward to hearing from you, and we thank you for your consideration.

Yours sincerely,  
Ria

**Ms Ria Joseph**

PhD Candidate/Project Officer  
Cancer Survivorship Program, Caring Futures Institute  
College of Nursing and Health Sciences, Flinders University  
Adelaide, South Australia

**Professor Raymond Chan**

Director and Matthew Flinders Professor of Cancer Nursing  
Caring Futures Institute  
College of Nursing and Health Sciences, Flinders University  
Adelaide, South Australia

**Associate Professor Nicolas Hart**

Deputy Lead (Cancer Survivorship Program) and Matthews Flinders Senior Research Fellow  
Caring Futures Institute  
College of Nursing and Health Sciences, Flinders University  
Adelaide, South Australia

**Professor Natalie Bradford**

Principal Research Fellow  
Cancer and Palliative Care Outcomes Centre  
School of Nursing, Queensland University of Technology  
Brisbane, Queensland



## Appendix 12: Participant workshop booklet (study 3)

# SYSTEMS-THINKING WORKSHOP OUTLINE

Date: 11/11/2022

Start time: 8.30am

End time: 4pm

Location: Level 1, Room 2, 182 Victoria Square, Flinders University, Adelaide

TIME	DESCRIPTION
8.30-9am	Introduction
9-10am	Session 1
10-10.20am	Morning Tea
10.20-11am	Session 2 (Part 1)
11am-12pm	Session 2 (Part 2)
12-1pm	Lunch
1-2pm	Session 3
2-2.20pm	Afternoon Tea
2.20-3.50pm	Session 4
3.50-4pm	Closing



## **SYSTEMS-THINKING MAPPING WORKSHOP FOR OPTIMISING DIETARY AND EXERCISE REFERRAL PRACTICES**

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### **BACKGROUND**

Optimal dietary and exercise care for cancer survivors requires effective strategies that address multifaceted processes at individual, interpersonal, organisational, community and policy levels. At the individual level, diet and exercise play an important role in addressing the physical and psychosocial effects experienced by cancer survivors. There is limited standardised guidance for cancer care professionals regarding the use of appropriate referral processes, to effectively provide dietary and exercise support to cancer survivors, including Indigenous and culturally and linguistically diverse communities. Therefore, essential elements of diet and exercise referral practices were developed through a modified Delphi consensus process, and underpinned by Cancer Australia's principles of cancer survivorship. Essential elements are aspirational, governing statements that can help medical and nursing health professionals implement and evaluate optimal dietary and exercise referral practices to achieve high-quality survivorship care for cancer survivors. Prior to the implementation of these essential elements, factors in the health system which can influence referral practices; and innovative strategies to address these system-level factors need to be identified.

'Systems thinking' involves exploring the characteristics of components within a system and how they interconnect to improve understanding of how outcomes emerge from these interactions. Complex systems, such as a health system, consist of many interactions between people, tasks, technology, environments (physical, social, and cultural), organisational structures and external factors. A health system framework can support researchers and policymakers in describing the structure, organisation, functions, and processes of a health system, which can help identify actions to improve health system performance. According to the WHO framework, six building blocks make up a health system, and include (1) service delivery, (2) health workforce, (3) information, (4) medical products, vaccines, and technologies, (5) financing and (6) leadership and governance. To strengthen health systems, these six health system building blocks need to be considered for areas to target for improvements to health services and for health outcomes to be sustainable. Given WHO is a widely used framework applied to a range of health system related studies, it can be used to facilitate key stakeholders' preferences and context-specific needs. Thus, the WHO building blocks can be used to identify system-level factors that may influence referral practices in a cancer setting.

### **PURPOSE OF WORKSHOP**

In this workshop, we will ask you to use a systems-thinking approach to understand, from a complex system perspective, (1) the interactions of the healthcare system which may influence referral practices; (2) identify system-level factors and to (3) identify innovative strategies to address these system factors, ultimately optimising dietary and exercise referral practices.

## Part 1. Introduction

- Acknowledgement of Country
- Format of the workshop
- Explanation of systems thinking, cognitive diagrams and causal loop diagrams
- Introduction to Cancer Australia's principles of cancer survivorship and essential elements of optimal dietary and exercise referral practices
- Description of the WHO health system building blocks framework

## Part 2. Workshop (4 x Sessions)

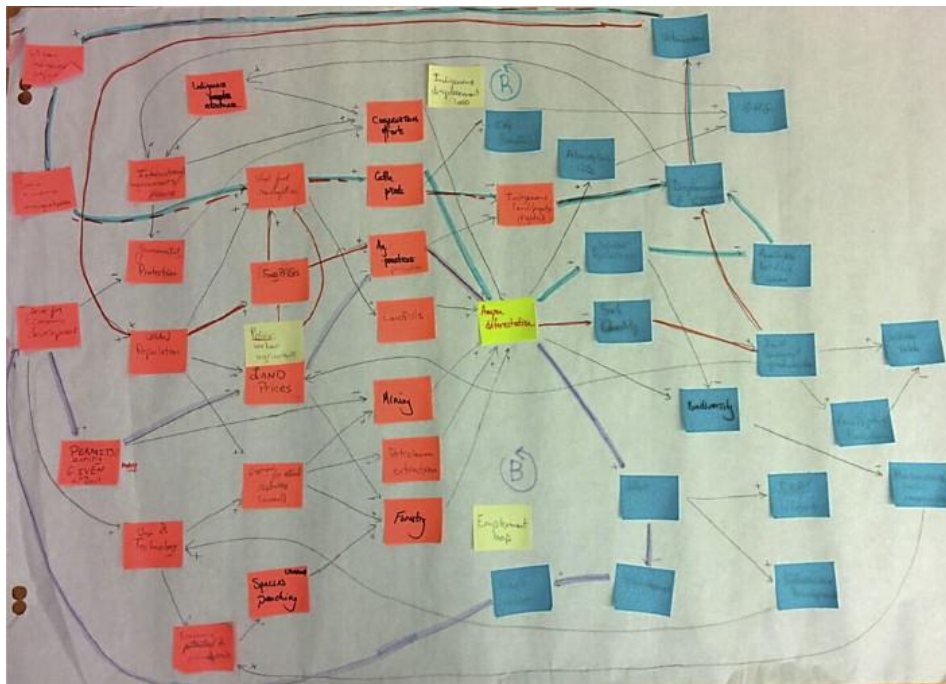
### SESSION 1 - SMALL GROUP DISCUSSION

This session will involve discussing how the health system works. Your group will be allocated one WHO building block and the session will involve identifying system-level factors that relate to your WHO building block and the essential elements of optimal dietary and exercise referral practices. The group will develop cognitive diagrams highlighting the identified system-level factors using sticky notes and markers.

## BREAK

### SESSION 2 (Part 1) - SMALL GROUP DISCUSSION

This session will involve discussing how the WHO building block allocated to you interact with the other building blocks and identifying relationships between them. The group will further expand on the cognitive diagrams highlighting the relationships between the system-level factors using markers.



### SESSION 2 (Part 2) – LARGE GROUP DISCUSSION

This session will involve discussing identified relationships with the larger group. A facilitator from each of the groups will summarise and present their cognitive diagrams.

*WHAT WILL BE PROVIDED (Session 1 and 2)*

- Essential elements of optimal dietary and exercise referral practices
- WHO building blocks and priorities
- Pre-prepared sheets of butcher paper
- Sticky notes
- Markers

**BREAK**

**SESSION 3 – SMALL GROUP DISCUSSION**

This session will involve discussing and summarising innovative strategies. These strategies should leverage system-level facilitators and address system-level barriers to optimise dietary and exercise referral practices.

*WHAT WILL BE PROVIDED (Session 3)*

- Cognitive diagrams from Session 1 and 2

**BREAK**

**SESSION 4 - LARGE GROUP DISCUSSION**

This session will involve discussing your group's top five strategies with the larger group for each WHO building block. A facilitator from each of the groups will summarise and present their group's top five strategies. Participants will be encouraged to translate these strategies into specific actions, timelines, and responsibilities (i.e., key stakeholders) to reach a desired outcome.

## **ESSENTIAL ELEMENTS OF OPTIMAL DIETARY AND EXERCISE REFERRAL PRACTICES**

### **Principle 1: Consumer involvement in person-centred care**

#### **Essential Elements**

1. People affected by cancer are informed about the benefits of diet and exercise for the management of cancer.

2. People affected by cancer are provided with information on dietary and exercise services available to support healthy lifestyles.
3. People affected by cancer are advised to access existing dietary and exercise services available to support healthy lifestyles.
4. People affected by cancer are empowered to take control of their health.
5. People affected by cancer are provided with referrals to dietitians and exercise professionals.

## **Principle 2: Support for living well**

### **Essential Elements**

6. People affected by cancer are best supported when their needs for referrals to dietitians and exercise professionals are evaluated at key transition phases (at diagnosis or end of treatment).
7. People affected by cancer are best supported when referrers are informed about the benefits of diet and exercise for the management of cancer.
8. Referrers are informed about the available dietary and exercise community programs, support groups and other services, and how to refer to these services.
9. People affected by cancer are best supported when general practitioners develop and review relevant Chronic Disease Management plans and incorporate dietary and exercise referrals for optimal care.
10. People affected by cancer are best supported when models of care in the community are adapted to optimally support healthy lifestyles and sustainable lifestyle changes, if required.

## **Principle 3: Evidence-based care pathways**

### **Essential Elements**

11. Referrals to dietitians and exercise professionals are based on grading systems or validated screening tools where possible to assist in identifying individual needs.
12. Referrals to dietitians and exercise professionals are based on individualised needs in accordance with evidence-based dietary and exercise guidelines.
13. Referrals to dietitians and exercise professionals are based on regular screening (i.e., MST, PA screening tool) of individual needs at key transition phases to facilitate timely referrals to appropriate services.
14. Dietary and exercise referrals are culturally tailored for Indigenous people, culturally and linguistically diverse (CALD) populations, and other vulnerable populations.

15. Referrals are directed to dietitians and exercise professionals (i.e., exercise physiologists, physiotherapists) with experience in cancer care (where possible) with consideration of risks.

#### **Principle 4: Coordinated and integrated care**

##### **Essential Elements**

16. Between people affected by cancer, referrers, and service providers, care is coordinated and integrated to develop and implement dietary and exercise referral pathways.
17. Between people affected by cancer, referrers, and service providers, there are clear, timely and effective bilateral communication processes adopted by various methods (e.g., email, telephone, shared medical records).
18. People affected by cancer have dietary and exercise care plans, assessments, and updated on progress and outcomes which service providers feedback to referrers.
19. People affected by cancer have routine evaluations of their dietary and exercise plans to improve quality of care.
20. People affected by cancer can access various modes of dietary and exercise service delivery (e.g., using telehealth) based on their individual needs and preferences.

#### **Principle 5: Data-driven improvements and investment in research**

##### **Essential Elements**

21. Dietary and exercise referrals can be optimised by collecting and evaluating quality data on the referral process and care outcomes using validated instruments and standardised protocols, where appropriate.
22. Dietary and exercise referrals can be optimised by translating research into practice, innovation and improvements in cancer care.
23. Research for dietary and exercise referral pathways should be continually invested in, and strengthened, to optimise outcomes for people affected by cancer.
24. Investment in research for dietary and exercise referrals practices should be produced in partnership with public and private sectors and organisations representing people affected by cancer together with governing bodies and industry.

## Workshop evaluation

**Please tick the perspectives you represent (ticks all that apply):**

- Clinical;  Policy;  Consumer;  Leadership;  Research;  Not-for-profit;  
 Government;  Administration;  Other: \_\_\_\_\_

Please give us feedback regarding the workshop by responding to the following questions (please tick the relevant box)

	Yes	No	Not Sure
1. Is this the first time you have adopted a systems-thinking perspective?			
2. Does your organization regularly use systems-thinking organization in a systematic way?			
3. Do you think your organization will benefit from using systems-thinking?			
4. Do you appreciate further training in applying a systems-thinking approach for yourself or your colleagues?			
5. What other areas of cancer survivorship or cancer control would benefit from a systematic systems-thinking exercise?			

Workshop Content	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
1. The information provided was clear and					

outlined the purpose of the workshop.					
2. There was enough time for discussion.					
3. The information I learned will allow me to adopt a systems-thinking perspective in my organization.					

<b>Workshop Organisation</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not Sure</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
1. The workshop was the right length of time.					
2. The venue and location were suitable.					
3. The handouts were useful.					

**General Comments**

A.) Please list your **top three** take home messages:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

B.) How could the workshop be improved?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

C.) Please feel free to state any additional comments that you may have.

\_\_\_\_\_

\_\_\_\_\_

*Thank you for your feedback.*

## Appendix 13: Facilitator workshop booklet (study 3)

### TABLE FACILITATOR'S GUIDE

#### CHECKLIST FOR FACILITATORS

Session	Task	Checklist
At the start and end of each session.	<b>Switch on audio recorder/phone</b> to record sessions and stop recording during breaks.	<input type="checkbox"/>
Start of session 1	Explain the purpose of the focus group.	<input type="checkbox"/>
Start of session 1	Explain the rules for the discussion.	<input type="checkbox"/>
Start of session 1	Address issues of confidentiality and remind participants that the sessions will be recorded as outlined in consent forms.	<input type="checkbox"/>
Session 2 (Part 1)	<b>Allocate 30 minutes for discussing the interactions</b> of your WHO building block and <b>10 minutes for prepping</b> for larger group discussion.	<input type="checkbox"/>
Session 3	Type up strategies on your laptop using Google Docs link below:	<input type="checkbox"/>
End of Session 3	<b>Ask participants to complete the evaluation questionnaire</b> (in their workshop booklets) following the workshop.	<input type="checkbox"/>
All sessions	Refer to protocol for examples of system-level factors and prompt questions if required.	<input type="checkbox"/>

#### Workshop Objective

The objective of this workshop is to co-develop a standardized state-wide evidence-based framework and model of cancer navigation and identify potential implementation strategies at the system level.

#### Instructions

##### WELCOME/INTRODUCTIONS

*Good morning. My name is \_\_\_\_\_.* [Introduce yourself to your group]

*Thank you for agreeing to be part of this workshop. We appreciate your willingness to participate.*

##### PURPOSE OF WORKSHOP

*In this workshop, we will ask you to apply a systems thinking approach to understand, from a complex system perspective, (1) the interactions of the healthcare system which may influence referral practices; (2) identify system-level factors and to (3) identify innovative strategies to address these system-level factors.*

##### GROUND RULES



*I just want to highlight that there are no right or wrong answers to these workshop discussions. We want to hear many different viewpoints and would like to hear from everyone where possible. We hope you can be honest even when your responses may not align with the rest of the group. In respect for each other, we ask that only one individual speak at a time in the group and that responses made by all participants be kept confidential.*

#### **AUDIO RECORDING**

*Also just wanted to let you know that we will be recording our conversations as highlighted in the consent forms. We want to make sure we capture everything you have to say. We assure you that all your comments will remain confidential.*

---

### **Part 1. Introduction**

- Acknowledgement of Country
- Format of the workshop
- Introduction to essential elements of dietary and exercise referral practices
- Description of the WHO health system building blocks framework
- Explanation of systems thinking, cognitive diagrams and causal loop diagrams

### **Part 2. Workshop (4 x sessions)**

#### **SESSION 1 – SMALL GROUP DISCUSSION**

This session will involve discussing how the health system works. Your group will be allocated one WHO building block and the session will involve identifying system-level factors that relate to your WHO building block and the essential elements of optimal dietary and exercise referral practices. The group will develop cognitive diagrams highlighting the identified system-level factors using sticky notes and markers. **Facilitators will add sticky notes to butcher papers during discussion with group (Ria + research team members will stick butcher paper + building blocks on the wall ready for group discussion in Session 2, Part 2).**

### **MORNING TEA BREAK**

**Examples of system-level factors for each building block (for facilitator use only)**

Building Block	Examples of system-level factors	Example prompt questions
<p>Service Delivery (Table 1)</p>	<ul style="list-style-type: none"> <li>• Access</li> <li>• Availability</li> <li>• Timeliness</li> <li>• Responsiveness</li> <li>• Satisfaction</li> <li>• Public-private relationships around service provision</li> <li>• Patient safety and quality of care</li> <li>• Integrated service delivery models and packages</li> <li>• Consumer engagement influencing demand for care</li> <li>• Infrastructure and logistics</li> <li>• Leadership and management</li> </ul>	<ul style="list-style-type: none"> <li>• How does the current referral process work? (i.e., referrals to dietitians and exercise professionals)</li> <li>• Who needs to be involved? Who is already involved?</li> <li>• Who has authority to make these decisions?</li> <li>• How does resourcing help? Are resources being allocated/utilised appropriately?</li> <li>• What challenges do rural and remote communities face?</li> <li>• What factors are specific to Aboriginal and Torres Strait Islander populations? And CALD communities?</li> <li>• <i>What factors of service delivery could influence referral practices?</i></li> <li>• <i>What factors of the health workforce could influence referral practices?</i></li> <li>• <i>What factors of information could influence referral practices?</i></li> <li>• <i>What factors of medical products, vaccines, and technologies could influence referral practices?</i></li> <li>• What factors of <i>financing</i> could influence referral practices?</li> <li>• <i>What factors of leadership/governance could influence referral practices?</i></li> <li>• <i>What services are available currently?</i></li> <li>• Is there capacity to manage resources for providing referrals?</li> <li>• What sort of education is required to be competent in providing referrals?</li> <li>• <i>Are staff qualified to provide referrals? Are they motivated to provide referrals?</i></li> <li>• How about financially? What options are available for cancer survivors? Are bundled payment options available? Is it cost-effective?</li> <li>• <i>In what ways are information systems being used/could be used?</i></li> <li>• Are the patient's and/or caregivers needs being considered?</li> <li>• <i>Are there organisational practices and policies in place to ensure referrals are being provided?</i></li> </ul>
<p>Health Workforce (Table 2)</p>	<ul style="list-style-type: none"> <li>• Qualified health professionals</li> <li>• Clinical support of staff</li> <li>• Recruitment and retention</li> <li>• Supply and distribution</li> <li>• Personnel management and performance systems</li> <li>• Training (pre-service and in-service)</li> </ul>	
<p>Information (Table 3)</p>	<ul style="list-style-type: none"> <li>• Health information systems</li> <li>• Management information systems</li> <li>• Data-informed service planning</li> <li>• Evaluation design</li> </ul>	
<p>Medical products, vaccines &amp; technologies (Table 4)</p>	<ul style="list-style-type: none"> <li>• Access and rational use</li> <li>• Public-private partnerships around technologies</li> <li>• Supply management</li> <li>• Quality and safety</li> </ul>	

Financing (Table 5)	<ul style="list-style-type: none"> <li>• Sustainable funding and resourcing</li> <li>• Revenue collection and pooling</li> <li>• Payment mechanisms: provider</li> <li>• Payment mechanisms: beneficiary</li> <li>• Resource allocation</li> <li>• Funding models</li> </ul>	<ul style="list-style-type: none"> <li>• Are up-to-date technologies being used to provide referrals to cancer survivors? (if at all)</li> <li>• Are cancer survivors being monitored and evaluated for referrals?</li> <li>• Are up-to-date and appropriate guidelines and protocols being used for referrals?</li> <li>• Is there is a time-efficient reporting system in place?</li> <li>• Are cancer survivors satisfied with the care?</li> </ul>
Leadership/Governance (Table 6)	<ul style="list-style-type: none"> <li>• Level of decision making</li> <li>• Institutional arrangements</li> <li>• Accountability</li> <li>• Scope and location of service providers</li> <li>• Consumer and stakeholder involvement</li> <li>• Organisational culture and champions</li> </ul>	<ul style="list-style-type: none"> <li>• Are services being provided on time? (e.g., at key timepoints when patients have increased needs for dietary and exercise support)</li> <li>• Have referral processes improved/changed?</li> <li>• Are modes of communications suitable for cancer survivors?</li> <li>• What is one thing that you are doing or could do in your setting that could improve referral practices?</li> <li>• What kinds of changes or alterations do you think you will need to make in the system (with regards to....) to optimise dietary and exercise referral practices in your setting?</li> <li>• What already exists (in terms of....) to support dietary and exercise referral practices?</li> <li>• What opportunities and strengths do you see? (within your healthcare setting)</li> <li>• What are likely issues or complications that may arise?</li> </ul>

## SESSION 2 (Part 1) – SMALL GROUP DISCUSSION

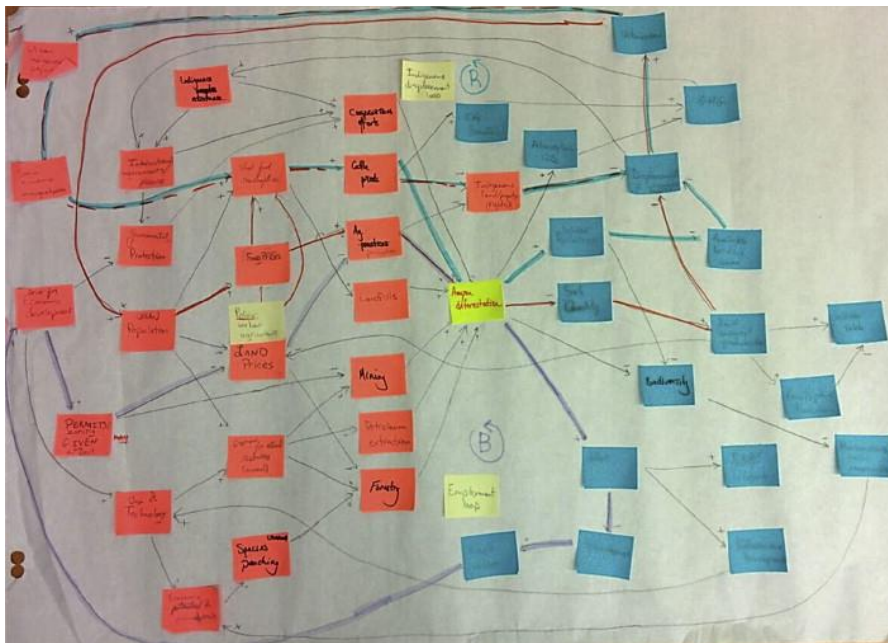
This session will involve discussing how the WHO building block allocated to you interact with the other building blocks and identifying relationships between them. The group will further expand on the cognitive diagrams highlighting the relationships between the system-level factors using markers **Facilitators will draw lines between system-level factors to highlight any relationships discussed in group.**

10.20-10.50am (30 minutes)- Small group discussion (Ria/research team members will set a timer to remind facilitators to start prepping for group discussion at 11am)

10.50-11am (10 minutes) – Prep for larger group discussion

### Example questions for facilitator:

- How does your building block interact with the other five WHO building blocks?
- How does *financing* influence *service delivery*?
- How much of an impact does the *health workforce* have on *service delivery*?
- How much of an influence does *leadership/governance* have on the remaining five building blocks?
- How can *information* inform *service delivery*?
- What factors are related?



## SESSION 2 (Part 2) – LARGE GROUP DISCUSSION

This session will involve discussing identified relationships with the larger group. **A facilitator from each of the groups will summarise and present their cognitive diagrams (Ria + research team members will add sticky notes to wall while each facilitator/participant is presenting).**

### Example questions for facilitator/chair:

- What similarities have you identified between the blocks?
- What differences have you identified?
- Have you found any of the relationships interesting/surprising?
- Can you talk about that more? Can you give me an example?

- Thank you. What do other people think?
- Does anyone else have any comments to add?

### **LUNCH BREAK**

#### **SESSION 3 – SMALL GROUP DISCUSSION**

This session will involve discussing and summarising innovative strategies. These strategies should leverage system-level facilitators and address system-level barriers to optimise dietary and exercise referral practices. **Facilitators will go through each of the system-level factors to initiate discussions in group regarding potential strategies. Facilitators will also type up strategies on their laptop using Google Docs link (Ria + research team members will type up system-level factors after Session 1 in Google Docs).**

#### **Example questions for facilitator/chair:**

- If you could make one change that would optimise dietary and exercise referral practices, what would you do?
- What system-level facilitators can be leveraged to address the system-level barriers?
- What potential strategies could be developed/implemented?
- Can you talk about that more? Can you give me an example?
- Thank you. What do other people think?
- Does anyone else have any comments to add?

### **AFTERNOON TEA BREAK**

#### **SESSION 4 – LARGE GROUP DISCUSSION**

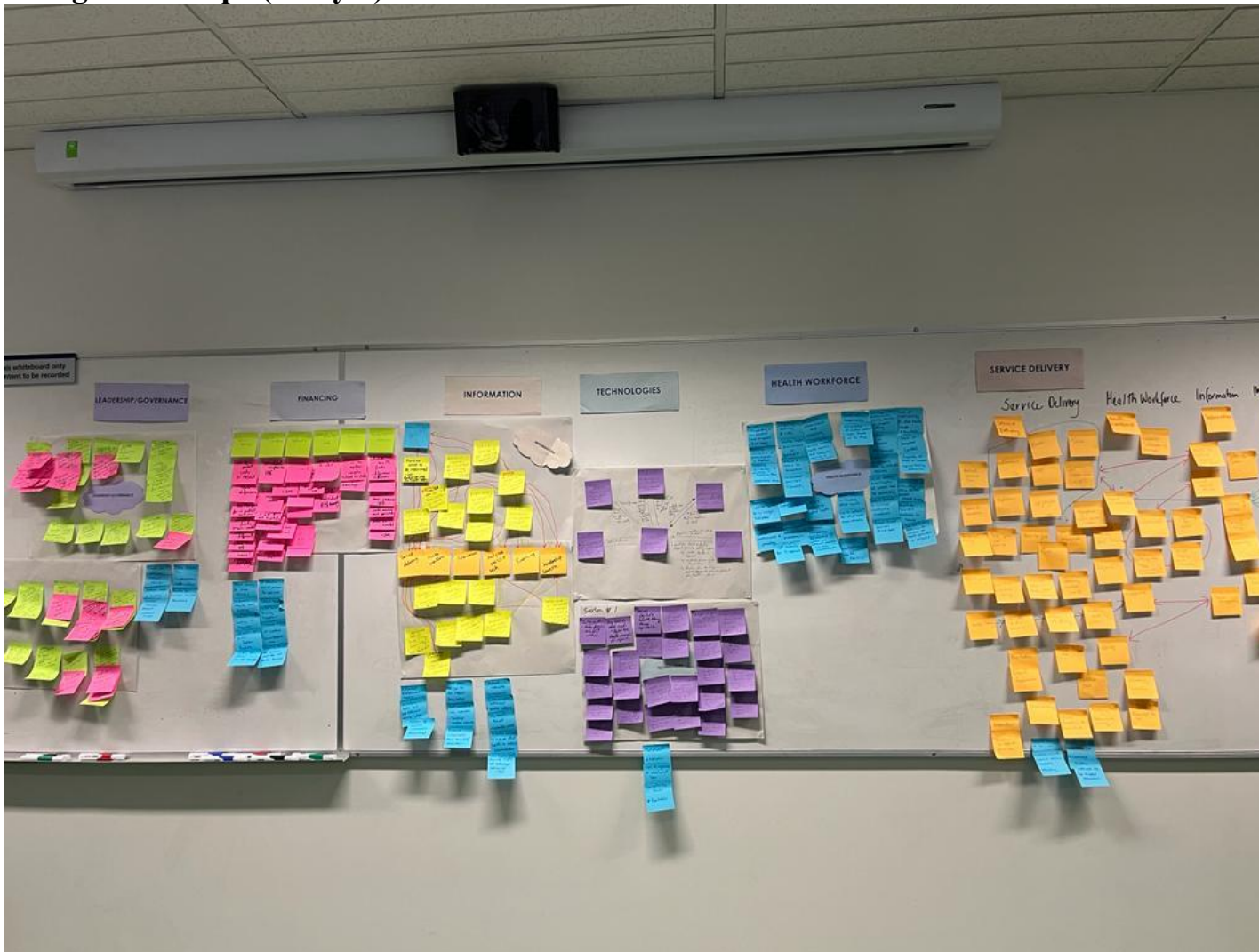
This session will involve discussing your group's top five strategies with the larger group for each WHO building block. A facilitator from each of the groups will summarise and present their group's top five strategies. Participants will be encouraged to translate these strategies into specific actions, timelines, and responsibilities (i.e., key stakeholders) to reach a desired outcome. **A facilitator from each of the groups will summarise and present their group's top five strategies.**

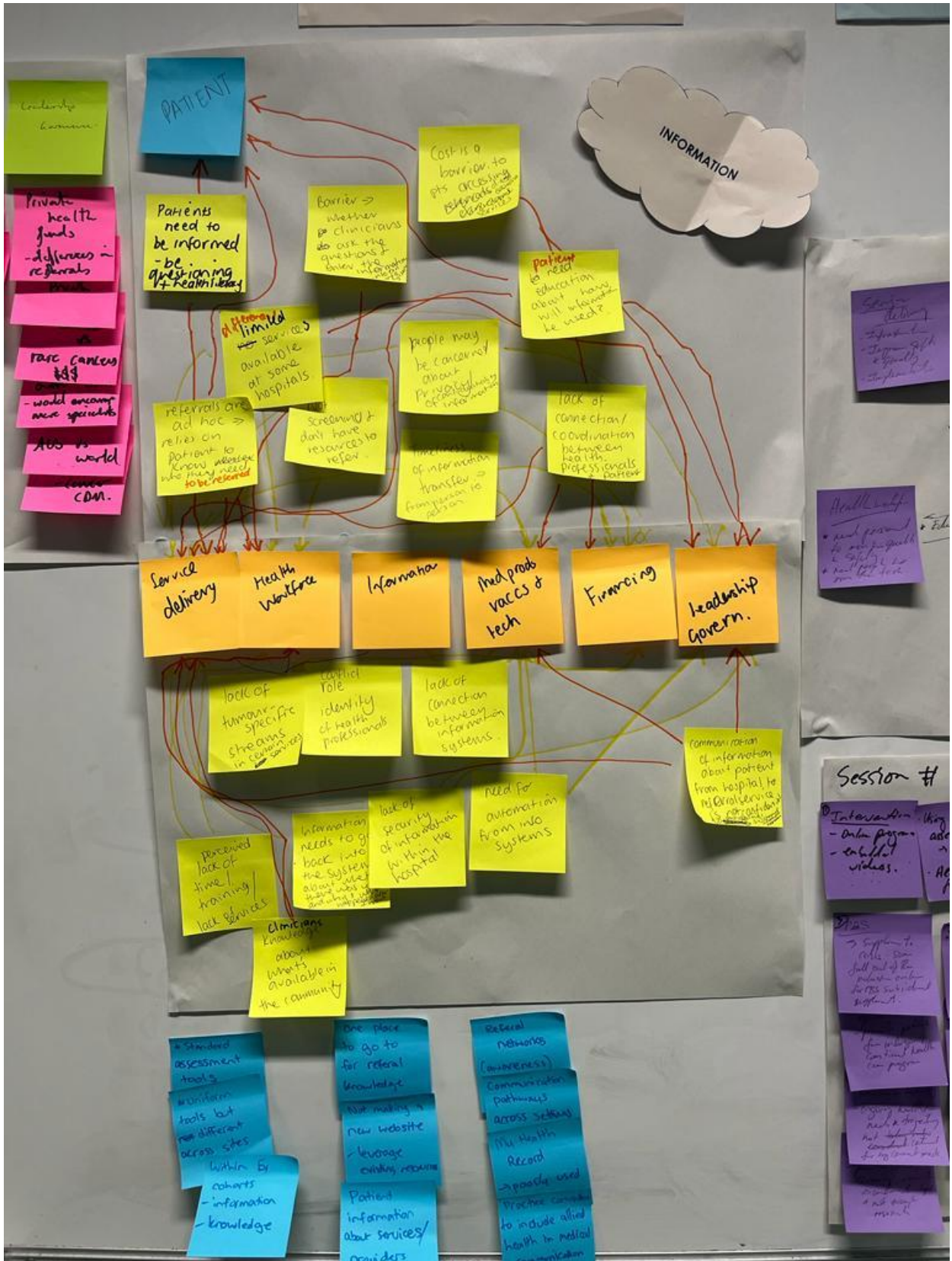
#### **Example questions for facilitator/chair:**

- If you could make one change that would optimise dietary and exercise referral practices, what would you do?
- How can we make these strategies actionable? (Who? What? When? How?)
- How can we implement these strategies?
- Who needs to be involved? Who is already involved?
- What already exists (in terms of....) to implement these strategies?
- How can we implement this?

### **CLOSIN**

## Appendix 14: Cognitive maps (study 3)





## Appendix 15: Barriers to dietary and exercise referrals (study 3)

Category	Barriers/Facilitators	
<b>Financing</b>	System-level	<ul style="list-style-type: none"> <li>• Resource allocation (e.g., grant funded services)</li> <li>• Lack of funding (e.g., federal vs state, state by state differences, private vs public system)</li> <li>• Activity based funding (ABF) in hospitals</li> <li>• MBS item billing (CDMP)</li> <li>• No clear funding pathway</li> <li>• Costs for common cancers vs rare cancers</li> </ul>
	Patient-level	<ul style="list-style-type: none"> <li>• Out of pocket costs for patient/patient finances</li> </ul>
<b>Service Delivery</b>	System-level	<ul style="list-style-type: none"> <li>• Infrequent and inconsistent screening practices by health professionals</li> <li>• Lack of advocacy for scope of practice</li> <li>• Inadequate use of guidelines and standards for measures and output</li> <li>• Lack of evaluation of data for Care MDT</li> <li>• Implementation of Optimal Care Pathways</li> <li>• Ad-hoc referrals (relies on patient knowledge re services)</li> <li>• Insufficient access to allied health support (i.e., 5 sessions per year)</li> <li>• Cost barriers</li> <li>• Geographic barriers</li> <li>• Lack of tumor specific streams in certain services</li> </ul>
<b>Information</b>	System-level	<ul style="list-style-type: none"> <li>• Lack of communication pathways between health professionals and patients across settings.</li> <li>• Lack of accreditation standards for outpatient/community compared to inpatients</li> <li>• Limited access to medical records for private providers</li> <li>• Lack of security of information within the hospital (e.g., patient concerns about privacy/confidentiality of information)</li> </ul>
	Provider-level	<ul style="list-style-type: none"> <li>• Lack of training and CPD</li> <li>• Conflict role identity of health professionals</li> <li>• Lack of awareness of resources/services.</li> <li>• Level of experience regarding knowledge of whether patient needs physiotherapist or exercise physiotherapist</li> <li>• Lack of community expertise for regional health</li> </ul>
	Patient-level	<ul style="list-style-type: none"> <li>• Lack of awareness of resources/services.</li> <li>• Lack of digital and health literacy</li> <li>• Trust and reliability of information for patients</li> </ul>
<b>Leadership/Governance</b>	System-level	<ul style="list-style-type: none"> <li>• Fragmented leadership/responsibilities involving peak bodies and accredited bodies such as APA, ESSA, DA, COSA, Nutrition Australia, Fitness Australia, cancer councils, care providers, GPs, LHNs, leadership mentoring systems</li> <li>• Lack of involvement of all stakeholders from the beginning resulting in a fragmented system</li> <li>• Lack of pathway/chain (e.g., Cancer Australia plan can be implemented into services)</li> <li>• Barriers in care coordination (e.g., My Health record is poorly used).</li> <li>• Lack of guidance for current clinical system</li> <li>• Lack of structure for cancer type differences</li> </ul>
<b>Medical Products/Technologies</b>	System-level	<ul style="list-style-type: none"> <li>• Technology limitations (e.g., data breaches)</li> <li>• Lack of connection between information systems</li> <li>• Technologies not supported by healthcare system/connectivity issues</li> </ul>
<b>Health Workforce</b>	System-level	<ul style="list-style-type: none"> <li>• Limited staff capacity/services</li> <li>• Lack of personnel to manage quality and safety</li> </ul>



		<ul style="list-style-type: none"> <li>• Resource allocation to different cancer types (some cancers get allocated more resources than others)</li> <li>• Lack of work-from-home resources</li> <li>• Limited services available at some hospitals</li> <li>• Leveraging existing resources such as my health record</li> </ul>
	Provider-level	<ul style="list-style-type: none"> <li>• Time constraints</li> <li>• Reluctance to refer patients from acute care due to reduced trust</li> <li>• Reluctance to own care</li> <li>• Risk-adverse</li> <li>• Lack of commitment</li> <li>• Contribution of students during their placements</li> </ul>
	Patient-level	<ul style="list-style-type: none"> <li>• Patient demand</li> </ul>