THE JOURNEY OF REGIONAL PEOPLE LIVING WITH CANCER: AN EXAMINATION OF HEALTH BEHAVIOURS AND ENGAGEMENT IN FOLLOW-UP CARE IN THE POST-TREATMENT PHASE

A Thesis submitted by

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Abstract

People living in regional communities are disproportionately impacted by cancer compared to metropolitan people, showing significantly poorer cancer outcomes and survival. Further, it has been established that engagement in follow-up medical care and healthy lifestyle behaviours post-treatment is critical for treatment efficacy, optimal recovery and long-term health and wellbeing. Unfortunately, regional populations generally show poorer health promoting behaviours, although there has been little examination whether this persists following cancer diagnosis and treatment. This thesis provides an in-depth examination of the health-promoting behaviours of regional people living with cancer following diagnosis and treatment and aimed to identify the 'regional' factors driving poorer health behaviours.

The thesis comprises four studies, the first being a scoping review of factors associated with health-promoting behaviours in regional populations with chronic health conditions, in order to inform the design of the remaining three studies. Given a paucity of literature within regional cancer populations, this review synthesised evidence from regional populations with any chronic health diagnosis. The scoping review findings provided impetus for the examination of individual characteristics in Study 2, 3 and 4, identifying key gaps within the current literature relating to adherence to long-term medical management in regional chronic health populations. While attitudes and beliefs were of particular interest to researchers, individual characteristics commonly used to distinguish regional populations (including stigma, fatalism, consideration of future consequences, resilience and barriers to help-seeking) and found to influence health help-seeking and preventive health behaviours had not yet been examined for their role in engagement in long-term medical management. Additionally, the importance of receiving information and rationale for ongoing medical management featured prominently in the literature, supporting the novel benefits of examining individual characteristics associated with regional populations in Study 2, 3 and 4, while accounting for key demographic factors (age, gender, income, education) and patient information (receipt of a Survivorship Care Plan).

The remaining three studies were part of a larger longitudinal cohort study (Travelling for Treatment) conducted in collaboration with the Cancer Council Queensland. The Travelling for Treatment program recruited regional people living with cancer in Queensland who were required to travel to major centres in order to receive treatment, and who stayed at one of Cancer Council Queensland's residential lodges while accessing cancer care. Studies 2, 3 and 4 of this thesis aimed to a) describe the profile of health-promoting behaviours at the time of attending a major centre to receive cancer care, b) examine how those behaviours changed throughout the 12-month period following care, and c) examine whether individual characteristics commonly associated with regional populations predicted health-promoting behaviours in the post-treatment period. In total, 273 participants completed questionnaire assessments at 3 time points (baseline, 6-months and 12-months) over the year following their visit to major treatment centres. Study 2 revealed that, upon entering initial treatment/care, participants showed poor receipt of information/knowledge about their cancer diagnosis. In terms of health behaviours, participants showed patterns of poor weight management, high rates of hazardous drinking and smoking, poor nutrition, and insufficient physical activity levels. Individual characteristics (including attitudes) played a limited role in explaining health status and health behaviours at baseline.

Study 3 results revealed that participants showed small improvements in some health behaviours by 6-months post-treatment/care in a major centre, however, participants were unable to maintain or further improve these behaviours long-term and returned to baseline levels by the 12-month time point. With respect to engagement in medical follow-up care, while adherence to follow-up appointments and tests was high, a large proportion of participants failed to adhere to ongoing recommended follow-up treatment.

Study 4 findings revealed that, in terms of the factors driving health-promoting behaviours, there were very few consistent predictors of health behaviours. In terms of individual characteristics, stigma and resilience were not predictive of health behaviours, although barriers to help-seeking did negatively predict fruit and vegetable consumption as well as smoking cessation, and fatalism negatively predicted vegetable consumption, exercise and smoking cessation at some time points. Female gender, older age and higher education were drivers of positive engagement in health-promoting behaviours.

The findings of this program of research suggest that there is significant room for improvement in the health-promoting lifestyle behaviours of regional people following treatment for cancer. Given the known benefits of positive health behaviours such as physical activity, optimal nutrition, reduced smoking and limited alcohol consumption on cancer outcomes, a greater level of support is required in order to assist regional people to make positive changes and to maintain them long-term. However, individual characteristics often associated with regional populations appeared to drive only some health behaviours, and based on this thesis, do not appear to be of substantial impact in determining the poor health behaviours of regional people living with cancer during the post-treatment period. Thus, intervention aimed at improving engagement in long-term cancer management should focus beyond the individual, to a system- and community-level.

Keywords: regional, rural, cancer survivorship, engagement, adherence, individual characteristics, attitudes, stigma, fatalism, consideration of future consequences, resilience, barriers to help-seeking

Certification of Thesis

This Thesis is the work of Arlen Kate Rowe except where otherwise acknowledged. The work is original and has not previously been submitted for any other award, except where acknowledged

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Student and supervisors' signatures of endorsement are held at the University.

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Abbreviations

ABS	Australian Bureau of Statistics
ACS	American Cancer Society
ACSC	Australian Cancer Survivorship Centre
AIHW	Australian Institute of Health and Wellbeing
CCA	Cancer Council Australia
CDC	Centers for Disease Control and Prevention
CRC	Colorectal Cancer
IoM	Institute of Medicine
NHMRC	National Health & Medical Research Council
PTSS	Patient Travel Subsidy Scheme
SCP	Survivorship Care Plan
SES	Socio-Economic Status
WHO	World Health Organization

Chapter 1: The Journey of Regional People Living with Cancer: An Examination of Health Behaviours and Engagement in Follow-up Care in the Post-Treatment Phase

Cancer, defined by the World Health Organization (WHO) as "…the growth of abnormal cells beyond their usual boundaries…" (WHO, 2019b), is the second leading cause of death worldwide, with 18.1 million new cases and 9.6 million deaths in 2018 (WHO, 2019b). It accounts for approximately 30.00% of registered deaths in Australia (Australian Institute of Health and Wellbeing [AIHW], 2017). Further, people living in regional areas experience significantly poorer cancer outcomes and survival than their metropolitan counterparts (Hartley, 2004; Phillips, 2009; Pozet et al., 2008).

Evidence suggests that 30.00-50.00% of cancer-related deaths worldwide can be avoided by engaging in healthy behaviours such as not smoking, limiting alcohol consumption and maintaining a healthy weight (WHO, 2019b). Unfortunately, regional Australians tend to exhibit poorer health habits and higher levels of health risk behaviours than those in urban areas (AIHW, 2019b; Cramb et al., 2011; Demark-Wahnefried et al., 2008; Dixon & Chartier, 2016). Similarly, patterns of medication adherence in people living with chronic health conditions suggest that regional people show poorer engagement in follow-up health care (Australian Bureau of Statistics [ABS], 2011; Franks, et al., 2005; Tan et al., 2016; Wan et al., 2007), although there is very little research examining this in the context of cancer. These behaviours common to regional populations, combined with sociodemographic risk factors and geographic isolation which necessitate travelling away from home to receive cancer treatment, are likely to further impact outcomes among regional cancer populations.

This thesis aims to examine the health behaviour profile of regional people living with cancer who travel in order to receive cancer treatment/care, over the 12-months following cancer diagnosis. In particular, it aims to explore socio-demographic, clinical, and individual characteristics commonly associated with regional residency, and seeks to identify potentially modifiable influences on health-promoting behaviours within this group.

The Burden of Cancer

Cancer poses a significant health and economic burden, accounting for approximately 16.00% of deaths globally and an ever-increasing economic cost (estimated at $US1.16 trillion in 2010) (Abbott et al., 2017; WHO, 2017). In Australia, cancer contributes to 19.00% of the country's total disease burden (AIHW, 2016) and costs the Australian economy over $AUD4.5 billion annually (AIHW, 2013).

The impact of a cancer diagnosis on individuals and their families is also high, placing a physical, emotional, and financial burden on those affected (Bhoo-Pathy et al., 2019; Clavarino et al., 2002; Drury & Inma, 2010; Emery, et al., 2013). Substantial advancements in the early detection and treatment of cancer have resulted in improved long-term survival rates, with 68.00% of Australians diagnosed with cancer from 2009-2013 surviving at least five years from diagnosis (AIHW, 2016; Gunnell et al., 2017; Spees, et al., 2015). However, people face significant long-term effects beyond initial cancer treatment, including increased health risks and psychological, social, physical, and economic impacts (Spees et al., 2015). With rising prevalence rates and improved treatments, there is an increasing need to address the ongoing care and quality of life of a growing population of cancer survivors, who have complex health needs following diagnosis and treatment (Rausch et al., 2012). This group are at heightened risk of recurrence of their primary cancers, development of secondary cancers, and are more susceptible to other chronic health conditions such as diabetes, osteoporosis, and cardiovascular disease (Abbott et al., 2017; Spees et al., 2015; Wiseman, 2008). The challenge of effectively managing long-term health and wellbeing following a cancer diagnosis also varies significantly between population groups, where certain groups are disproportionately burdened by cancer.

Regional Populations in Australia

Approximately 28.00% of Australians reside in non-metropolitan areas (AIHW, 2019b). In Queensland, being the most decentralised mainland state in Australia, 54.00% of the population lives outside of the capital city (Hausdorf, et al., 2008), meaning that more than half of the population are classified to live outside of major cities; in inner regional, outer regional, remote and very remote locations (ARIA; ABS, 2011) . Compared to those living in major cities, regional Australians can be broadly characterised as an older population, with lower levels of education, greater proportions of Aboriginal and/or Torres Strait Islander peoples, lower socio-economic status (SES), lower rates of employment, and poorer access to services including specialist healthcare (AIHW, 2019b). In turn, lower SES is associated with increased likelihood of poor health, greater likelihood of engagement in risky lifestyle behaviours, higher rates of disability and death, and a shorter lifespan (AIHW, 2017).

In addition to demographic and socio-economic differences, chronic health conditions such as asthma, osteoarthritis, diabetes, and heart-related diseases occur more frequently outside of metropolitan areas of Australia (AIHW, 2017). Further, regional populations tend to show poorer engagement in health-promoting lifestyle behaviours. As shown in Table 1.1, a greater proportion of regional individuals smoke, fall within the overweight/obese category, and engage in risky alcohol consumption than those in major cities. While the proportion of individuals meeting national guidelines with respect to vegetable consumption (five servings per day) is equally poor across all remoteness groups (with less than 1 in 10 people consuming 5+ servings of vegetables per day), a lower proportion of those living in regional areas met the national guidelines for fruit consumption (two servings per day) than those living in major cities (AIHW, 2019b). Engagement in physical activity was low across all remoteness groups, with under half of individuals meeting recommended national guidelines (AIHW, 2019b).

Table 1.1

Key health behaviours across remoteness groups in Australia (AIHW, 2019b)

Remoteness Group	**Smoking**	**Overweight/ Obese**	**Diet**		**Alcohol (risky)**	**Physical Activity**
			Fruit	Vegetable		
Major Cities	12.80%	65.10%	51.80%	6.80%	14.70%	46.00%
Inner Regional	16.50%	71.00%	47.30%	9.00%	18.80%	46.70%
Outer Regional/Remote	19.60%	70.30%	46.80%	8.10%	24.40%	44.90%

Cancer in Regional Populations

According to the AIHW (2019a), after adjusting for age, cancer diagnosis rates are highest in inner and outer regional areas of Australia, with 513 and 511 cases per 100,000 respectively, compared to 488 in major cities, 490 in remote areas, and 445 in very remote areas. People living with cancer in regional areas also show significantly poorer cancer outcomes and survival overall (Pozet et al., 2008; Underhill et al., 2009). For example, age-standardised mortality rates for all cancers within Australia between 2012 and 2016 increased with remoteness (AIHW, 2019a). In Queensland, regional people living with cancer are up to 31% more likely to die within five years of diagnosis than metropolitan people living with cancer (Cramb, et al., 2011). Individuals with low SES – a common characteristic of regional populations - are significantly more likely to be diagnosed with, and to die from, lung cancer (AIHW, 2017). Similarly, low-income colorectal cancer survivors have been found to experience significantly higher levels of pain interference and fatigue, as well as lower physical functioning and higher depression scores than those in higher-income brackets (McDougall et al., 2019). While living outside of metropolitan areas produces additional logistical challenges in access to primary health-care services, evidence suggests that regional residence alone does not appear to account entirely for the observed disparities in cancer survival and outcomes (Abbott et al., 2017; Ireland et al., 2017).

Factors Influencing Cancer Outcomes and Survival

Whilst substantial evidence exists to highlight the impact that geographic location has on health status and health outcomes more broadly, a growing body of research suggests that it is not location itself that leads to cancer health disparities, rather an intricate relationship between geography and the characteristics of the individual and their environments that compounds and further complicates this relationship (Fraser et al., 2005; Ireland et al., 2017; Smith et al., 2008).

Unfortunately, despite increasing recognition of other potentially important factors in determining regional cancer outcomes, only limited research has progressed beyond examination of cancer outcome inequities as a by-product of location or distance to cancer treatment centres and services (Abbott et al., 2017; Chow et al., 2013; Tan et al., 2016). It is possible that many important relationships remain unexamined and their influences are instead masked by the existence of, and focus on, the relationship with geographic remoteness in isolation of other potentially important variables (McCullough & Flowers, 2018).

Socio-Demographic Influences

Recently, research has investigated the socio-demographic factors that may be contributing to regional disparities in cancer outcomes and survival. In particular, SES and education have been highlighted as potentially compounding influences which affect cancer outcomes (McDougall et al., 2019; Myint et al., 2019; Youl, et al., 2019). For example, Myint and colleagues (2019) found that disparities in prostate cancer survival between regional and metropolitan people in Appalachian Kentucky (United States) were explained by high poverty rates and low education levels. McDougall and colleagues (2019) found both low health literacy and lower levels of health insurance to be associated with greater pain interference and poorer physical functioning in colorectal cancer (CRC) patients regardless of geographic location. Youl and colleagues (2019) reported that treatment decisions among regional people living with cancer were influenced by the financial costs of treatment and education levels (with lower levels of education signifying lesser likelihood of involvement in the treatment decision-making process). Therefore, factors associated with SES and education may disproportionately affect regional people living with cancer, who are broadly categorised as lower SES and to have lower levels of education, and these factors may play a larger role in cancer outcomes than geographic location on its own.

Clinical Influences

Examination of the clinical factors that may influence cancer outcomes sheds further light on the potential interplay of these factors within the regional context. In a systematic review of geographical differences in colorectal cancer (CRC) management and outcomes, Ireland and colleagues (2017) found that, while evidence more broadly supports a pattern of poorer survival in regional people living with CRC compared to their metropolitan counterparts, sociodemographic, clinical, and treatment characteristics may play a complex, influential role in cancer outcomes and survival. Individual characteristics (such as age, gender, Indigenous status, and health insurance status) along with system-level factors (including access, wait times, surgeons, and hospital case-loadings) appeared to be more influential in instances of deviation from clinical management guidelines than geographic location itself, for people living with CRC.

Further, in a systematic review of geographical variations in clinical management of CRC in Australia, Crawford-Williams et al (2018) found that, in addition to age and potential differences across treatment sites, clinical type factors such as position of tumour, lymph node invasion, involved margins, and comorbidities all influence CRC treatment decisions.

Similarly, comorbid conditions in people living with prostate cancer have been demonstrated to influence survival, with increasing comorbidity scores associated with increased mortality and poorer cancer-related outcomes (Myint et al., 2019). This supports the notion that the general health of individuals, as well as the clinical characteristics of their cancer diagnosis, may play an important role in cancer outcomes beyond the challenges of geographic remoteness. Further, the observed differences in management across service sites may be due to a range of individual and health service factors that correspond to geographic location, rather than geographic location itself.

It is clear from the evidence available to date that the regional-metropolitan divide in cancer outcomes is far more complex than geographic location alone. Whilst many of these demographic and access factors were found to likely play some part in explaining geographic disparities, their level of influence on cancer outcomes, and whether other factors may also contribute to outcomes remains unclear (Crawford-Williams et al., 2018; Ireland et al., 2017). A greater understanding of existing relationships will be necessary to move forward and narrow the gap between regional and metropolitan cancer outcomes.

The Cancer Care Pathway

Examining the care pathway that a person living with cancer negotiates from diagnosis to survivorship may assist in understanding other factors that could potentially contribute to poorer outcomes among regional cancer survivors. Tertiary cancer treatment centres are primarily located in high-volume metropolitan areas, meaning that many regional people are required to travel in order to receive treatment. On completion of treatment and after returning home, contact with and access to support services and facilities that were available during the treatment process is significantly diminished (Spees et al., 2015). Therefore, continuation of post-treatment care and support requires significant coordination efforts on behalf of the individual; with the onus typically on them to undertake an active role in monitoring signs and symptoms, adhering to medication regimes, managing psychological and physical sequelae, recognising the need and advocating for support, and making healthy lifestyle behaviour choices to reduce the risk of ongoing health complications (Eakin et al., 2007). Thus, the post-treatment ‘cancer survivorship’ phase may play a particularly important role in cancer outcomes, especially for regional people.

Cancer Survivorship

Definition of Cancer Survivorship

The definition of survivorship within cancer literature has evolved as more is understood about the period following a cancer diagnosis. It is generally agreed that survivorship does not refer to a single circumstance of ‘beating’ cancer and is not limited to a specific time period following a cancer diagnosis; rather it refers to the continued health-related experiences of individuals from the time of diagnosis onwards (Feuerstein, 2007; Khan, et al., 2012). Survivorship is therefore defined as the period from the point of receiving a cancer diagnosis until end of life (related or unrelated to the cancer diagnosis) or recurrence of cancer (Feuerstein, 2007; Khan, et al., 2012). This definition encapsulates the full experience of patients following diagnosis, irrespective of cancer type or individual/clinical differences (such as stage, treatment type or prognosis). This program of research focuses on a discrete period within survivorship, the post-treatment period, referring to the immediate period following diagnosis and primary treatment.

Essential Components of Survivorship Care

According to the Institute of Medicine (IoM; 2006), there are four essential components of survivorship care for people living with cancer. First, there must be a focus on the prevention and detection of new and/or recurrent cancers. Second, there must be surveillance for cancer progression/recurrence or for the emergence of secondary cancers. Third, survivorship care must incorporate appropriate medical, lifestyle, and/or psychological interventions for the management of the consequences of cancer and/or cancer treatment (discussed in more detail in Chapter 2). This includes management of symptoms and side-effects, psychological distress, and financial toxicity. Finally, quality survivorship care must involve effective coordination between treatment specialists and primary health care providers to meet all of the health needs of the patient, including education and information sharing, guidance in adopting healthy lifestyle behaviours, and assistance in accessing relevant local support services.

Engagement with these post-treatment components in survivorship play a key role in determining longer-term outcomes for people living with cancer (WHO, 2019b). Following initial treatment, patients are recommended to undertake ongoing medical-related follow-up care in order to reduce the risk of future cancer-related health complications. They may be required to continue medications or other treatments for an extended period of time after their initial treatment and will be required to participate in ongoing screening and monitoring for symptoms of progression/relapse. They may also require assistance to manage the immediate side-effects and long-term or late effects of cancer treatment (Wiley, et al., 2015).

In addition to undertaking medical management post-treatment, guidelines published by the Australian Cancer Survivorship Centre recommend survivors engage in several healthy lifestyle behaviours (including adhering to a healthy diet, weight-management, physical exercise, smoking cessation, and limiting alcohol consumption) known to promote positive recovery and protect against future sequelae (Wiley et al., 2015). As with medical follow-up care, engagement in these health-promoting behaviours also forms a critical component of survivorship, maximising positive outcomes and preventing relapse or further deterioration in health (Tan et al., 2016). However, there is currently limited understanding of what engagement in survivorship care looks like, especially for people living in regional areas where support services and access to ongoing care is hampered.

Adherence to Long-Term Cancer Management

The WHO defines adherence in the context of the long-term management of chronic conditions to be "…the extent to which a person's behaviour - taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider…" (Sabaté, 2003; p.3). In the context of cancer, this would include all of the behaviours outlined above, from continuation of necessary medication and adjuvant treatment, to screening and monitoring behaviours, and engagement in health-promoting lifestyle behaviours (Wiley et al., 2015).

The known risks of non-adherence to long-term management in chronic conditions are significant and varied, including poorer treatment efficacy, failure to recover, disease progression, reduced quality of life, increased risk of additional health complications, and comorbid conditions, lost years of life, decreased ability to remain in the workforce, increased personal/familial financial burden, and increased stress in relationships (Chia et al., 2006; Eakin et al., 2007; Fishbein et al., 2017; Gugssa Boru et al., 2017; Heckman, 2007; Khanam et al., 2014; Putman, 2004; Schectman et al., 2002; Sabaté, 2003, Schootman et al., 2013). Similarly, in people living with cancer, failure to adhere to long-term management regimes can reduce clinical benefit from treatment, inhibit positive recovery, and increase the risk of further health-related complications (Sabaté, 2003; Spees et al., 2015; Wiley et al., 2015).

Aside from the negative consequences to the individual themselves, the impacts of non-adherent behaviours continue to be felt both economically and systemically through an increased healthcare burden (Abbott et al., 2017; Fadare et al., 2014; Ma, 2016). As such, improving adherence behaviours after diagnosis has become a recognised effective target for tackling chronic conditions and managing an increasing economic healthcare burden (Sabaté, 2003).

Adherence in Regional Populations

Unfortunately, evidence suggests that on average only 50.00% of people living with chronic disease consistently adhere to their recommended management regimes (Nieuwlaat et al., 2014; Sabaté, 2003). Regional populations, once again, appear to show poorer engagement in long-term condition management than metropolitan populations. For example, within Australia, regional people living with an asthma diagnosis experienced poor outcomes, displaying limited medication knowledge, suboptimal device technique, and poor adherence to clinical management recommendations (medication adherence and knowledge/ownership of an asthma action plan) (Franks, et al., 2005). Regional Australians with diabetes have also shown poorer outcomes in cardiovascular risk management compared with metropolitan Australians with diabetes, reported to be potentially explained by differences in intensity of and compliance to recommended treatment (Wan et al., 2007). Adherence behaviours in regional populations will be covered in greater detail in Chapter 2.

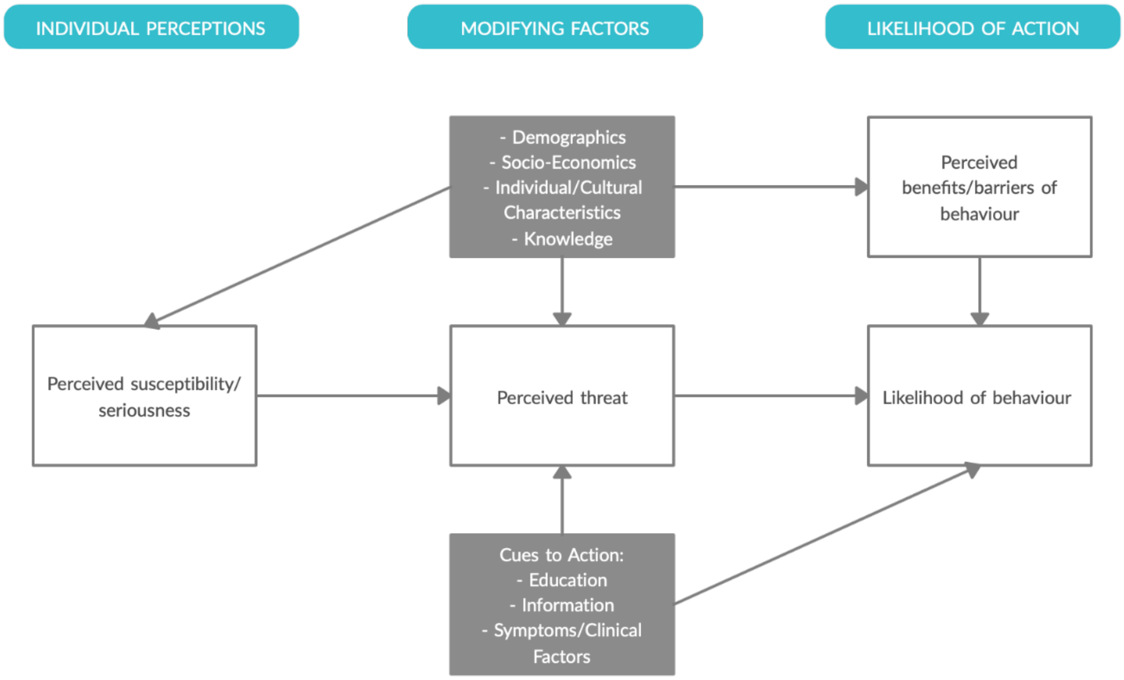
Despite growing recognition of the importance of survivorship behaviours on cancer outcomes, engagement in health management behaviours has received a small amount of attention to date, particularly within vulnerable groups such as regional populations. As such, little is currently known about the relationship between geographical location, adherence behaviours, and cancer outcomes in regional cancer populations. In the United States, one study by Tan and colleagues (2016) found that poorer rates of adherence to adjuvant endocrine therapy in a rural Appalachian breast cancer population mapped similarly geographically to observed disparities in broader health outcomes (poorer adherence with increasing rurality). Similar results of poorer adherence in rural areas were found in a sample of almost one million US women with breast cancer (Daly et al 2017). Thus, the observed patterns of poorer outcomes across regional populations with chronic health conditions in Australia could potentially be indicative of poorer adherence patterns in regional people living with cancer. In turn, adherence to health management behaviours could potentially contribute to observed health disparities. These patterns also suggest that factors associated with the geographical context more broadly may influence adherence behaviours. In the absence of specific evidence regarding adherence in Australian regional populations however, theory may assist in understanding potential factors at play.

Theoretical Influences on Adherence in Regional Populations

According to the Health Belief Model (HBM; Rosenstock, 1966), values, attitudes, and beliefs play an important modifying role in determining whether an individual engages in a specific health behaviour. If the individual believes a significant threat to their health exists (through their perceived susceptibility to the illness, and their perception of the severity of the illness), and that the benefits of engaging in preventative behaviours against that threat outweigh the costs and barriers, then the likelihood of engagement increases. Such processes may be particularly applicable to the post-treatment cancer survivorship period, where the experience of cancer diagnosis and treatment may provide a ‘cue to action’ for positive health behaviour change. As can be seen in Figure 1.1, these perceptions are influenced by a number of modifying factors, including socio-demographics and other individual and cultural characteristics, suggesting that individual and cultural values, attitudes, and beliefs may either encourage or discourage the prioritisation of engaging in protective health behaviours (Austin et al., 2002).

Figure 1.1

The Health Belief Model (Rosenstock, 1966)



There is a small body of literature to draw from that has identified potential individual and cultural factors unique to regional populations that may broadly influence health decisions and health behaviours. The concept that there are characteristics unique to regional populations beyond socio-demographics and location is not new; nor is the idea that these unique characteristics play an important role in health behaviours (Bettencourt et al., 2007; Weaver & Gjesfjeld, 2014). In particular, individual and cultural values, attitudes, and beliefs are frequently cited as key factors distinguishing regional populations from their metropolitan counterparts (Bettencourt, et al., 2007; Cloke & Milbourne, 1992; Strasser, 2003). Regional individuals are often described as independent, conservative, hard-working, and fatalistic by nature; holding traditional values of self-reliance, resilience, and stoicism in the face of adversity, which supports an underlying attitude that places health as low priority (Bettencourt et al., 2007; Dixon & Welch, 2000; Weaver & Gjesfjeld, 2014). In particular, fatalism is described as a belief that events are controlled by external forces and that the individual is unable to influence these (Niederdeppe & Levy, 2007). From a HBM perspective, the belief that an individual is unable to control or alter health events or circumstances (such as a cancer recurrence) may serve to discourage engagement in health behaviours that prevent either primary occurrence or recurrence of adverse health conditions, regardless of how threatening it is perceived (Niederdeppe & Levy, 2007). In an exploration of regional-metropolitan health differentials, Dixon & Welch (2000) found that regional values impacted not only health service utilisation, but supported a different understanding of health, illness, and health service needs. Regional individuals were more likely to view health as the absence of disease and to therefore see health services as 'cures', as opposed to services for the 'maintenance' of good health (Dixon & Welch, 2000). Relating this to the survivorship period, this would suggest that attitudes reinforcing the curative nature of cancer treatment could potentially result in less acknowledgement and understanding of the importance of ongoing cancer care, and a reluctance to participate in ongoing treatment and prevention activities.

Further, performance and productivity were reported to be important indicators of wellbeing in regional communities, suggesting that regional individuals measure illness or disability by the degree to which it affects their productivity, or ability to carry out traditional roles within the home and community (Elliot-Schmidt & Strong, 1997). This culminates in seeking medical attention as a last resort, and often only at later stages of illness and disease, when symptoms significantly affect productivity (Cramb et al., 2011; Strasser, 2003; Tropman et al., 2017; Weaver & Gjesfjeld, 2014), and may be conceptualised as consideration of future consequences, which has been shown to impact upon health decision-making (Strathman, et al., 1994).

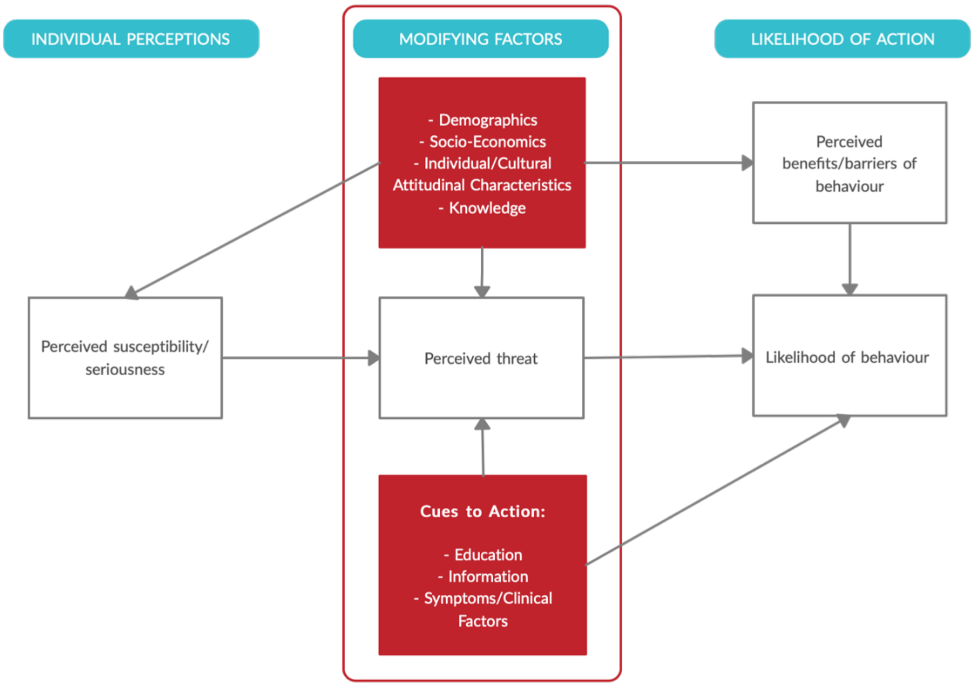
Stigma, or negative attitudes toward health-related help-seeking, has also been shown to impact on mental health help-seeking in regional communities (Hoyt, et al., 1997) and it is conceivable that experiences of stigma discourage support-seeking regardless of the perceived health threat; therefore acting as yet another barrier to healthy behaviours in the survivorship period (Austin, et al., 2002; Weaver & Gjesfjeld, 2014). Thus, there are several distinct individual characteristics commonly associated with regional populations in particular that may play a role in healthcare or health behaviour decisions for this group. As such, the cultural context of regionality may ultimately impact on cancer outcomes, survival, and quality of life, and warrants closer examination specifically within the cancer survivorship period. Applying the HBM, it is foreseeable that the same beliefs that prevent health help-seeking and preventative behaviours in the early stages of illness/disease (Emery et al., 2013; Fennell et al., 2017) could also translate into a reluctance to undertake protective or preventative behaviours in the post-treatment phase of cancer survivorship. However, the role of individual characteristics, such as attitudes and beliefs, in the cancer survivorship phase among regional populations remains unexamined to date.

Aims of the Research

The overall aim of this program of research is to provide an in-depth exploration of the post-treatment health management behaviours of regional people living with cancer, and to identify and examine factors that impact on their engagement with recommended medical care and health-promoting lifestyle behaviours during the post-treatment survivorship period. The overall program of research is summarised in Figure 1.2. In particular, this research focuses on the modifying factors as described in the HBM, specifically those factors shown to influence health behaviours in regional populations, but not yet explored within regional people living with cancer in the post-treatment survivorship period.

Figure 1.2

Overview of Program of Research Within the Health Belief Model



Specific Objectives

The specific objectives of this research are:

1. Identify factors that influence engagement in health-promoting behaviours for people living with a cancer diagnosis residing in a regional area.
2. To understand the experience of regional people living with cancer travelling to metropolitan cities for cancer treatment in Queensland at risk of poorer cancer outcomes, forming a baseline profile. This profile will include a description of the demographics, clinical characteristics, and health-promoting behaviours of a sample of regional people living with cancer at the time of attending a metropolitan centre for treatment, as guided by the findings from Objective 1.
3. To examine engagement in recommended health-promoting behaviours over the 12-month period following seeking cancer treatment/care in a metropolitan centre.

4. To identify the role of individual characteristics in shaping engagement in follow-up care and healthy lifestyle behaviours for regional people living with cancer following seeking cancer treatment/care in a metropolitan centre, as guided by the findings from Objective 1.

Study Significance

Given the expected exponential growth in the survivor population, the increased risk of ongoing health complications associated with survivorship, and the well-documented poorer cancer outcomes associated with geographic location, this research will contribute to a currently limited understanding of health management behaviours in regional cancer populations during the post-treatment period. Data collected throughout this program of research will form a unique profile of regional cancer survivor populations, allowing comprehensive analysis and identification of factors that influence post-treatment health management behaviours within this group. This research will significantly contribute to the current body of research in cancer survivorship in several ways. First, it will provide essential knowledge of the current implementation and provision of recommended follow-up cancer care. Current international literature suggests that regional people living with cancer are not provided clear directives and coordinated care upon completion of treatment and return to regional areas – a distinct recommendation of the Australian Cancer Survivorship Centre (ACSC) (Wiley et al., 2015). As such, quantifying the provision, uptake, and adherence to these guidelines in an at-risk sample may provide impetus to inform policy and to direct efforts to integrate these recommendations more effectively and extensively into routine care. Second, an understanding of the provision of post-treatment information and its relationship to post-treatment behaviours in regional areas may influence policy and practice change within Australia. It will have the potential to inform the future allocation of resources and services to support a healthy transition into survivorship for regional cancer survivors and inform specific target areas to improve post-treatment coordinated care in regional populations. Third, a clearer picture of post-treatment behaviours in regional cancer populations, and whether adherence to recommended behaviours is problematic for this group, has potential to provide valuable insight and to inform the effective delivery and communication of cancer care information to regional populations in the post-treatment phase. This could take the form of highlighting areas of change in routine care provision and clinical management guidelines. Finally, this research forms the first step in identifying the underlying contributors to regional cancer disparities during survivorship. This research takes a unique approach to investigating health behaviours in regional populations, by examining individual characteristics that may impact (positively or negatively) on engagement in recommended post-treatment behaviours.

Thesis Overview

This thesis consists of eight chapters across four core research studies. Chapter 2 provides a review of literature with respect to the survivorship period and adherence behaviours, and the potential role that geographical context plays. Study 1 (Chapter 3) then presents a systematic scoping review of the current body of evidence relating to factors that are known to influence adherence and engagement behaviours specifically in regional populations with a chronic disease diagnosis. It was originally intended that this review be limited to regional cancer populations however, a paucity in the literature required that the review be extended to encompass regional populations with any chronic disease diagnosis. The findings of Study 1 informed the design of Studies 2, 3, and 4, providing further rationale for the factors examined within these studies based on current available evidence. Chapter 4 outlines the methodological approach adopted for Studies 2, 3, and 4. These studies form part of the *Travelling for Treatment* program, a large-scale longitudinal cohort study conducted by the University of Southern Queensland and Cancer Council Queensland. Therefore, data for

Studies 2, 3, and 4 were collected via the longitudinal recruitment and data collection processes used in the Travelling for Treatment program. Study 2 (Chapter 5) presents an in-depth baseline profile of regional people living with cancer who travel to metropolitan areas for cancer treatment/care with respect to demographics, clinical characteristics, individual characteristics, receipt of survivorship information, and health behaviours prior to cancer treatment/care. Study 3 (Chapter 6) examines how health behaviours, as well as engagement with recommended medical follow-up activities change throughout the 12-month period following cancer treatment/care. Study 4 (Chapter 7) examines the baseline demographic, clinical, informational, and individual predictors of engagement in health management behaviours (both health behaviours and medical follow-up) at 6- and 12-months following cancer treatment/care, as guided by the findings of Study 1. Finally, an overall discussion of this program of research, including its strengths and limitations, implications, future research recommendations and conclusions is presented in Chapter 8.

Chapter 2: Cancer Survivorship and Post-Treatment Care in Regional Populations

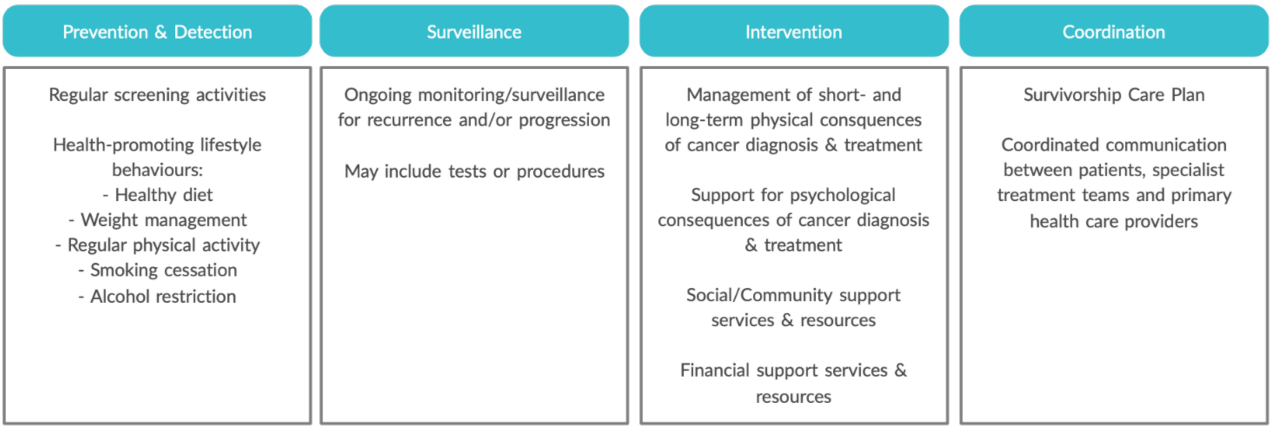
With a growing survivor population, there is an urgent need for better understanding in meeting the complex, ongoing health needs of cancer survivors and addressing the persistent disparities in outcomes and survival for regional cancer populations. As indicated in Chapter 1, an increasing body of literature has highlighted the importance of ongoing cancer care, beyond initial diagnosis and treatment, for both optimal recovery and long-term wellbeing. This has led to the incorporation of core post-treatment activities into government health directives and Survivorship Care Plan (SCP) recommendations worldwide. However, to date, there has been limited examination as to whether these recommendations are routinely implemented and the extent that people living with cancer engage in these post-treatment activities, particularly for those groups with known increased vulnerability such as those living in regional areas. In order to address geographical disparities in outcomes and survival and to inform effective solutions to reduce the ongoing health impact of a cancer diagnosis for regional populations, attention must be directed beyond geographical barriers. Understanding engagement in recommended post-treatment cancer care and factors that may impact this engagement for people living with cancer in regional areas is a critical step in determining whether behaviours in the survivorship period drive the observed disparities. As such, this chapter examines the current state of evidence within the post-treatment cancer phase.

Essential Survivorship and Post-Treatment Activities in Regional Populations

Figure 2.1 provides a summary of the essential domains of survivorship care and the core activities that fall within each of these care domains, as outlined by the Institute of Medicine (2006) and governing bodies worldwide (CCA, 2015; Vardy et al., 2019, WHO, 2020). Critical components of survivorship care across the four domains (prevention and detection, surveillance, intervention, and coordination) include participation in ongoing screening and surveillance activities, the adoption of health-promoting behaviours, intervention for the management of short- and long-term physical, psychological and social consequences of diagnosis and treatment and the effective coordination of the long-term health care of the individual. This emphasis on both medical and behavioural aspects of survivorship care aligns well with the WHO (Sabaté, 2003) definition of adherence in the long-term management of chronic disease. Each of the essential survivorship care domains will now be discussed in turn.

Figure 2.1

Components of Cancer Survivorship Care (IoM, 2006)



Prevention & Detection	Surveillance	Intervention	Coordination
Regular screening activities Health-promoting lifestyle behaviours: - Healthy diet - Weight management - Regular physical activity - Smoking cessation - Alcohol restriction	Ongoing monitoring/surveillance for recurrence and/or progression May include tests or procedures	Management of short- and long-term physical consquences of cancer diagnosis & treatment Support for psychological consequences of cancer diagnosis & treatment Social/Community support services & resources Financial support services & resources	Survivorship Care Plan Coordinated communication between patients, specialist treatment teams and primary health care providers

Prevention and Detection

Cancer Screening. Screening activities play a significant role in ongoing health management in cancer survivorship (Bellizzi, et al., 2005). The early detection of recurrence and secondary cancers, as well as monitoring cancer progression, is critical for early intervention and sustaining long-term survival and quality of life. However, evidence regarding engagement in screening and surveillance activities following a cancer diagnosis is limited. Eakin et al. (2007) reported a general trend of increased engagement in screening behaviour among Australian skin cancer survivors compared to a non-cancer comparison group, similar to findings in the United States and Korea (Bellizzi et al., 2005; Cho, et al., 2010), although these behaviours were still considered sub-optimal

(Cho et al., 2010). Engagement in preventative cancer screening behaviours is reported to be poorer in regional Australia (AIHW, 2016), with higher rates of later-stage diagnosis of regional people living with cancer (Cramb et al., 2011). This evidence supports a general pattern of poor engagement in screening prior to a cancer diagnosis which may continue even after diagnosis and treatment. However, a more thorough examination of screening behaviours is required to confirm whether this pattern accurately depicts regional Australian survivor populations, when ongoing screening becomes even more important. With the addition of geographical barriers that are known to negatively impact on screening participation in the general population (Cramb et al., 2011; Lotfi-Jam, et al., 2009), it is possible that post-treatment screening behaviours could also be problematic for regional people living with cancer.

Health-Promoting Lifestyle Behaviours. A healthy transition into survivorship shifts from a focus on treatment to one of long-term wellness and self-management (Wiley et al., 2015). Lifestyle and environmental factors have long been documented as key in reducing cancer burden, including reducing health risk in the survivorship period (Akinyemiju, et al., 2017; Danaei, et al., 2005). In particular, there has been a growing interest in the impact of physical activity (Gunnell et al., 2017; Pollard, et al., 2009; Wiley et al., 2015), smoking (Gritz, 2005; Pollard et al., 2009), dietary behaviours (Pollard et al., 2009), excess body weight (Kushi et al., 2012; Wiley et al., 2015), and alcohol consumption (Kwan et al., 2010) in survivorship.

Healthy Diet and Weight Management. Approximately 5.00% of cancer cases in Australia can be attributed to obesity (WHO, 2020; GLOBOCAN data 2012). Not only is weight a key risk factor for cancer, maintaining a healthy body weight in the survivorship period assists in a healthy recovery after treatment and reduces the risk of additional health issues such as heart disease, high blood pressure, and diabetes (ACSC, 2017). Additionally, being overweight or obese is associated with higher rates of recurrence of multiple cancers and poorer survival (CCA, 2015; Rock et al., 2012). Cancer Council Australia recommends achieving and maintaining a BMI between 18.5 and 25 kg/m^2 for optimal health in survivorship (CCA, 2015). A key factor in managing overall weight and BMI is nutrition. Most dietary advice focuses on the consumption of fruit and vegetables as a nutrient-dense option that promotes satiety and can, therefore, assist in healthy weight management and wellbeing (ACSC, 2017; CCA, 2015). Survivorship recommendations align with the national guidelines for the general public of two servings of fruit and five servings of vegetables daily (ACSC, 2017; CCA, 2015; National Health & Medical Research Council [NHMRC], 2013).

In the general Australian population, two-thirds of adults are classified as overweight or obese, with approximately half of the population (51.30%) consuming two or more serves of fruit per day and 10.00% meeting the recommended daily five servings of vegetables (AIHW, 2019). A greater proportion of regional individuals are overweight or obese (approximately 70.00%) compared to metropolitan (65.00%; AIHW, 2019). While the proportion of individuals meeting nutritional recommendations are reported not to be significantly different between metropolitan and regional populations, the additional challenges associated with regional living (such as accessibility and socio-economic status) likely amplifies the risks of poor diet within an already vulnerable population. There is currently very little research which has examined diet and nutrition in Australian regional people during the cancer survivorship period. In one recent study, Ristevsk and colleagues (2020) showed that rural people living with cancer who received tailored nutrition and health coaching were able to improve their food choices.

Physical Activity. Reported benefits of physical activity for cancer survivors include improved physical and mental wellbeing, reduced cancer-specific and all-cause mortality, improved management of treatment-related side effects, reduced fatigue, and improved health-related quality of life (Carmack, et al., 2011; Holick et al., 2008; Kenfield et al., 2011; Meyerhardt et al., 2006; Newton & Galvão, 2013; Schmitz et al., 2005). The Clinical Oncology Society of Australia’s Model of Survivorship Care (Vardy et al., 2019) recognises the importance of regular physical activity for optimal recovery and long-term wellbeing. Survivors are encouraged to gradually increase levels of physical activity as guided by their treatment team (CCA, 2015), with a goal of gradually building towards meeting national physical activity guidelines of 150-300 minutes of moderate-intensity or 75-150 minutes of vigorous-intensity physical activity each week (a minimum of approximately 30 minutes per day, five days per week; ACSC, 2017; Australian Government Department of Health, 2019). Newton, Taaffe and Galvao (2019) further argue that exercise guidelines should be tailored according cancer type, patient health and comorbidity status. Worldwide, regional health populations tend to show poorer rates of physical activity than their metropolitan counterparts. In Australia, physical activity has been found to be insufficient in regional areas, with less than half of individuals meeting national physical activity guidelines (AIHW, 2019b; Goodwin et al, 2020). Further, regional South Australian cancer survivors were more likely to report not engaging in any physical activity than metropolitan survivors (32.90% vs 26.20%), possibly accounted for by area-level socio-economic status (Gunn et al., 2020). Similarly, in the United States, rural cancer survivors were found to show lower rates of physical activity than those in metropolitan areas (50.70% vs 38.70%) and this, in turn, was associated with a greater likelihood to report poorer health status and health-related unemployment. The combination of this general tendency towards lower levels of physical activity in regional areas and factors such as lower socio-economic status and greater area-level disadvantage likely puts regional people living with cancer at significant risk of failing to meet this recommendation. Failure to engage in sufficient levels of physical activity is likely to negatively impact positive recovery and long-term wellness in survivorship and could be a contributing factor to poorer cancer survival in regional areas. However, more research is required to determine engagement in physical activity during the survivorship period for regional Australians.

Smoking. The WHO (2020) reports that tobacco use currently accounts for 25.00% of all cancer-related deaths worldwide. With such a significant impact on primary cancer diagnosis and survival, it is not surprising that smoking cessation is strongly encouraged following a cancer diagnosis (ACSC, 2016; CCA, 2015). In survivorship, tobacco smoking can negatively impact cancer treatment and is associated with an increased risk of treatment toxicity, recurrence, new primary diagnoses, and death (Centers for Disease Control and Prevention [CDC], 2020b; Jassem, 2019). In a Chinese study of smoking in cancer survivorship, Tao and colleagues (2013) found that survivors who continued to smoke after diagnosis had a 59.00% increased risk of death compared to those who did not smoke after diagnosis. To date, the relationship between smoking during the survivorship period and cancer outcomes in Australia has not been extensively examined. In one of the only Australian studies reporting smoking prevalence in regional survivors, Gunn and colleagues (2020) found that 7.70% of regional South Australian cancer survivors continued to smoke after a cancer diagnosis. With a greater proportion of regional Australians in the general population smoking than those in metropolitan areas, and some evidence that a high proportion of survivors continue smoking following a cancer diagnosis (Gunn et al., 2020; Tao et al., 2013), it is likely that smoking behaviours within regional cancer populations are problematic and negatively impact on cancer outcomes. A greater understanding of such behaviours and factors that prevent the cessation of smoking for regional people living with cancer is an important step in addressing disparities.

Alcohol Consumption. In 2015, alcohol was reported as the sixth highest contributor to the burden of disease in Australia, accounting for 4.50% of total disease burden (AIHW, 2019). Alcohol has been identified as a risk factor for multiple primary cancers, including mouth, throat, larynx, oesophagus, liver, breast, rectum, and colon cancer and, although limited, evidence suggests alcohol is also a risk factor for cancer recurrence (American Cancer Society [ACS], 2020; Rock & Demark-Wahnefried, 2002; Rock et al., 2012). As such, Cancer Council Australia (CCA) and the ACSC recommendations suggest that survivors limit alcohol to no more than two standard drinks per day, in alignment with national guidelines for the general population (ACSC, 2017; CCA, 2015). According to the AIHW (2019), 16.10% of Australian adults exceed the lifetime risk guideline of two standard drinks per day. When examined across geographic contexts, a greater proportion of regional individuals exceed national alcohol consumption recommendations than those in metropolitan areas;

14.70% in major cities compared to 18.80% in inner regional areas and 24.40% in outer regional/remote areas (AIHW, 2019; Goodwin et al., 2020). Such statistics suggest that alcohol consumption behaviours may, therefore, also be problematic for regional cancer survivors during the survivorship period; however, this has not been explicitly examined.

Surveillance

Following a cancer diagnosis and treatment, it is recommended that patients undertake a series of activities to monitor for progress or recurrence of their cancer or the development of secondary or other primary cancers (ACSC, 2017; IoM, 2006; Wiley et al., 2015). The specific requirements for surveillance and the frequency of surveillance activities is dependent on many individual factors, including cancer type, treatment type and the individual's health status (ACSC, 2017; Wiley et al., 2015). Irrespective of tailoring to the individual, surveillance regimes typically entail diagnostic and pathology tests, assessments of recovery, and the investigation of new symptoms as they arise (CCA, 2015; Wiley et al., 2015).

In the absence of easily accessible follow-up services, there is likely a greater reliance on self-management activities to assist with long-term survivorship management. Follow-up appointments provide an opportunity for individuals to report difficulties or concerns related to their cancer, such as the development of symptoms, changes in health status (e.g. weight or appetite), mental health needs, or difficulties experienced in performing everyday activities (CCA, 2015). The logistical challenges of regional living such as longer waiting times for health services, reduced access to support services, and the need to travel for specialist consultation may serve as an additional barrier to the prompt reporting of such concerns, leaving the individual to deal with the consequences on their own. However, to date, there has been no examination of engagement in follow-up cancer care, or of the factors that influence this engagement for regional people living with cancer.

Intervention

Management of Consequences of Cancer/Cancer Treatment. The impacts of a cancer diagnosis and cancer treatment are extensive and not limited to the management of the cancer alone. Thus, intervention approaches may be varied and specific to the individual, but generally incorporate the management of long- and short-term side-effects resulting from diagnosis and treatment, as well as psychological support, social and community support resources, and financial support (IoM, 2006). There is currently little understanding of engagement in post-treatment interventions or access to these services for regional people living with cancer. For example, in a systematic review of geographical differences in CRC management in Australia, Ireland et al. (2017) found only two studies examining access to psychosocial support in regional areas. These studies suggested that regional participants rely on their local GPs and peers for support, however there was insufficient evidence to determine the level of access to and use of support services by regional people.

Coordination

Survivorship Care Plans (SCPs). One of the primary strategies endorsed worldwide to promote effective coordination between health care providers is the SCP. The SCP is a written (or digital) record of the individual's diagnosis, treatment, follow-up care, and behavioural recommendations for ongoing health following diagnosis and treatment (CDC, 2020a; Schootman, et al., 2013). These patient-centred plans are provided to the individual by the treating specialist and are intended to play a key role in improving health behaviours, quality of life, and long-term survival following cancer treatment through enhanced communication and coordination of care, the provision of education, diagnostic information, treatment details, required follow-up and treatment schedules, and recommended health-promoting behaviours (Schootman et al., 2013; Wiley et al., 2015). This formalised, individual-specific instruction may be especially important for regional people, who have reduced access to services and healthcare. The regional person living with cancer faces many additional burdens which are likely to adversely affect their transition post-treatment. In addition to reduced contact with specialist treatment providers and limited local access to specialist follow-up services, many regional people living with cancer face issues of financial toxicity, feelings of isolation, a lack of psychosocial support, and difficulties returning to everyday life in a predominantly labour-intensive workforce (Schootman et al., 2013). As a result, they are more likely to experience greater levels of stress and distress than metropolitan cancer populations, making this group particularly vulnerable and in need of greater understanding and support during the post-treatment period (Abbott et al., 2017; Bettencourt, et al., 2007; Murray et al., 2004; Reid-Arndt & Cox, 2010; Schootman et al., 2013; Thorndyke, 2005). Therefore, SCPs may be of particular importance in this group. However, little is known about the current provision and uptake of SCPs in Australia, especially whether they are utilised effectively by those living in regional areas.

Summary of Survivorship and Post-Treatment in Regional Populations

While there is vast evidence supporting the importance of engaging in ongoing cancer care activities and health-promoting behaviours following a cancer diagnosis, less attention has been given to the impact of geographical context on an individual's ability to adopt such a regime. Regional cancer survivors face many additional barriers to a positive transition post-treatment that may either directly or indirectly influence engagement in health-promoting behaviours during survivorship. In addition to challenges associated with distance, reduced contact with support, and access to services, many regional survivors face significant barriers to returning to everyday life within their regional communities (Schootman, et al., 2013).

To date, little is understood about engagement in recommended survivorship care following diagnosis and treatment for regional people living with cancer. However, evidence within the general population shows that regional individuals consistently display poorer engagement in health-promoting behaviours. It is important that a thorough understanding is developed regarding whether these behaviours continue to be problematic in the cancer survivorship period or whether some regional people living with cancer are able to adapt and engage in health-promoting behaviours post-treatment. Additionally, factors relating to geographical context that may contribute to poorer engagement in regional survivor populations must be identified and examined in order to fully understand the potential factors driving these behaviours. This chapter will now turn to an examination of the literature examining the factors associated with engagement in healthy behaviours and adherence to medical management in chronic disease populations.

Factors That Influence Adherence and Engagement Behaviours

In 2003, the WHO released a report on adherence to long-term therapies within chronic disease populations. This document sought to inform and guide policy-makers and health managers on the effective implementation of both national and local policies for improving health outcomes and health systems while reducing the economic burden of non-communicable chronic diseases (NCDs). Importantly, the report proposes that improving long-term adherence to health behaviours and medical management may be the most feasible and effective way to reduce the burden of chronic conditions on both the individual and the economy as a whole (Sabaté, 2003).

According to the WHO (Sabaté, 2003), long-term adherence is influenced by multiple factors across five core dimensions: social/economic factors; therapy-related factors; patient-related factors; condition-related factors, and health system/healthcare team-factors (see Figure 2.2). As such, the WHO compiled evidence relating to each of these dimensions across a broad range of chronic health conditions including cancer, tuberculosis, HIV/AIDS, mental and neurological conditions, substance dependence, hypertension, and asthma, and guidance was offered as to those factors within each dimension shown to play an important role in adherence. A summary of sample items falling within each of these dimensions is detailed in Figure 2.3 and each dimension will be discussed in detail. It should be noted that these dimensions have been proposed for adherence to long-term therapies and management in chronic health conditions and has not been applied to regional populations specifically.

Figure 2.2

The Five Dimensions of Adherence (Sabaté, 2003)

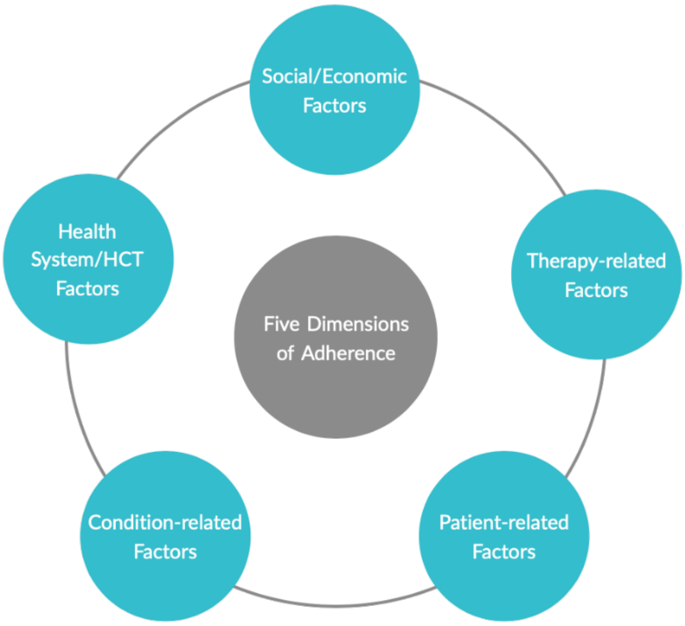
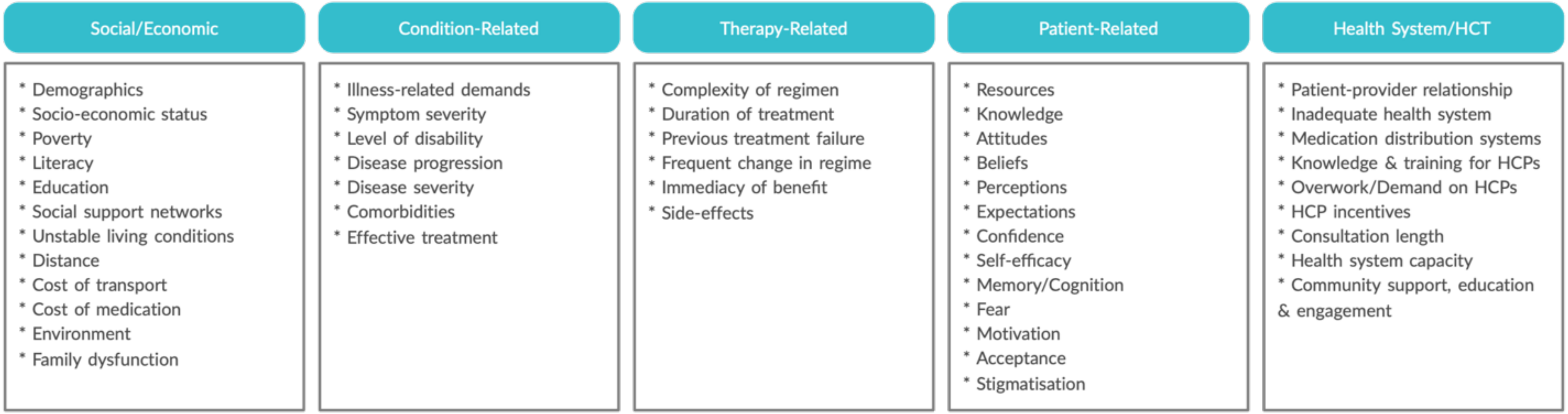


Figure 2.3

Breakdown of the Five Dimensions of Adherence (Sabaté, 2003)



Social/Economic

- Demographics
- Socio-economic status
- Poverty
- Literacy
- Education
- Social support networks
- Unstable living conditions
- Distance
- Cost of transport
- Cost of medication
- Environment
- Family dysfunction

Condition-Related

- Illness-related demands
- Symptom severity
- Level of disability
- Disease progression
- Disease severity
- Comorbidities
- Effective treatment

Therapy-Related

- Complexity of regimen
- Duration of treatment
- Previous treatment failure
- Frequent change in regime
- Immediacy of benefit
- Side-effects

Patient-Related

- Resources
- Knowledge
- Attitudes
- Beliefs
- Perceptions
- Expectations
- Confidence
- Self-efficacy
- Memory/Cognition
- Fear
- Motivation
- Acceptance
- Stigmatisation

Health System/HCT

- Patient-provider relationship
- Inadequate health system
- Medication distribution systems
- Knowledge & training for HCPs
- Overwork/Demand on HCPs
- HCP incentives
- Consultation length
- Health system capacity
- Community support, education & engagement

The following provides a summary of findings from the WHO (Sabaté, 2003) report, specifically, the factors that were determined to impact on adherence to long-term management of chronic health conditions.

Social/Economic Factors

Socio-economic status (SES), although inconsistently found to be an independent predictor of adherence behaviours, was proposed to play a moderating role on adherence to long-term management in circumstances of low SES where individuals may be forced to choose between competing demands (e.g. paying for essential living expenses versus purchasing medication) on already limited resources (Albaz, 1997; Belgrave, 1997). Other factors implicated include literacy, education status, employment status, social and familial support, living conditions, distance to treatment centres, economic hardship, costs of transport and medication, environmental situations, and culture and beliefs around health conditions and their treatment (Albaz, 1997; Belgrave, 1997; Erwin, 1999). While race has been identified to be a predictor of adherence, WHO (Sabaté, 2003) reports that cultural factors and social inequalities are often behind these noted racial differences (Siegel, 2000). Age was also reported inconsistently to impact on adherence to long-term care, with the recommendation being made to consider age separately within groups based on condition, characteristics of the individual and developmental age group (Fotheringham, 1995; Burkhart et al., 2001).

Therapy-Related Factors

Demands and duration of treatment, stability and consistency in treatment regime, previous treatment experiences, treatment-related side-effects/symptoms, and support in managing treatment-related challenges have all shown to modify health management behaviours of people living with chronic disease. Characteristics unique to individual conditions have been increasingly recognised to modify the influence of common factors on adherence behaviours in unique ways. As such, the presence or absence of these unique characteristics is believed to increase or decrease adherence to long-term management.

Patient-Related Factors

The exact contribution of resources, knowledge, attitudes, beliefs, perceptions, and expectations in adherence - while recognised to play some modifiable role, is not yet adequately understood (Gupta & Horne, 2001; Horne, 1999; Horne et al., 1999, 2001; Miller & Rollnick, 1999; Petrie & Wessely, 2002). The impacts of cognition (forgetfulness), psychological distress, motivation and an individual's knowledge, beliefs and understanding of their condition and its management have all been highlighted to influence management behaviours in some way, yet require further examination (Sabaté, 2003).

Condition-Related Factors

Illness-related demands associated with chronic conditions can play a key role in influencing adherence to long-term management. The experience of symptoms and disease progression, health-related quality of life, level of disability, and the availability of effective treatments all have the potential to influence the individual's behaviours. Comorbid conditions, including mental health and drug and alcohol abuse have been shown to play a modifying role in management behaviours (Ciechanowski et al., 2000).

Health System/Healthcare Team Factors

Although limited research has examined its relationship with health management behaviours, factors shown to influence management behaviours include patient-provider relationships, availability and accessibility, provider knowledge and skill in the management of chronic conditions as well as aspects of service delivery (Rose et al., 2000). Service delivery factors include consultation times, patient education and follow-up, the ability to establish community support, the capacity for self-management, and an understanding of adherence and appropriate interventions to increase adherent behaviours.

Applying the WHO (Sabaté, 2003) Model to Regional Populations

Importantly, while identifying individual factors that have been shown to influence adherence to long-term health management, evidence provided by WHO (Sabaté, 2003) also stresses the importance of the relationship between factors. As such, interventions focussing on a single dimension of the model may, in fact, have limited effectiveness on health management_behaviours, as it neglects to both acknowledge and address the multidimensional influences that work together to determine behaviour and ultimately health outcomes. Additionally, the environmental context within which an individual exists (e.g. regional populations and Indigenous populations) may further compound or moderate relationships with adherence (McCurdy et al., 2012), and the WHO advocates that solutions for improving adherence behaviours may ultimately need to be tailored according to the individual differences of groups.

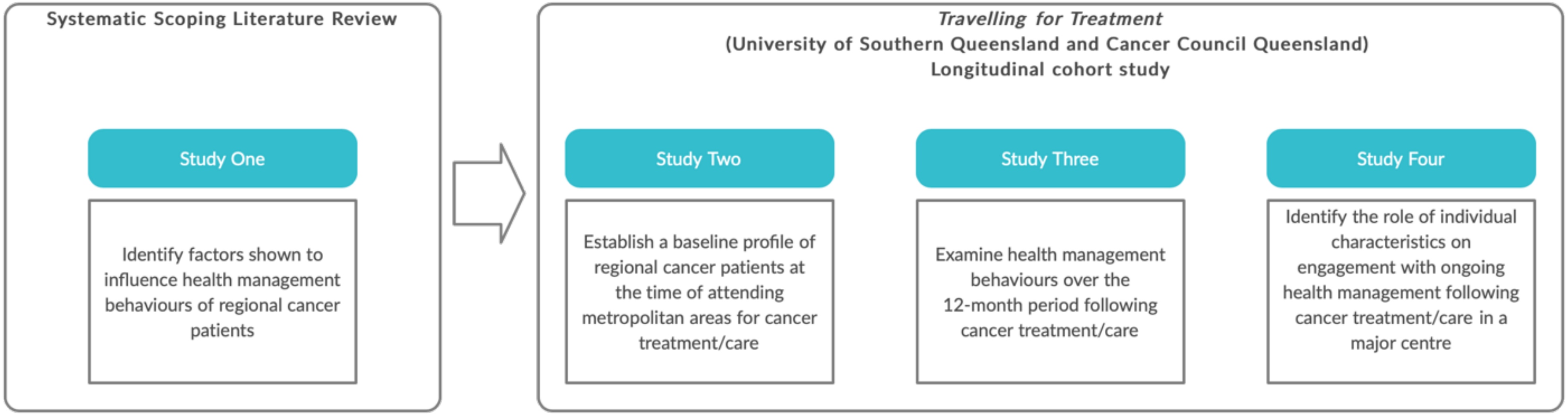
Thus, while the WHO model and domains provides a comprehensive overview of the factors that influence adherence to chronic health management regimes in the general population, it also highlights that these factors are likely complex, inter-related, and different in specific environmental contexts. It was proposed that the uniqueness of certain populations (e.g. regional people) may influence adherence behaviours in other ways, but as yet, there is very little substantiated evidence examining exactly what this may be. More importantly, there is limited understanding of how these factors may work together to either promote or inhibit adherence to health management behaviours within different populations like regional Australians who face additional challenges in accessing follow-up care and health-related services. Thus, while there is good evidence to highlight the factors associated with adherence more generally, there is a need to determine whether these apply to regional populations who are the focus of this program of research, before specific hypotheses can be made regarding the most relevant factors to examine in the survivorship period.

Summary

Existing evidence shows two main gaps in the literature that should be addressed in order to fully understand the behaviours of regional people in the cancer survivorship period, and thus form the basis of this program of research. The progression of studies is summarised in Figure 2.4.

Figure 2.4

Progression of Studies Within This Program of Research



First, there has not yet been a clear examination and understanding of post-treatment (survivorship) behaviours in regional people living with cancer. Current evidence from the general regional population would suggest that health behaviours in the survivorship period could be problematic for regional cancer survivors and could potentially play an influential role in determining cancer outcomes (AIHW, 2019; Goodwin et al., 2020; WHO, 2019b). However, this needs to be examined explicitly within regional people living with cancer, which will be achieved through the longitudinal Travelling for Treatment study described in Chapters 4-7.

Second, there is currently a limited understanding of what factors promote or inhibit engagement in post-treatment behaviours specifically for regional people living with cancer. While the WHO dimensions (Sabaté, 2003) provide some guidance around the factors important to long-term management of chronic conditions, it is not known which factors are relevant to regional populations or how the regional cancer context compounds or moderates these influences. The first study in this program of research (Chapter 3) seeks to address this gap by conducting a systematic scoping review (which allows for the inclusion of evidence irrespective of methodology or quality) of factors that have been found to be important influences on adherence to long-term survivorship care specifically within regional populations. The first study was designed to subsequently inform the design of Travelling for Treatment, in terms of the constructs relevant for assessment. Preliminary searches confirmed that evidence specifically pertaining to regional cancer survivors was limited; thus the review was expanded to include regional people living with any chronic health diagnosis. It was anticipated that the inclusion of the most common chronic health conditions worldwide (diabetes, cardiovascular disease, chronic obstructive pulmonary disease, chronic respiratory disease; WHO, 2018) would allow for a greater understanding of factors influencing engagement in follow-up care and health-promoting behaviours within regional chronic health populations.

Chapter 3: Study 1 - Factors Associated with Adherence to Long-Term Management of Chronic Health Conditions in Rural Populations: A Scoping Review

Following on from the literature review in Chapter 2, the purpose of Study 1 is to determine the current state of evidence regarding factors that influence adherence to medical management and engagement in health-promoting behaviours for people with a cancer diagnosis living in a regional area. A scoping review was conducted to achieve this; however, due to limited research focusing specifically on cancer populations, this review was extended to include regional populations with any chronic health condition diagnosis. The body of evidence identified in the review was examined using the WHO's Dimensions of Adherence (Sabaté, 2003) as a guide.

Method

Research Design

This review employs the methodological framework for the conduct of systematic scoping reviews defined by the PRISMA Extension for Scoping Reviews guidelines (PRISMA-ScR; Tricco et al., 2018).

Search Strategy

An initial search was conducted to identify relevant key words and index terms, and to assist in the development of the review protocol. The protocol (see Appendix A) was subject to feedback from the research team and the University's research librarian, and refined accordingly, prior to conducting searches across relevant databases.

A comprehensive search of the literature published from January 1990 to August 2019 was conducted using databases psycARTICLES, psycINFO, Psychology and Behavioural Sciences Collection, Academic Search Ultimate, Scopus, PubMed, MEDLINE, CINAHL, The Cochrane Library, and ProQuest Dissertations and Theses. The Boolean search phrase (for Title and Abstract) included the following search terms: (adher* OR engage* OR participat* OR continu* OR commit* OR complia*) AND (health behav* OR medical regime$ OR “healthy lifestyle” OR weight OR “weight management” OR BMI OR “body mass index” OR overweight OR obes* OR smoking OR cigarette$ OR nicotine OR tobacco OR alcohol* OR drinking OR “fruit and vegetable” OR nutrition OR diet OR exercise OR “physical activity” OR “active lifestyle” OR medication OR “adjuvant treatment” OR “adjuvant therapy” OR surveillance OR monitor* OR followup OR “care plan”) AND (factor$ OR predict* OR influen* OR characteristic$ OR cultur*) AND (cancer* OR neoplasm$ OR "chronic health" OR "chronic illness" OR “chronic condition” OR “chronic disease” OR condition OR “cardiovascular disease” OR “chronic obstructive pulmonary disease” OR “COPD” OR diabetes OR asthma OR “chronic respiratory disease”) AND (rural* OR regional OR remote OR isolated OR small town OR geograph*). See Appendix B for exact search phrases adopted for each database.

Inclusion Criteria

In accordance with the a-priori protocol, articles were considered eligible if they assessed: (a) a regional (geographically remote) population, including any population outside of metropolitan or urban areas; (b) participants with a past or present diagnosis of any chronic health condition; (c) health-promoting lifestyle behaviours (specifically physical activity, nutrition, weight management/BMI, alcohol intake, smoking) or medical management (follow-up treatment, medication, screening, surveillance, monitoring); and (d) factors associated with adherence or engagement. No restrictions were applied based on study design, publication type or country of origin. Eligibility was restricted to adult populations (18+ years) and to articles published from 1990 to 2019 in the English language. With only one article published prior to 2000 meeting inclusion criteria, it was deemed that this was sufficient to adequately represent the current state of knowledge pertaining to the research aims.

Selection Process

The selection process involved five stages: initial searching, removal of duplicates, title and abstract screening, full text screening, and manual screening of reference lists. Once duplicates were removed, articles were screened for relevance by title and those not meeting eligibility criteria were removed. Abstracts of potentially eligible articles were then reviewed, using the predetermined inclusion criteria. Full-text articles were further examined against inclusion criteria. Any disagreement with respect to inclusion was resolved through discussion with the research team. Reference lists of the final selection of articles were manually searched and potentially relevant articles subject to an identical selection process.

Data Collation

Data was collated alphabetically into a single extraction spreadsheet in Microsoft Excel. Information extracted for each article included:

- Referencing/citation data (author/s, title, year);
- Sample characteristics (setting/country, sample size, condition type);
- Study design and methodology;
- Definitions/measurement of rural;
- Definitions/measurement of adherence; and
- Items (associated with adherence) examined and relevant outcomes.

Categorisation of Items into WHO Dimensions of Adherence

Individual variables (referred to as items) examined for their association with adherence were categorised into five overarching dimensions, suggested by the WHO to affect adherence to long-term therapies (Sabaté, 2003). These dimensions include social/economic factors, therapy-related factors, patient-related factors, condition-related factors, and health system/healthcare team factors. A breakdown of each dimension with sample items is provided in Table 3.1, along with the author-generated grouping based on data from the current study.

Over 600 individual items were examined across the selected studies, with a great deal of variation in how factors were operationalised. Therefore, individual items were first grouped in alignment with the WHO dimensions, and then further grouped into smaller categories based on intended constructs within each WHO dimension. For example, items addressing subjective support, objective support, instrumental support, and family support were combined into a category named "supportive factors" within the WHO social/economic factors dimension. This strategy would allow for a more meaningful discussion of findings given the diversity in measurement. Dimensions, categories and individual items were reviewed for accuracy by the research team, and any disagreement concerning categorisation was resolved through discussion.

Table 3.1

Breakdown of WHO Dimensions of Adherence (Sabaté, 2003) & Author-Generated Categories Based on the Included Studies

WHO Adherence Dimension	WHO Categories of Items Within Dimensions		Categories Formed Based on Included Studies
Social/Economic Factors	• socio-economic status • poverty • illiteracy • education • lack of effective social support networks • unstable living conditions	• long distance from treatment centre • high cost of transport • high cost of medication • changing environmental situation • culture and lay beliefs about treatment • family dysfunction	• age • gender • education/literacy • family/ relationship status • income/ employment • SES/ poverty • race/ ethnicity/ migrant status • health insurance status • travel/ distance • costs • geographic location • supportive factors
Therapy-Related Factors	• complexity of medical regimen • duration of treatment • previous treatment failures • frequent changes in treatment	• immediacy of beneficial effects • side-effects • availability of support to deal with side-effects	• side-effects • medical/ treatment regimen • medication/ treatment type • treatment duration • alternative treatments • self-efficacy, skills & self-administration
Patient-Related Factors	• resources • knowledge • attitudes • beliefs • perceptions • expectations • confidence/self-efficacy	• forgetfulness • anxieties/fears about possible adverse effects • motivation • non-acceptance of disease or monitoring • behavioural or psychotherapy classes • feeling stigmatised by disease	• patient beliefs & attitudes • knowledge, information & understanding • individual capacity/ cognition • lifestyle factors & behaviours
Condition-Related Factors	• illness-related demands faced by patient • severity of symptoms • level of disability	• progression and severity of disease • effective treatment • comorbidities	• disease type • symptoms & severity • disease duration • comorbidities • disease progression/ prognosis • risky lifestyle behaviours • family history • clinical markers • health status • mental health

WHO Adherence Dimension	WHO Categories of Items Within Dimensions		Categories Formed Based on Included Studies
Health System/Healthcare Team	patient-provider relationship inadequate health system reimbursement poor medication distribution systems lack of knowledge and training for healthcare professionals on adherence/managing chronic diseases overworked healthcare professionals	lack of incentives on performance lack of incentives on performance short consultations weak capacity of system to educate patients and provide follow-up inability to establish community support and self-management capacity	patient-provider relationship & trust provider skills (i.e. knowledge, communication) health facilities & services medication/treatment access & availability

Analytic Strategy

The primary aim of this review was to synthesis information on factors influencing adherence to long-term health management behaviours in regional populations with a chronic health condition. Items examined within the eligible studies were first classified into their relevant WHO dimensions (as described in Table 3.1), and given the large numbers of individual items, were subsequently examined based on dimension and category. Data were presented in a number of ways. First, to provide a profile of the nature and content of the research, the overall number of eligible articles within each dimension and category were presented descriptively via frequency and percentages. Second, as many studies examined multiple individual items within a single category (e.g. time with family, time with friends, reliance on family, reliance on friends, all within the ‘Supportive Factors’ category), it was deemed necessary to describe data based on the number of individual items within each category in order to allow more meaningful interpretation of the evidence. Third, given extreme variation in study methodology and analysis, to accurately understand the relationship between the examined items and adherence, it was reported a) whether or not studies statistically examined the link between items and adherence, b) if they did statistically examine the relationship, whether results were statistically significant or not; and c) the direction of those relationships. Finally, qualitative studies falling within each dimension and category were reviewed and commentary provided for any notable themes or relationships with adherence. Only data explicitly addressing the research aims were recorded and considered in this review. In alignment with JBI guidelines (Peters et al., 2017), eligible studies were not assessed for methodological quality.

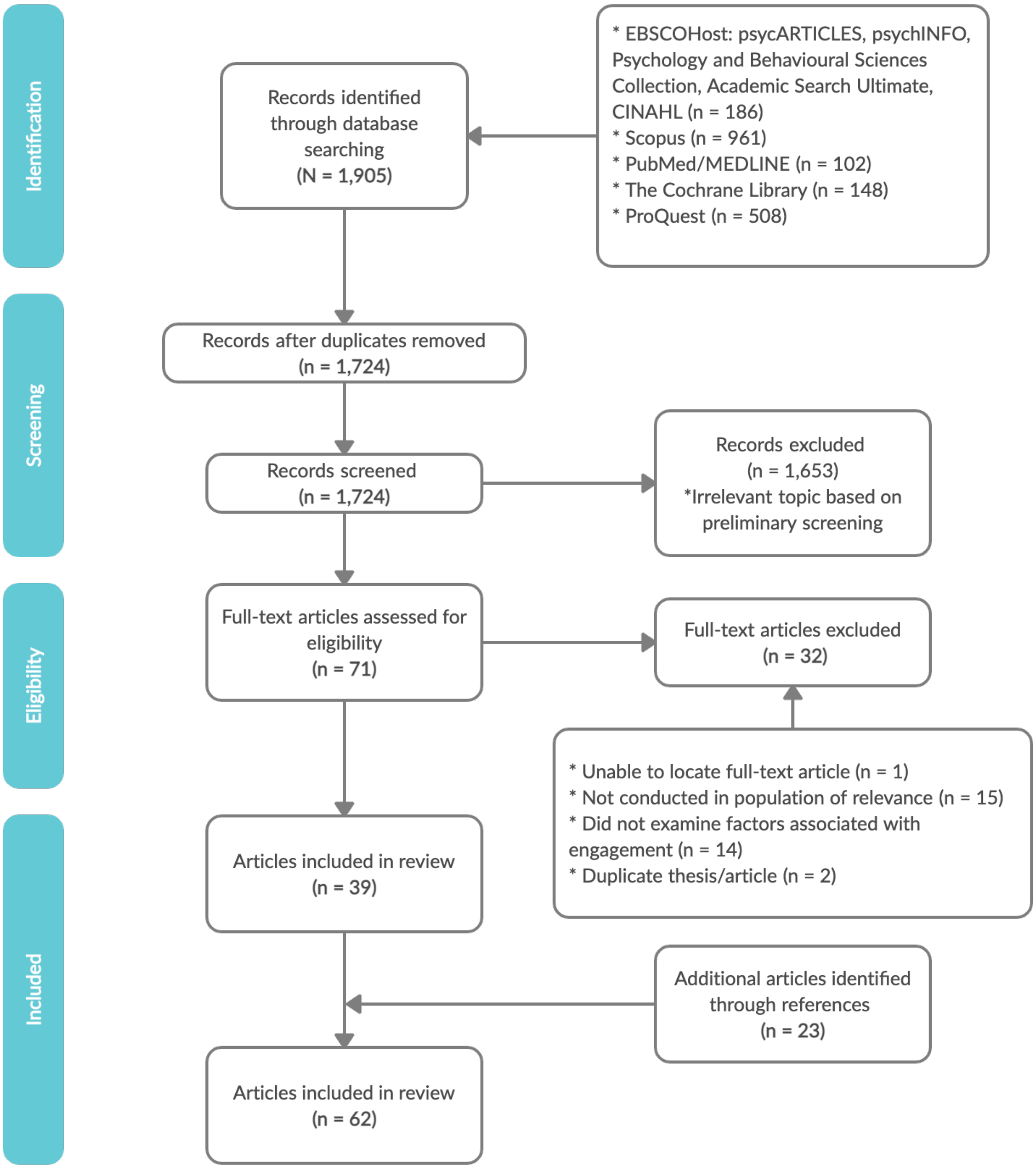
Results

Article Selection

A detailed summary of the study selection process is provided in Figure 3.1. The initial search produced a total pool of 1905 articles. Following removal of duplicates 1724 article abstracts were screened, and full-text review was conducted on 71 articles. Thirty-two articles were excluded during full-text screening, leaving a pool of 39 articles for inclusion. Finally, reference lists of the included articles were manually searched for additional relevant articles. Through this process 23 additional articles were identified for inclusion, resulting in a final pool of 62 articles included in this review.

Figure 3.1

Flowchart of Study Selection



Study Characteristics

The characteristics of the 62 articles included in the review are provided in Table 3.2. The majority of studies were conducted within diabetes and heart-related conditions including hypertension, cardiovascular disease, stroke, and heart failure, with sample sizes ranging from 16 to 4,097. Only 11.29% of studies were conducted in cancer populations, with a combined sample size of 740 (range 16 - 428). A large proportion of the studies were conducted within the United States and India, while the remaining studies represented areas across Australasia, Europe, South America, and Africa. There was a mix of quantitative (62.90%), qualitative (24.19%) and mixed methods (12.91%) studies included. The majority of included studies were published in the last 10 years (77.42%).

Table 3.2

Sample Characteristics of Studies Included for Review

Characteristic		*n*	%^{a}
Health Condition			
	Diabetes	22	35.48
	Heart conditions: CVD, stroke, hypertension, heart failure	17	27.42
	Chronic Disease (unspecified)	8	12.90
	Cancer (non-specific, breast, lymphoma, endometrial)	7	11.29
	HIV/AIDS	5	8.07
	Tuberculosis	2	3.23
	Psychiatric	2	3.23
	Asthma	1	1.61
Sample Size			
	0-99	19	30.65
	100-499	35	56.45
	500+	8	12.90
Sample Country			
	United States	19	30.65
	India	15	24.19
	China	3	4.84
	Australia	3	4.84
	South Africa	3	4.84
	Bangladesh	2	3.23
	Canada	2	3.23
	Mexico	2	3.23
	Thailand	2	3.23
	Uganda	2	3.23
	Ethiopia	1	1.61
	Columbia	1	1.61
	Egypt	1	1.61
	France	1	1.61
	Kenya	1	1.61
	Malawi	1	1.61
	Pakistan	1	1.61
	South Korea	1	1.61
	Sri Lanka	1	1.61
	Vietnam	1	1.61
Study Methods			
	Quantitative	39	62.90
	Qualitative	15	24.19
	Mixed Methods	8	12.91
Data Collection Method			
	Survey/Questionnaire	30	48.39
	Interview/Focus Group	31	50.00
	Medical Records/Test Results	12	19.35
Publication Year			
	1990 – 1999	1	1.61
	2000 – 2009	13	20.97
	2010 – 2019	48	77.42

Note. N = 62. Two studies were conducted in multiple health populations, accounting for 64 health conditions in total.

[a] reported as a percentage of the 62 studies

Definitions and Measurement of Adherence

The WHO defines adherence to long-term therapies as "…the extent to which a person's behaviour - taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider…" (Sabaté, 2003; p.3). This definition clearly outlines both medical and behavioural recommendations as important aspects of adherence that should be considered. When comparing this definition to those adopted across studies included in this review, significant discrepancies were noted. Most notably, only 30.65% (*n* = 19/62) of studies provided a theoretical definition of adherence. Of those studies, only nine (9/62, 14.52%) referred to the WHO definition of adherence (Sabaté, 2003). A further five studies (*n* = 5/62, 8.07%) provided alternative definitions that aligned with the WHO definition, incorporating both medical and behavioural recommendations in their definition. The remaining five studies (*n* = 5/62, 8.07%) provided alternative definitions that only entailed adherence to medications. The other 43 studies (69.35%) did not provide a definition of adherence.

There was significant variance in the outcome measures employed to assess adherence. The most common approach to measuring adherence was using dosage counts (*n* = 23/62 studies, 37.10%), primarily ratios of taken versus missed medication within a fixed period, or a patient's report of the number of missed doses within a fixed period. However, the cut-offs used to determine adherence versus non-adherence varied greatly across these studies. For instance, patients were categorised as "adherent" or "compliant" based on cut-off ratios ranging from ≥60.00% in some studies through to no less than 100.00% of dosage taken in other studies. Other measures of adherence utilised across studies included the Morisky Medication Adherence Scale (*n* = 11/62, 17.74%), self-reported engagement in health behaviours (*n* = 7/62, 11.29%), clinical markers (such as measures of glycemic control; *n* = 5/62, 8.07%), regularity or cessation of visits to healthcare professionals (*n* =

4/62, 6.45%), and the Summary of Diabetes Self-Care Activities (SDSCA) measure (*n* = 3/62, 4.84%). A range of other instruments were used sparingly across studies, including the Brief Medication Questionnaire (*n* = 1/62, 1.61%), the Asthma Adherence Instrument (*n* = 1/62, 1.61%), the Behavioural Risk Factor Surveillance System (BRFSS; *n* = 1/62, 1.61%), and the WHO Global Physical Activity Questionnaire (*n* = 1/62, 1.61%). A number of studies (*n* = 9/62, 14.52%) did not measure levels of adherence, but focused on qualitatively examining patients' *reasons* for not adhering.

In total, 70.97% (*n* = 44/62) of studies focused solely on either adherence to medication (*n* = 36/62, 58.07%), or health behaviour engagement (*n* = 8/62, 12.90%), failing to incorporate the full range of behaviours - both medical and behavioural - as encompassed by the WHO (Sabaté, 2003) definition. Only 29.03% (*n* = 18/62) of studies examined both medical and behavioural recommendations as representative of adherence.

Examination of Factors Impacting on Adherence

A summary of the identified categories of items within each WHO dimension is shown in Table 3.3. The total number of studies examining each dimension and each category; the number of studies in each category demonstrating a statistically significant relationship with adherence, no statistically significant relationship, and/or descriptive or qualitative evidence; and the total number of items within each category are reported. For example, age was examined through 34 items, via 30 separate studies, showing that some studies examined age in multiple ways (e.g. as a continuous variable, and as a grouped variable).

Table 3.3

Factors Associated With Adherence in Regional Populations With a Chronic Health Condition

	Analysis Results			Total Individual Items examined (n)	Total studies (n)	Percentage of studies (%)
Dimension	Significant (n)	Non-Significant (n)	No Statistical Analysis (n)			
Dimension 1: Social Economic					**53**	**85.48**
1.1 Age	18	16	0	34	30	48.39
1.2 Gender	9	24	1	34	29	46.77
1.3 Education/Literacy	5	17	1	23	20	32.26
1.4 Family/Relationship status	5	16	1	22	16	25.81
1.5 Income/Employment	4	17	1	22	16	25.81
1.6 SES/Poverty	0	4	1	5	5	8.07
1.7 Race/Ethnicity/Migrant Status	2	3	1	6	5	8.07
1.8 Health Insurance Status	3	3	2	8	6	9.68
1.9 Travel/Distance	3	4	12	19	17	27.42
1.10 Costs	3	3	17	23	21	33.87
1.11 Geographic Location	1	3	0	4	4	6.45
1.12 Supportive Factors	18	23	23	64	22	35.48
Dimension 2: Condition-Related					**40**	**64.52**
2.1 Disease Type	0	0	3	3	3	4.84
2.2 Symptoms & Severity	8	9	13	30	20	32.26
2.3 Disease Duration	8	6	0	14	12	19.35
2.4 Comorbidities	2	5	1	8	8	12.90
2.5 Disease Progression/Prognosis	2	4	2	8	6	9.68
2.6 Risky Lifestyle Behaviours	8	20	1	29	12	19.35
2.7 Family History	1	5	1	7	7	11.29
2.8 Clinical Markers	2	4	0	6	6	9.68
2.9 Health Status	4	14	0	18	13	20.97
2.10 Mental Health	4	6	0	10	8	12.90
Dimension 3: Therapy-Related					**35**	**56.45**
3.1 Side-Effects	0	8	12	20	11	17.74
3.2 Medical/Treatment Regimen	10	10	8	28	20	32.26
3.3 Medication/Treatment Type	4	8	1	13	9	14.52
3.4 Treatment Duration	1	3	1	5	5	8.07

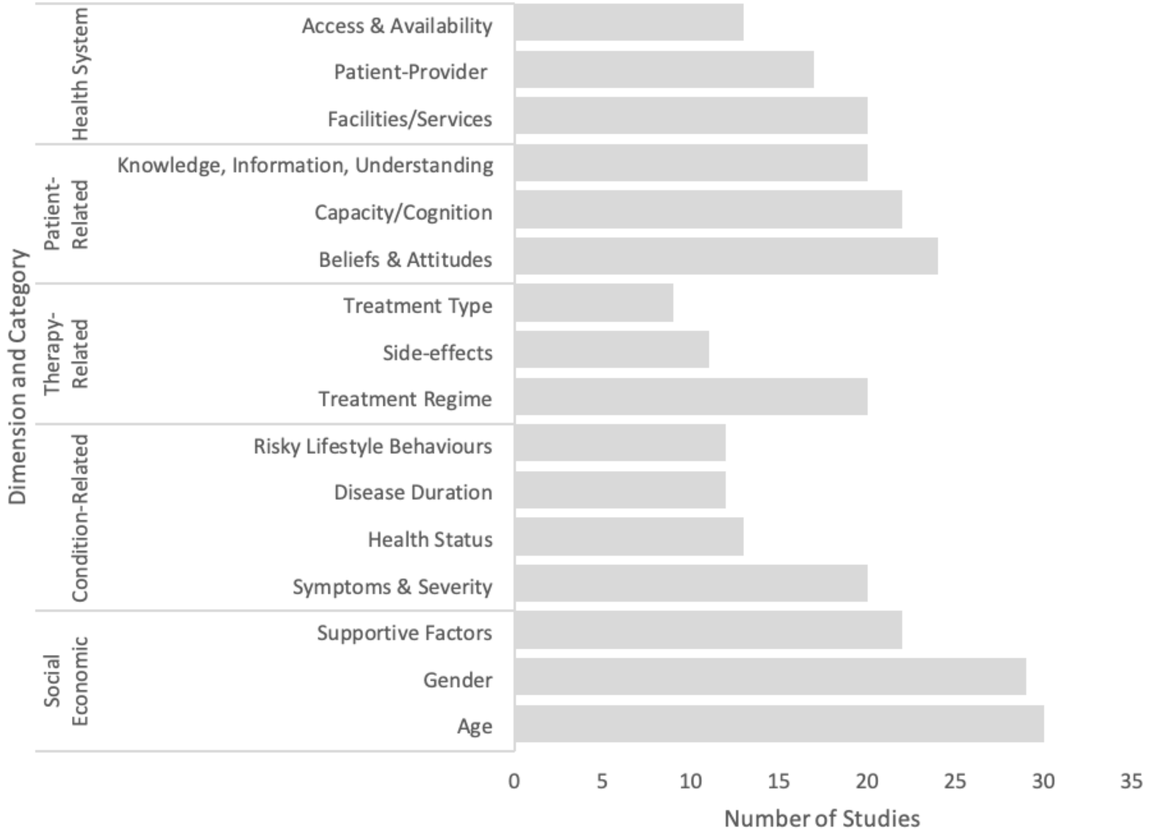
Dimension	Analysis Results Significant (n)	Non-Significant (n)	No Statistical Analysis (n)	Total Individual Items examined (n)	Total studies (n)	Percentage of studies (%)
3.5 Alternative Treatments	3	3	4	10	7	11.29
3.6 Self-efficacy, Skills & Self-administration	4	1	2	7	6	9.68
Dimension 4: Patient-Related					**41**	**66.13**
4.1 Patient Beliefs and Attitudes	22	25	29	76	24	38.71
4.2 Knowledge, Information & Understanding	9	5	15	29	20	32.26
4.3 Individual Capacity/Cognition	5	4	20	29	22	35.48
4.4 Lifestyle Factors & Behaviours	6	4	21	31	19	30.65
Dimension 5: Health System/Health Care Team					**32**	**51.61**
5.1 Patient-Provider Relationship & Trust	7	8	22	37	17	27.42
5.2 Provider Skills (i.e knowledge, communication)	1	1	1	3	3	4.84
5.3 Health Facilities & Services	6	4	17	27	20	32.26
5.4 Medication/Treatment Access & Availability	3	1	9	13	13	20.97

Note. N = 62. Percentage of studies reflects the percentage of total studies.

For those items that demonstrated significant relationships with adherence, results, including the direction of significant relationships are discussed in further detail according to each of these dimensions. Particular attention is given to items within the patient-related and health system/health care team dimensions, which are of primary interest to this program of research. For those items where the majority of research failed to find a statistically significant relationship between the category and adherence, no further discussion of the direction or magnitude of those relationships is provided. Detail regarding individual items and results can be found in the original study. Figure 3.2 visually depicts the categories most often examined under each of the five dimensions.

Figure 3.2

Most Common Categories of Influence Within Each Dimension



Dimension 1: Social Economic

Table 3.3 provides a summary of all items that fell within the Social Economic Factors dimension. In total, 85.48% (53/62) of studies examined at least one social or economic item in relation to adherence within regional populations. Of the 264 individual items mentioned in these studies, 204 (77.27%) were statistically examined for their relationship with adherence. The most commonly examined categories within the social economic dimension were age (*n* = 30/62 studies, 48.39%), followed by gender (*n* = 29/62, 46.77%), supportive factors (*n* = 22/62, 35.48%), and costs (*n* = 21/62, 33.87%).

The categories with the strongest evidence were gender, education, income, and supportive factors. Of the 34 gender-related items statistically examined across studies, 24 (70.59%) were found to have no relationship with adherence. Of the nine analyses in which adherence appeared to be influenced by gender, seven of these showed females were more adherent and two showed males were more adherent. For education-related items, of the 22 items statistically examined across studies, 17 (77.27%) were found to have no relationship with adherence. Of the five analyses reporting a statistically significant relationship between education items and adherence, three showed increasing adherence with increasing levels of education. Of 22 income-related items, 17 (77.27%) showed no statistically significant relationship with adherence. Four income items were shown to have a statistically significant relationship with adherence, all reporting increased adherence with increasing income. Supportive factors were examined across 22 separate studies, with 23 items (56.10%) showing no statistically significant relationship to adherence, and 18 items (43.90%) showing a statistically significant relationship to adherence. All 18 of those items showed increases in adherence behaviours with greater levels of support.

For the remaining categories falling within this dimension there was no clear consensus regarding whether categories were related to adherence, with relatively equal numbers of analyses showing a statistically significant relationship as those showing no statistically significant relationship. Although age was the most commonly reported category, 16 of the 34 items (47.06%) examined reported no statistically significant relationship. In instances where a statistically significant relationship to adherence was identified, 77.78% (*n* = 14/18) showed that adherence increased with increasing age, 11.11% (*n* = 2/18) found adherence decreased with increasing age, and 11.11% (*n* = 2/18) were unclear on the direction of the relationship. Of the six cost-related items that were statistically examined in relation to adherence, three (50.00%) found no significant relationship to adherence, and three (50.00%) found poorer adherence as costs increased.

Three specific categories within the social economic dimension were also examined extensively via qualitative measures: travel/distance, costs, and supportive factors. Approximately 63.16% (*n* = 12/19) of travel- and distance-related items were examined qualitatively, across 10 studies. These studies highlighted distance, the need to travel, and a lack of transport (both public and private) as key challenges preventing adherence. Although only three analyses demonstrated a significant relationship between cost and adherence in quantitative studies, 15 additional qualitative studies indicated that cost was a significant barrier to an individual's adherence, with higher medication/treatment costs being proposed to result in poorer adherence. Finally, 10 studies qualitatively reported on the importance of support in adherence. The presence of a supportive environment and instrumental, objective, and subjective support was reported to play an important role in promoting positive adherence, in line with the quantitative findings.

Dimension 2: Condition-Related

Approximately 64.00% (*n* = 40/62) of included studies examined at least one condition-related item and its relationship with adherence. Of 133 individual items examined by these studies, the relationship between 112 (84.21%) condition-related items and adherence was examined statistically, making it one of the strongest dimensions with respect to identifying the influence and magnitude of the effect of these items on adherence. Overall, 17 symptom and severity-related items were statistically examined across nine separate studies, with eight items showing a statistically significant relationship with adherence, and nine items showing no relationship with adherence. All eight items showed decreasing adherence as symptoms and severity increased. An additional 12 studies provided qualitative data relating to the influence of symptoms and severity. Contrary to the quantitative data, these studies reported that greater levels of symptoms and severity promoted higher levels of adherence across these studies, and that a lack of symptom relief after taking medication negatively influenced adherence.

With respect to disease duration, six items reported no statistically significant relationship with adherence, however of the eight items that were statistically related to adherence, 75.00% (*n* = 6/8) showed greater adherence the longer patients had been diagnosed, one reported the opposite relationship and one did not report a clear direction. Several categories within this dimension were consistently found not to show a statistically significant relationship with adherence, including comorbidities (*n* = 5/7 items across 6 studies), risky lifestyle behaviours (*n* = 20/28 items across 12 studies), family history (*n* = 5/6 items across 6 studies), clinical markers (*n* = 4/6 items across 6 studies), disease progression (*n* = 2/6 items across 4 studies) health status (*n* = 14/18 items across 12 studies), and mental health (*n* = 6/10 items across 8 studies).

Dimension 3: Therapy-Related

Thirty-five studies (56.45%) reported on therapy-related factors. Eighty-three items were examined across the 35 studies, with 66.27% (*n* = 55/83) being statistically examined with respect to their relationship with adherence. The most commonly examined category across studies was medical/treatment regimen (*n* = 20/35, 57.14%), followed by side-effects (*n* = 11/35 studies, 31.43%), however neither were clearly related to adherence. Items associated with the medical/treatment regimen were equally found to have a statistically significant relationship (*n* = 10/20, 50.00%, mostly showing that more complex or time-intensive regimens were associated with poorer adherence) as no significant relationship with adherence and there were no statistically significant relationships between the eight side-effect items examined and adherence.

The strongest evidence within this dimension was for self-efficacy, skills and self-administration. Four of the five (80.00%) items analysed within this category were found to have a statistically significant relationship with adherence, showing that adherence increased as self-efficacy and skills increased. Of the four (out of 12, 33.33%) individual medication/treatment type items found to have a statistically significant association with adherence, results were unclear. Specifically, analyses made comparisons between a variety of treatments/medications and found differences in adherence based on type; however, generalised patterns were not clear given that analyses were conducted on individual treatments/medications (see original studies for specific medication details). Treatment duration was found to have a statistically significant relationship with adherence in only one of the four items (25.00%) examined across four separate studies.

There was inconsistent evidence with respect to the remaining therapy-related categories. Half (*n* = 3/6) of the items relating to alternative treatments found a significant relationship with adherence (mostly showing that the use of alternative treatments was associated with poorer adherence), while the other half reported a non-significant relationship.

Despite a lack of strong quantitative evidence, qualitative data showed 12 items across nine studies that indicated the presence of side-effects from treatment or medication would likely result in poorer adherence. Likewise, qualitative data also showed eight items across six separate studies that highlighted medical/treatment regimen issues associated with adherence. In particular, treatment schedule length, numbers of medications required to be taken, and difficulty in taking these medications were reported to have a potentially detrimental effect on adherence.

Dimension 4: Patient-Related

Approximately two-thirds (*n* = 41/62, 66.13%) of included studies examined at least one item falling under patient-related factors, making it the second-most commonly examined dimension behind social-economic factors. However, almost half of patient-related items were not examined statistically (*n* = 81/166, 48.80%), making this dimension the second poorest (only to the fifth dimension) with respect to the quality of methodology used to explore relationships with adherence. As a result, no firm statements can be made with respect to the influence of these factors on adherence. However, broader commentary on the areas of focus within the research can be made. The most commonly examined categories within this dimension were patient beliefs and attitudes (*n* = 24/62, 38.71%), and individual capacity/cognition (*n* = 24/62, 38.71%).

The patient beliefs and attitudes category had the greatest proportion of research activity across all dimensions, with 76 individual items assessed. Despite the volume of research focusing on patient beliefs and attitudes, only 61.84% (*n* = 47/76) of these items were statistically examined to determine their influence on adherence, with 25 items reporting no statistically significant relationship with adherence. Of the 22 items showing a statistically significant relationship, there was a common trend that positive beliefs and attitudes promoted greater adherence. Overall, the studies focused on broad health- and illness-related beliefs applicable to general chronic health populations such as health locus of control, perceptions of treatment benefits and barriers, and condition severity and susceptibility, rather than focusing on attitudes or beliefs hypothesised to be specific to regional populations. Only one study examined the role of stigma on adherence, finding no statistically significant relationship to exist.

Patient knowledge, information, and understanding was examined via 29 items across 20 studies (*n* = 20/62, 32.26%). Of the 14 items (*n* = 14/29, 48.28%) that were statistically examined within this category, nine (*n* = 9/14, 64.29%) showed a significant relationship with adherence, while five (*n* = 5/14, 35.71%) did not. In those instances where significant relationships were identified, the direction of relationships was consistently positive, with adherence increasing as knowledge, information, and understanding increased. Qualitative data, provided across ten separate studies, supported the quantitative findings, highlighting the crucial role of knowledge and information acquisition in promoting adherence, along with the need for understanding the rationale for treatment, the benefits of treatment and the risks of non-adherence.

Individual capacity/cognition (e.g. hopelessness, stress, forgetfulness, reminders, problem solving skills) was examined through 29 items across 22 separate studies (*n* = 22/62, 35.48%), with only nine of those items (*n* = 9/22, 40.91%) examined via statistical analysis. Of those nine items, five (*n* = 5/9, 55.56%) were found to be statistically significantly related to adherence. Those cases reporting a statistically significant relationship consistently indicated that higher capacity/cognition, better memory, and problem-solving skills were associated with increased adherence.

Thirty-one items representing patient lifestyle factors and behaviours were examined across 19 separate studies (*n* = 19/62, 30.65%). Items falling within this category pertained primarily to the adjustment of lifestyle in order to accommodate adherence to treatment and/or management regimes and the challenges around this adjustment (e.g. busyness, time constraints, inconvenience, adjusting social behaviours, incorporating healthy lifestyle behaviours, and utilising supports available). This category was poorly represented with respect to the quality of analysis with 67.74% (*n* = 21/31) of items not subjected to any statistical analysis. Of the ten items that were statistically analysed, six (*n* = 6/10, 60.00%) showed a relationship with adherence, while four (*n* = 4/10, 40.00%) did not. Those items with a significant relationship showed that the patient's ability to adapt their lifestyle to incorporate adherence behaviours was associated with greater adherence. An additional 21 items were examined qualitatively across 13 studies, raising issues around being able to make necessary lifestyle adjustments to support adherence, building external accountability to assist in continued adherence, and the impact of event-based disruptions (e.g. stopping taking medication in order to drink at specific social events) and employment barriers (e.g. work schedule does not support adherent behaviours).

Dimension 5: Health System/HCT

Thirty-two studies examined items that fell within the health system and health care team dimension (*n* = 32/62, 51.61%), including categories associated with the patient-provider relationship (*n* = 17/62, 27.42%), provider skills (*n* = 3/62, 4.84%), health facilities and services (*n* = 20/62, 32.26%), and access/availability to medication/treatment (*n* = 13/62, 20.97%). This dimension was the poorest with respect to the quality of analysis, with 56.58% (*n* = 43/76) of items not examined statistically.

Patient-provider relationship and trust (*n* = 17/62, 27.42%) was the third most commonly addressed category across all dimensions with respect to the number of items examined, behind patient beliefs and attitudes (Dimension 4), and supportive factors (Dimension 1). A total of 37 individual items were examined across 17 separate studies, encompassing the patient-provider relationship, patient experience, and satisfaction with providers, regularity of visits, and provider communication. Of the 15 items that were statistically examined, seven (*n* = 7/15, 46.67%) showed a statistically significant relationship with adherence, while eight (*n* = 8/15, 53.33%) did not show a significant relationship. Of those that did show a relationship, better communication from providers, greater patient satisfaction with providers, and positive patient-provider relationships were associated with increased adherence.

Provider skills, including their training, experience and qualification was examined via three items across three (*n* = 3/62, 4.84%) studies, of which two were statistically examined. One study showed a significant relationship suggesting increased provider skills was related to greater adherence, whereas the other study found no significant relationship. The single qualitative study examining provider skills also suggested that a provider's condition-specific training and experience may positively influence adherence.

Factors associated with health facilities and services were examined via 27 items across 20 studies (*n* = 20/62, 32.26%), specifically focused on the influence of the facility type or location (e.g. geographic location, specific site comparison, private vs government facilities). Only ten items (*n* = 10/27, 37.04%) were statistically analysed with respect to their relationship with adherence, with six (*n* = 6/10, 60.00%) of those items showing a significant relationship. However, these analyses focused mostly on comparisons of adherence between individual service sites, with some studies showing adherence to be better in patients of private and/or university-based health service providers compared to public/community services. An additional 17 items related to issues with inadequate services, service delays, and inadequate opening hours of facilities were qualitatively reported across eight studies (*n* = 8/62, 12.90%) to have a potentially negative influence on adherence.

The final category falling within the health system and health care team dimension was medication/treatment access and availability. In total, 13 items across 13 (*n* = 13/62, 20.97%) studies were categorised under medication/treatment access and availability. Less than one-third (*n* = 4/13, 30.77%) of medication/treatment access items were statistically analysed, with three of those items showing a significant relationship with adherence. In all three analyses, greater access to and availability of medication/treatment was associated with an increase in adherence. The remaining nine studies qualitatively reported that a lack of availability and access to medications and treatments may result in poorer adherence.

Discussion

This study originally sought to identify factors that influence adherence to follow-up care for regional people living with cancer, including both medical follow-up and engagement in health-promoting behaviours for positive recovery and long-term wellbeing. A paucity of literature within regional cancer populations resulted in an extension of this study to include regional populations with any chronic health diagnosis. The scoping review resulted in 62 included studies, with over 630 items associated with adherence examined across all five dimensions of the WHO model: social economic, condition-related, treatment-related, patient-related, and health systems/health care teams (Sabaté, 2003). There was significant diversity in how adherence was defined and measured even within the same chronic condition. Factors concerning the patient-related and health systems/health care team dimensions were particularly prominent alongside social economic factors, highlighting the potential importance of these factors specifically for regional populations.

Defining and Measuring Adherence

The World Health Organization promotes a holistic approach to the management of chronic health conditions, acknowledging both medical and behavioural components of healthcare as integral to long-term wellbeing (Sabaté, 2003). Despite substantial evidence supporting the role health behaviours play in optimal long-term care, less than one-quarter of studies included in this review acknowledged both medical and behavioural components within their definition of adherence. Further, less than one-third of studies incorporated the measurement and analysis of both medical and behavioural components when examining adherence. Almost 60.00% of studies focused solely on the medical aspects of condition management, with evidence relating to adherence strongly biased towards medication adherence. There was limited focus on other medical-related behaviours such as regularity of visits to healthcare professionals, engagement in follow-up tests, or medical procedures. While some variation in specific post-diagnostic activities across health conditions is expected, this was also apparent within the same conditions. A growing body of research supports a holistic approach to long-term management of conditions such as cancer, diabetes, and heart disease, and thus examination of adherence (and the impact of adherence on health outcomes) needs to extend to incorporate all recommended components of health care. There was a similar lack of consistency with respect to the adherence measures adopted across the literature, even within the same health conditions. This hampers the ability to accurately identify the proportion of patients who are in fact adherent, as well as confirm the influential factors associated with adherence.

Factors Associated with Adherence and Engagement with Follow-up Care

Overall, factors that have been identified through this scoping review align with those factors identified by the WHO (Sabaté, 2003) and fit well within the WHO domains. However, some key patterns were evident in the literature that highlight domains that may be of particular importance to regional populations, or that lack sufficient evidence to fully understand their roles within the regional context.

Patient-Related Factors. Based on frequency of examination, patient attitudes and beliefs have been of particular interest to researchers investigating adherence to long-term management, with two-thirds of the included studies examining at least one item within this domain. Unfortunately, this domain was also one of the poorest with respect to the quality of methodology used, and statistical evidence does not allow for concrete identification of relationships with adherence. However, two core areas within this domain received significant attention, thus highlighting their potential significance to adherence for regional people.

Patient Beliefs and Attitudes. The greatest proportion of items across all categories and dimensions fell under patient beliefs and attitudes, showing a general trend of positive patient beliefs and attitudes being associated with increased adherence. Research within this category primarily focused on beliefs and attitudes associated with health behaviours more broadly, as identified within the Health Belief Model (HBM; Rosenstock, 1966; see Chapter 1). These included locus of control, perceived benefits and barriers, and perceived severity and susceptibility - direct beliefs and attitudes referred to within the HBM. There was a notable absence of literature examining unique individual-level regional constructs such as stoicism and fatalism which have been previously implicated in regional health behaviours generally (Bettencourt et al., 2007; Ma, 2016; Niederdeppe & Levy, 2007; Strasser, 2003; Weaver & Gjesfjelf, 2014). Such beliefs and attitudes could be conceptualized within the HBM as modifying factors, specific to the individual and context that may play a contributory role in ultimate health behaviours. Thus, while the current literature provides some indication of the potential relevance of individual-level factors to adherence in a regional population, key characteristics theoretically associated with regionality and health still require examination. Given the clear link between regional attitudes, health beliefs, and health behaviours (Dixon & Welch, 2000), it is imperative to determine their role in influencing behaviours in the post-diagnostic period for people living with chronic conditions such as cancer.

Patient Knowledge, Information and Understanding. Approximately one-third of studies examined at least one item that fell within the category of patient knowledge, information, and understanding. Those studies showing a relationship with adherence showed greater adherence with increasing knowledge, information, and understanding. This evidence was heavily supported by qualitative data, highlighting the importance of not only being provided with the relevant information required for ongoing condition management, but in understanding the rationale behind that regime and the risks associated with non-adherence. These findings align well with literature that suggests that regional people must take on a greater level of responsibility for managing their ongoing health care once they return home to regional areas. In the absence of easily accessible support, guidance and advocacy, the receipt of information (such as that contained within the SCP) and an adequate understanding of the rationale for the recommended regime may play a particularly important role in supporting adherence and engagement for regional people living with cancer.

Supportive Factors. The second most commonly reported category across all dimensions was supportive factors. With extreme variation in the ways that support was conceptualized and measured across studies, only 44.00% showed a significant relationship with adherence. However, this category was also one of the strongest represented qualitatively. Across both quantitative and qualitative literature, greater levels of support were associated with higher adherence, suggesting that ongoing support may play a critical role in influencing adherence to long-term health care in regional populations. While the evidence in this review supports a strong need for patient support, current literature emphasises a noticeable reduction in supports for regional people living with cancer as they return to their homes after having had treatment in metropolitan areas (Spees et al., 2015). Thus, supportive factors may play a much more distinct role in adherence for people living regionally.

Future Directions

Two core challenges in conducting research within this field were identified and will require attention in future research. First, a standardised definition of adherence and consistency in the operationalisation of adherence is required in order to allow for more meaningful and accurate examination. While recommended behaviours vary greatly across health conditions, a holistic approach to long-term management is widely accepted as beneficial, and thus offers an opportunity to create a standardised system for measurement. Second, evidence supports the critical role of adherence on health outcomes, and thus monitoring of adherence to follow-up care should be routinely included when examining long-term chronic health conditions and health outcomes. This would allow for a greater understanding of both adherence and the factors that influence it, informing areas for targeted intervention to ensure optimal adherence and thus optimal health outcomes.

Strengths and Limitations of This Review

This scoping review adopted as comprehensive research strategy as possible, producing an a priori protocol that included the feedback from the University's Research Librarian, and was subject to review by the research team and refined based on feedback. Both the identification of relevant studies and data extraction were subject to second review. Additionally, the approach of examining the literature based on WHO dimensions rather than individual items allowed for a more meaningful synthesis of the current evidence to examine its relevance in the regional context. In alignment with the adopted scoping review guidelines (Peters et al., 2017; Tricco et al., 2018), all studies on the topic were included irrespective of design and were not assessed for quality. While this enabled broad commentary on the quality of the evidence provided in the literature, a systematic approach was not taken, nor feasible in this review. While the scoping review methodology allowed for examination of the broader body of literature on this topic, it prevented a more in-depth investigation of the magnitude of relationships between factors and adherence. Further, this review examined factors influencing adherence across all chronic conditions. In addition to the variance in recommended outcome behaviours denoting adherence across different conditions, it is possible that factors may differ in importance across different medical conditions, however this was not examined within this review due to the paucity of literature. Finally, the exclusion of literature in languages other than English may also have restricted evidence included in this review.

Summary

This scoping review synthesised data from disparate sources of information and across various chronic health conditions, with the findings highlighting three notable gaps in the current evidence-base for adherence in regional chronic health populations, which this program of research subsequently aims to address. First, the findings provide impetus for the examination of the individual-level factors of particular interest within this program of research. As discussed in Chapter 1, characteristics such as stigma, fatalism, consideration of future consequences, stoicism, and resilience have been identified as distinct characteristics of regional populations. These factors have not yet been examined with respect to adherence to long-term management within regional chronic health populations, despite strong support for the potential role they may play. Further, the findings suggest that patient knowledge, information, and understanding is another key area of interest for researchers that warrants closer investigation. As discussed earlier, many regional people living with cancer receive treatment in major cities before returning home, where access to their treatment team and the support services offered during treatment is limited. Thus, the receipt of information on the ongoing management of their health condition may play a particularly important role for regional people living with cancer. Finally, the current state of evidence lacks methodological rigour allowing for the concrete identification of statistical relationships and evaluation of the magnitude of these relationships. This program of research seeks to meet each of these gaps within the literature through a longitudinal cohort study of regional people living with cancer in Queensland, Australia.

Chapter 4: Methodology Guiding Studies 2, 3 and 4

Study Aims

The overall aim of this series of studies is to provide an in-depth exploration of the post-treatment health management behaviours of regional people living with cancer, and to identify and examine factors that impact on their engagement with recommended medical care and health-promoting lifestyle behaviours during the post-treatment survivorship period. As the overall program of research was exploratory in nature, the primary aim of each individual study was underscored by several focused research questions.

Study 2 Aims and Research Questions

The second study in the overall program of research seeks to establish a baseline health profile of regional people living with cancer at risk of poorer cancer outcomes. Using self-report data pertaining to participants' demographics, clinical factors, individual characteristics, and health behaviours over the 12 months prior to recruitment, it seeks to examine three core research questions:

1. What is the baseline profile of regional people living with cancer who travel to receive treatment with respect to demographics, clinical factors, individual characteristics, informational factors (receipt of a written or digital SCP or ACSC-endorsed information) and existing health behaviours/indicators?
2. Do baseline demographic, clinical factors, attitudinal factors, informational factors, and health behaviours/indicators differ across geographic remoteness areas? That is, do people living with cancer in different regional areas (e.g. inner regional or outer regional) differ in their demographic, clinical, individual and health behaviour profiles?
3. Are any individual (attitudinal) factors predictive of baseline health-promoting lifestyle behaviours/indicators after accounting for demographics and clinical factors?

Study 3 Aims and Research Questions

After establishing a baseline profile of regional people living with cancer who travel to receive treatment, Study 3 sought to provide an examination of participants' health behaviours and adherence to medical recommendations over a 12-month post-treatment period. Specifically, it aims to answer the following research questions:

1. Do participants show improvements in health-promoting lifestyle behaviours in the 12 months following their treatment and return home to regional areas?
2. How do participants engage in follow-up care over the 12 months following seeking cancer treatment/care?

Study 4 Aims and Research Questions

Study 4 aims to identify the role of attitudinal factors on engagement in follow-up care and healthy lifestyle behaviours in the post-treatment for regional people living with cancer. The core research question for Study 4 is:

1. Do individual (attitudinal) characteristics predict engagement in follow-up cancer care and health-promoting lifestyle promoting behaviours above and beyond the influence of demographic, clinical and informational factors at 6- and 12-months post treatment?

Research Design

The research questions of studies two, three and four will be addressed through one large-scale, longitudinal cohort study conducted with regional people living with cancer who are required to travel to metropolitan areas to receive cancer treatment (Human Research Ethics Approval: H17REA152). These studies are a part of a larger program of research, the Travelling for Treatment study, which is an ongoing collaborative research program conducted between the University of Southern Queensland and Cancer Council Queensland. This specific research project includes data collected at three separate time points: baseline

(Time 1; time of recruitment), 6-months post recruitment (Time 2) and 12-months post recruitment (Time 3; see Figure 4.1 below). As can be seen in Figure 4.1, self-reported questionnaires are completed at each time point whereas interviews are completed at only Time 1. Table 4.1 outlines the information collected at each of the time points to address the aims of each study. The context within which these time points sit are described in the study context below. The aims and methodology for the three studies are presented together in this chapter.

Figure 4.1

Flowchart Showing Questionnaire and Interview Delivery Time Points

Table 4.1

Table Showing Information Collected at Each Time Point for Study 2, Study 3 and Study 4

Study	Baseline (Time 1)	6 Months (Time 2)	12 Months (Time 3)
Study 2	• Demographics • Clinical Characteristics • Healthy Lifestyle Behaviours • Individual Characteristics	• Receipt of Cancer Survivorship Care Plans • Receipt of Survivorship Information	
Study 3	• Healthy Lifestyle Behaviours	• Self-reported medical adherence • Healthy Lifestyle Behaviours	• Self-reported medical adherence • Healthy Lifestyle Behaviours
Study 4	• Demographics • Clinical Characteristics • Healthy Lifestyle Behaviours • Individual Characteristics	• Self-reported medical adherence • Healthy Lifestyle Behaviours • Receipt of Cancer Survivorship Care Plans • Receipt of Survivorship Information	• Self-reported medical adherence • Healthy Lifestyle Behaviours • Receipt of Cancer Survivorship Care Plans • Receipt of Survivorship Information

Study Site and Context

Studies two, three and four were conducted across the six Cancer Council Queensland (CCQ) accommodation lodges, which are located in regions designed to reach the greatest numbers of the Queensland population. The six lodges are located in Queensland's major city (Brisbane and South Brisbane) and major regional centres throughout Queensland, Australia (Toowoomba, Rockhampton, Townsville, and Cairns). Figure 4.2 shows a map of lodge locations across Queensland, which are located in the most densely populated areas of the State.

Figure 4.2

Map of Cancer Council Queensland Lodge Locations

The CCQ accommodation lodges are self-contained, independent living facilities that are available to individuals (and family members) who are required to travel to metropolitan areas to receive cancer treatment. The lodges allow individuals to stay close to treatment facilities (that are not available near their residential area), with their partner or family members if required, and provide regular transport services to assist in travelling to and from medical appointments throughout their stay. Additional support services are offered to individuals throughout their stay at the lodge, including a range of educational, social and emotional support services (on-site and via telephone), and events. CCQ estimates approximately 1,500 people living with cancer access their lodges each year. Length of stay is dependent on the medical and treatment needs of each individual, ranging from overnight stays to several months. The facilities are also available to the family members who can help support them during their time away from home. Some individuals return to the lodge at regular intervals (e.g. weekly or monthly) to receive ongoing treatment or follow-up cancer care.

Accommodation costs are either fully subsidised or at a low fee through the Queensland Government’s Patient Travel Subsidy Scheme (PTSS; Queensland Government, 2019). The PTSS (Queensland Government, 2019) initiative provides financial assistance to eligible patients who need to travel to access specialist medical services that are not readily available in their local area. The subsidy assists with the costs of travel and accommodation, to attend the closest public hospital or health facility to their home that provides the medical services required.

Eligibility for PTSS is based on the following criteria:

1. The patient is a Queensland resident or a patient with no fixed address;
2. The patient is eligible for Medicare (Australian publicly-funded universal health care insurance scheme);

3. The patient is accessing a medical service that is:
    - recommended as medically necessary by the patient's doctor;
    - listed as an essential specialist medical service;
    - not available within 50km of the patient's nearest public hospital; and
    - the closest service of its kind.

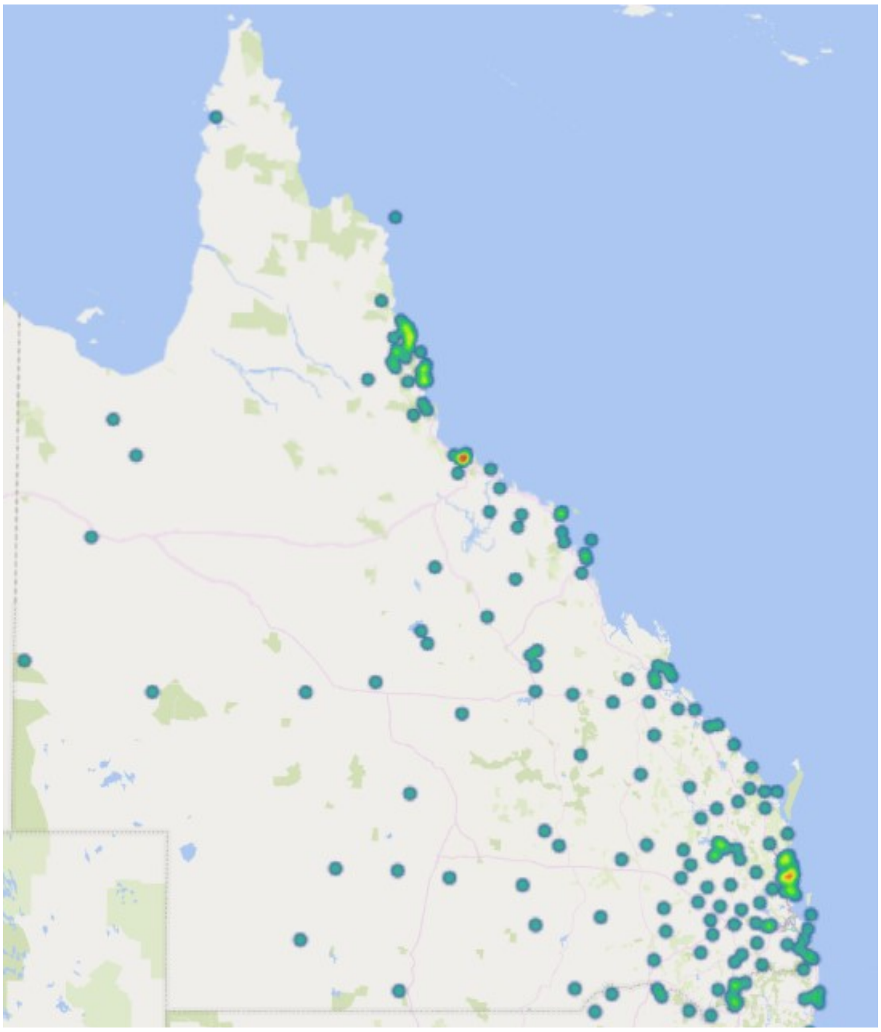
The context of this study was that participants were recruited for baseline assessments whilst attending one of the CCQ lodges. That is, they were attending a CCQ lodge for treatment or ongoing medical appointments related to their cancer, although it may not have been their first lodge attendance. While the timing of follow-up assessments occurred at the same point for all participants, the timing of the baseline assessment in relation to each participant's original diagnosis and treatment differed. Inclusion and exclusion criteria for the studies are described below.

Participants

Participants were recruited for a period of approximately 15.5 months (from 11 September 2017 to 31 December 2018) and were followed for 12 months after their baseline assessment. The participant pool comprised of 273 people living with cancer, with a mean age of 64.79 years (SD 10.69). Approximately 57.00% of participants were male. These participants were recruited from the pool of individuals who temporarily reside at CCQ lodges. This group is a purposive sample, identified through previous research in Queensland, Australia (Cramb et al., 2011) as a particularly vulnerable group (lower socio-economic status, with no or limited private health care or access to private accommodation). Importantly, evidence shows that regional people living with cancer also experience significantly poorer cancer outcomes than those living in metropolitan areas (Cramb, et al., 2011). Participants represented a wide array regional areas throughout and communities throughout Queensland, Australia and its 1.85 million square kilometres of land, as shown in Figure 4.3

Figure 4.3

Map of Participant Residential Locations Throughout Queensland



Eligibility criteria required participants to be 18 years and older, to have a current cancer diagnosis and be attending the CCQ lodges to undergo cancer treatment or be undergoing ongoing cancer care. Participants were required to be able to read and understand English to participate in the study. Eligibility was not based on cancer type, stage or treatment type.

Recruitment and Data Collection Procedures

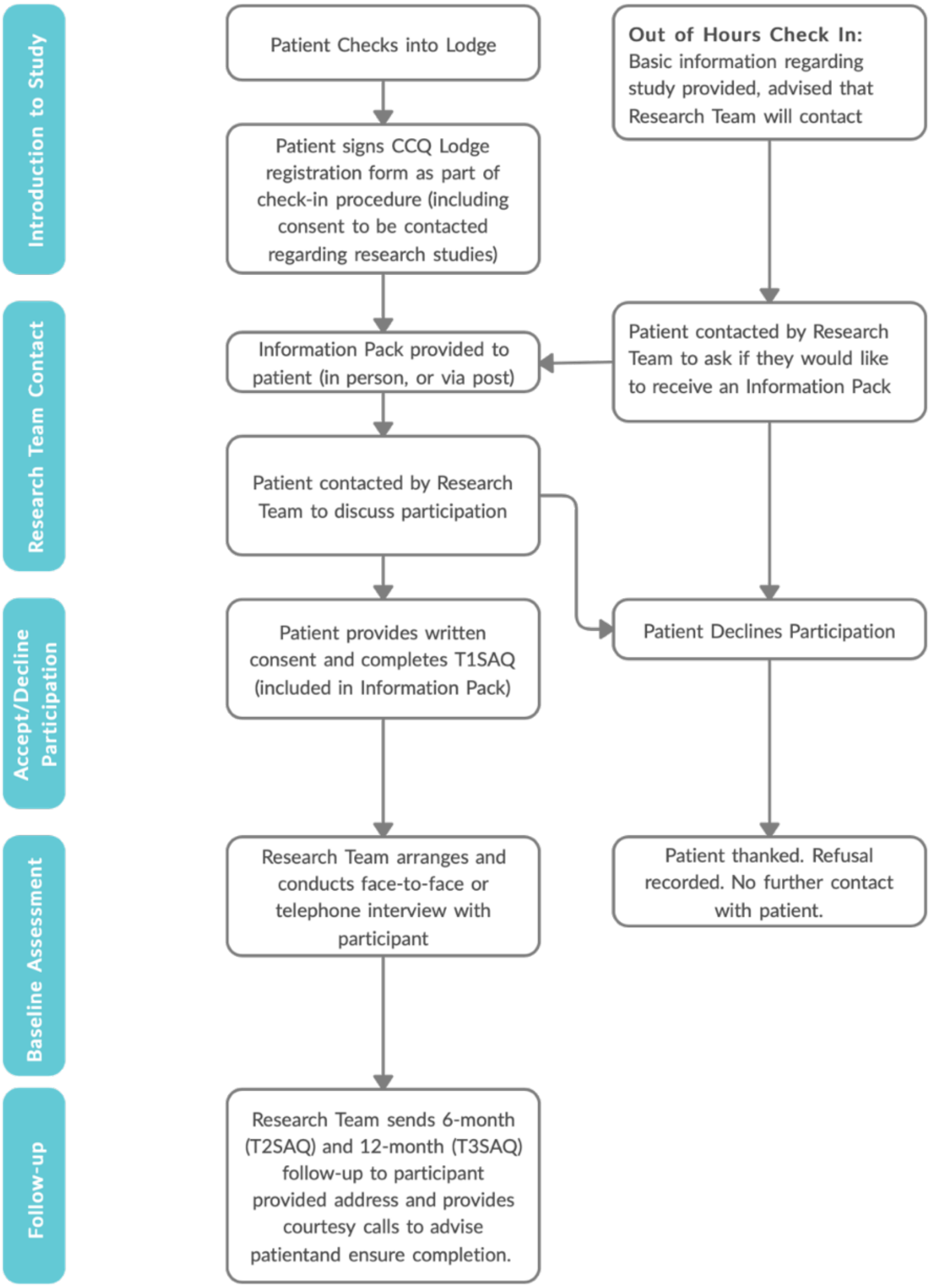
In staying at the CCQ lodges, individuals are required to complete a privacy statement in which they agree to be contacted by other departments (including research) within CCQ if relevant. Upon arrival at the lodge, eligible participants were informed about the study by lodge administration staff and provided with an information pack containing an information sheet, consent forms for the study and baseline questionnaire. Individuals who declined participation at this stage were recorded by lodge administration staff and the research team had no further contact with them. Individuals accepting the information pack were informed that a member of the research team would contact them shortly regarding potential participation in the study. The research team was then provided with the individual's contact information. Those who checked in to lodges after office hours were provided with a basic information sheet about the study with their lodge paperwork and advised that a member of the research team would contact them regarding the study. All individuals were then contacted by a member of the research team approximately one week after check-in and asked if they would like to participate. Those who declined were not contacted again regarding the study. Those who wished to participate were advised to read and complete the consent forms and baseline questionnaire, and to return these in the provided reply-paid envelope at their earliest convenience. The baseline questionnaire included demographic questions, questions about current health status and health behaviours, as well as measures of attitudinal characteristics.

Additionally, participants were required to complete a 30-45 minute interview. Interviews were conducted face-to-face in a private room at the CCQ lodge or via telephone, at the participant's convenience. During the structured interview, particpants were asked questions about their experiences having to travel for treatment and staying at the lodge. Relevant to the current study, participants were asked information about their current cancer diagnosis and treatment.

Follow-up questionnaires were sent to participants at their home address at 6- and 12-months post-baseline after a courtesy reminder call was made to advise the participant that it was being sent. Participants were again encouraged to complete the questionnaire and to return it in the provided reply-paid envelope at their earliest convenience. Follow-up questionnaires included questions about their engagement in follow-up medical cancer care and health-promoting lifestyle behaviours, along with questions regarding whether they had received a SCP or any information generally contained within these plans (via checklist). Figure 4.4 offers a visual representation of the recruitment procedures adopted.

Figure 4.4

Flowchart of Participant Recruitment Procedure



Measures

Participants completed three self-administered questionnaires and one structured interview exploring demographic information (baseline only), cancer and treatment characteristics (baseline only), attitudinal characteristics (baseline only), health and clinical management behaviours (all timepoints), and receipt of SCPs or information contained within SCPs (6- and 12-months post-baseline). The measures completed at each time point are summarised in Table 4.2.

Table 4.2

Summary of Measures Completed at Each Time Point

Data Collection Time Point	Construct/Data Collected		Measures
Time 1 only	Demographics	Date of Birth, Gender, Residential Postcode, Aboriginal/Torres Strait Islander Identification, Country of Birth, Relationship Status, Number of Dependents, Household Annual Income, Education	Self-Report
	Clinical Characteristics	Date of Diagnosis, Site of Cancer, Treatment Status, Cancer Stage, Cancer Recurrence, Previous Cancer, Treatment Received within Past 12-months	Self-Report
		Comorbid Conditions	Charlson Comorbidity Index
	Attitudinal Characteristics	Stigma	Stigma Scale for Chronic Illness (SSCI-8)
		Fatalism	Health Fatalism Scale (pre-determinism subscale)
		Consideration of Future Consequences	Consideration of Future Consequences Scale
		Barriers to Help-Seeking	Mansfield Barriers to Help-Seeking Scale (Need for Control and Self-Reliance, and Minimising Problems and Resignation subscales)
		Resilience	The Brief Resilience Scale (BRS)
Time 1, Time 2 & Time 3	Health Behaviours/ Indicators	Height (Time 1 only), Weight	Self-Report
		Alcohol Consumption	AUDIT-C
		Smoking	Self-Report
		Average Daily Fruit and Vegetable Intake	Self-Report
		Physical Activity	Godin Shephard Leisure Time Exercise Questionnaire
Time 2 & Time 3	Clinical Management Adherence Variables	Attendance at scheduled and/or recommended medical appointments	Self-Report
		Follow-up tests (as required)	Self-Report
		Additional treatment (as required)	Self-Report
Time 2 & Time 3	Informational Factors	Receipt of Survivorship Care Plan	Self-Report Checklist
		Receipt of Australian Cancer Survivorship Centre recommended information	Self-Report Checklist

Demographics

At baseline, participants provided demographic information, including residential postcode, date of birth, gender, and Aboriginal/Torres Strait Islander identification. Additionally, participants were asked to report their number of dependents, relationship status, educational attainment, and household income. Postcode was used to ascertain area-level socio-economic status (SES) via the Socio-Economic Indexes for Areas (SEIFA; Australian Bureau of Statistics, 2016) and geographic location via the Accessibility and Remoteness Index of Australia (ARIA; Australian Bureau of Statistics, 2011). For clarity, Table 4.3 provides a summary of participant-reported demographics and how these items were used in the current study.

Table 4.3

Summary of Participant Demographic Variables Used in Study

Variable	Measure/ Item Responses	Coding for Study
Date of Birth	Day, month and year	Used to calculate age
Gender	o Male o Female o Other	As no participants selected “Other”, dichotomous “Male/Female” variable created
Residential Postcode	4-digit response	Used to determine SEIFA percentile (and quartiles) and ARIA categories. Due to small sample sizes falling within remote and very remote categories of the ARIA, participants were re-grouped into “Inner Regional/Outer Regional” groups for the purpose of analysis.
Aboriginal/Torres Strait Islander Identification	o No o Yes, Aboriginal o Yes, Torres Strait Islander o Yes, both Aboriginal and Torres Strait Islander o I’d rather not say	Due to small sample size within the “Yes” categories, dichotomous “Yes/No” variable created
Australian Born	o Yes o No	Dichotomous “Yes/No” variable
Relationship Status	o Married/de facto o In a relationship o Single o Divorced o Widowed	Due to large number of categories and small frequencies within some categories, dichotomous “In a Relationship/Not In a Relationship” variable created
Number of Dependents	Numerical response o	Continuous variable
Household Annual Income	o Less than $20,000 o $20,001 to $30,000 o $30,001 to $50,000 o $50,001 to $80,000 o $80,001 to $100,000 o $100,001 to $120,000 o $120,001 to $150,000 o $150,001 to $200,000 o More than $200,000 o I’d rather not say	Due to large number of categories and small frequencies within some categories, dichotomous “$30,000 or less/Greater than $30,000” variable created
Education	o Primary School o Year 10 o Year 11 o Year 12 o TAFE/Apprenticeship o University Degree o Other (please specify)	Due to large number of categories and small frequencies within some categories, categorical variable created with the following levels: Middle School Senior School Tertiary/Trade

Clinical Characteristics

Clinical data collected for this study are summarised in Table 4.4. During the interview at baseline, participants were asked to provide information on their current cancer diagnosis, including the cancer type and the date of diagnosis. Date of diagnosis was used to calculate the number of days from diagnosis to completion of each questionnaire. Where possible, self-reported cancer type was verified against the Queensland Cancer Registry, a population-based registry of all cases of cancer diagnosed within the State. In instances where Registry data were not available (for example, for diagnoses not routinely reported, such as non-melanoma skin cancer), self-report data were relied upon. With respect to treatment, participants were asked at each data collection time point whether they were currently undergoing treatment or had undergone treatment since the last questionnaire. Participants were also asked to report the type/s of treatments they had received. Types of treatment were used to descriptively describe participants at baseline, however, due to sample sizes within treatment groupings, participants were coded as "Yes/No" to receiving any treatment within the period for the purposes of analysis.

Table 4.4

Summary of Participant Clinical Characteristics Used in Study

Variable	Measure/ Item Responses	Coding for Study
Date of Diagnosis	Day, month and year	Used to calculate number of days since diagnosis
Cancer Type	o Lung cancer o Colorectal/bowel cancer o Prostate cancer o Breast cancer o Other (please specify)	Self-reported cancer type was validated using the Queensland Cancer Registry where possible. Based on frequency of responses, cancer types were grouped as follows for the purposes of analysis: o Breast o Head and Neck o Skin o Prostate o Colorectal o Lung o Other Cancers
Treatment Status	o Yes, in treatment o No, not in treatment	Dichotomous "In Treatment/Not In Treatment" variable
Cancer Stage	o Known by Patient o Unknown by Patient	Dichotomous "Known/Unknown" variable
Cancer Recurrence	o Yes o No	Dichotomous "Yes/No" variable
Previous Other Cancer Diagnosis	o Yes o No	Dichotomous "Yes/No" variable
Treatment Received	Open-text questions during baseline interview. At times 2 and 3, response options were: o Surgery o Radiation Therapy o Chemotherapy o Other (please specify)	For descriptive purposes at baseline, treatment was grouped into: o Surgery o Radiation Therapy o Chemotherapy o Other treatments For analytical purposes, participants were grouped as: o Received treatment o Did not receive treatment
Total Number of Comorbid Conditions	Charlson Comorbidity Index	Frequency of reported conditions used for descriptive purposes. For analytical purposes, total Charlson Comorbidity Index score was utilised

Health Behaviours and Indicators

At each timepoint, data pertaining to key health behaviours and health indicators were collected. The health behaviours of particular interest in this study are those identified by the ACSC and CCA (ACSC, 2017; CCA 2015) and evidenced to promote both positive recovery and ongoing wellbeing: adhering to a healthy diet, weight management, physical exercise, smoking cessation, and limited alcohol consumption (Wiley et al., 2015).A summary of each of these variables is provided in Table 4.5 and explained in greater detail thereafter.

Table 4.5

Summary of Participant Health Behaviours and Indicators Used in Study

Variable	Measure/ Item Responses	Coding for Study
Body Mass Index	Self-Report of height (baseline only) and weight (all timepoints)	Body Mass Index calculated using height and weight data
Substance Use	Alcohol Use Disorders Identification Test (AUDIT-C)	Total score produced per measure guidelines. Dichotomous “Hazardous/ Non Hazardous Drinking” variable produced per measure guidelines.
Tobacco Use	Self-Report of having ever smoked If “Yes” to ever smoked, how often in the past 12-months o Not at all o Less often than weekly o At least weekly (but not daily) o Daily	Dichotomous “Yes/No” variable created based on self-reported frequency of smoking behaviour in past 12-months o Yes = those who had smoked at all in the past 12-months o No = those who had not smoked at all in the past 12-months
Nutrition	Self-Reported average number of daily servings of fruit per day Self-Reported average number of daily servings of vegetables per day	Continuous variable of number of servings reported for each (fruit and vegetables). Dichotomous “Met/Not Met” variable created for each (fruit and vegetables), indicating whether self-reported daily average met recommended nutritional guidelines (2 servings of fruit, 5 servings of vegetables per day).
Physical Activity	Godin Shephard Leisure Time Physical Activity Questionnaire	Total score produced per measure guidelines.

Variable	Measure/ Item Responses	Coding for Study
		Scores categorised according to measure guidelines into: o active o moderately active o insufficiently active/sedentary

Body mass index (BMI). Participants' self-reported height (at baseline only), and weight (at each time point) was used to calculate body mass index (BMI). Participants were categorised into underweight (<18.5 BMI), normal weight (18.5-24.9 BMI), overweight (25.0-29.9 BMI), or obese (>29.9 BMI) using guidelines as detailed by the World Health Organization (2019a).

Substance use. Alcohol consumption was assessed at each time point using the Alcohol Use Disorders Identification Test (AUDIT-C; Bush, 1998). The AUDIT-C is a 3-item screening instrument utilised to identify hazardous levels of alcohol consumption. Each question uses a 5-point response scale, where 0 = least frequent/no engagement in the drinking behaviour and 4 = most frequent engagement. A sample item is "How often do you have a drink containing alcohol?", where 0 = *never*, 1 = *monthly or less*, 2 = *2-4 times a month*, 3 = *2-3 times a week,* and 4 = *4 or more times a week*. Scores from the three items are summed for a total score range of 0-12, with higher scores broadly representing a greater likelihood that drinking behaviours are affecting the individual's safety. The AUDIT-C has demonstrated acceptable internal consistency with test-retest alphas of .65 - .85 (Bradley et al., 1998). Scores ≥ 4 for men and ≥ 3 for women is indicative of hazardous drinking behaviours. At baseline, participants were asked to self-report on drinking behaviours within the past 12 months. At timepoints 2 and 3, participants were asked to self-report on drinking behaviours in the previous 6 months (between data collection timepoints).

Tobacco use. Smoking behaviours were assessed at each timepoint using two questions from the National Health Survey (ABS, 2018). Participants were asked if they had ever smoked tobacco cigarettes (yes/no response scale). If yes, participants were asked to indicate how often they had smoked cigarettes in the last 12 months (6 months at timepoint 2 and 3) using a 4-point response scale (1 - not at all, 2 - less often than weekly, 3 - at least weekly (but not daily), 4 - daily).

Nutrition. Nutritional behaviours were assessed by asking participants 1) how many servings of fruit and, 2) how many servings of vegetables they ate on an average day. These variables were analysed in two ways. First, the self-reported average number of servings per day was used as a continuous variable. Second, the number of servings reported by each individual was compared to national recommendations, which suggest two servings of fruit and five servings of vegetables be eaten per day (NHMRC, 2013). Each participant was categorised as having “Met/Not Met” national guidelines for fruit, vegetable, and the combined fruit and vegetable recommendations.

Physical Activity. Physical activity was measured using the Godin Shepard Leisure Time Physical Activity Questionnaire (Godin, 2011; Godin & Shephard, 1985). Participants self-reported the number of strenuous, moderate, and light exercise sessions (longer than 15 minutes in duration) they engaged in within the past seven days. Following the original author’s instructions for scoring, a total score was obtained by multiplying the number of strenuous sessions by nine, moderate sessions by five and mild sessions by three to produce an overall score (Godin, 2011; Godin & Shephard, 1997). Scores equal to or greater than 24 are categorised as 'active', total scores of 14 to 23 are categorised as 'moderately active', and totals less than 14 are categorised as 'insufficiently active/sedentary'. The GSLT has been frequently used within oncology research, with evidence supporting its use in measuring and ranking activity levels for cancer survivors for the purposes of identifying correlates and its influence on health-related outcomes (Amireault, et al., 2015). As a baseline measure of physical activity before diagnosis, participants were asked to report on their physical activity during a 'typical' 7-day period. For time points 2 and 3 participants were asked to report on a typical 7-day period within the last 6 months.

Clinical Management Behaviours

A summary of clinical management adherence variables adopted is provided in Table 4.6. The complexity and variability of treatment and follow-up regimes for people living with cancer creates challenges in uniformly measuring and quantifying adherence to clinical management regimes. Adherence was measured via self-reported engagement in recommended follow-up medical care. The items measured to represent adherence were guided by the follow-up cancer care recommendations of the Australian Cancer Survivorship Centre described in Chapter 2 (Wiley, et al, 2015). At 6- and 12-month follow-up, participants were asked to answer the following questions related to the previous 6 months since completing their last questionnaire; “as recommended by your health care professional:

1. Have you attended your scheduled and/or recommended medical appointments to date?
2. Have you undertaken any follow-up tests that you were required to take to date?
3. Have you had further treatment that you were required to have since returning home?”

Participants were required to respond “Yes” if they had completed these activities as required or recommended by their treatment team, "No" if there were activities required/recommended but not completed, or "Does not apply to me" if they were not required/recommended to undertake any of these activities. For the purposes of analysis, participants were categorised as to whether they had “met” or “not met” requirements/recommendations. Those participants who self-reported having met requirements/recommendations and those participants who reported no requirements/recommendations were categorised as having “met” requirements/recommendations asked of them. Those participants who self-reported having not completed required/recommended clinical management activities were categorised as having "not met" requirements/recommendations.

Table 4.6

Summary of Clinical Management Adherence Variables Used in Study

Variable	Measure/ Item Responses	Coding for Study
Attendance at all scheduled and/or recommended medical appointments	○ Yes ○ No ○ Not applicable to me	Dichotomous "Yes/No" variable produced where: ○ Yes = those who self-reported adherence + those who self-reported that this clinical management behaviour was not applicable to them ○ No = those who self-reported not adhering
Undertaken all scheduled and/or recommended follow-up tests	○ Yes ○ No ○ Not applicable to me	Dichotomous "Yes/No" variable produced where: ○ Yes = those who self-reported adherence + those who self-reported that this clinical management behaviour was not applicable to them ○ No = those who self-reported not adhering
Further treatment as recommended by treatment team	○ Yes ○ No ○ Not applicable to me	Dichotomous "Yes/No" variable produced where: ○ Yes = those who self-reported adherence + those who self-reported that this clinical management behaviour was not applicable to them ○ No = those who self-reported not adhering

Individual Characteristics

At baseline, participants were asked to complete a series of measures relating to specific individual characteristics identified in the literature as potential contributors to health-related behaviours, especially within regional populations. Table 4.7 provides a summary of each of the constructs measured, the instrument used for measurement and its psychometric properties. Each measure will be discussed further below.

Table 4.7

Summary of Measures for Individual Characteristics

Attitudinal Construct	Instrument of Measure	Psychometrics
Stigma	Stigma Scale for Chronic Illness	α = .89 item-total correlations ≥.45
Consideration of Future Consequences	Consideration of Future Consequences Scale	α = .80 - .86 2wk test re-test = .76 5wk test re-test = .72
Fatalism	The Constructed Meaning Scale	α = .81 2 factors (57.3%), each contributed substantially (≥ .51 loadings) α = .86 (predetermination), α = .80 (luck), α = .82 (pessimism), α = .88 whole scale.
Barriers to Help-Seeking	Mansfield Barriers to Help-Seeking Scale (Need for Control and Self-Reliance, and Minimising Problems and Resignation subscales)	α = .79 - .93 (subscales) α = .95 whole scale
Resilience	The Brief Resilience Scale	α = .80 - .91

Stigma. Stigma was measured using the Stigma Scale for Chronic Illness (SSCI-8; Molina et al., 2013). The SSCI-8 is an 8-item short-form measure designed to assess enacted and internalised stigma within populations living with a chronic illness. Enacted stigma refers to physical experiences involving others, whereas internalised stigma refers to inner processes (thoughts and feelings) of the respondent. The SSCI-8 utilises a 5-point response scale, where 1 = '*Never*' and 5 = '*Always*' in response to a series of statements focused on experiences concerning the respondent's illness. Items were modified to replace 'illness' with 'cancer'. For example, "Because of my illness, some people seemed uncomfortable with me" was modified to "Because of my cancer, some people seemed uncomfortable with me". Scores for each item are summed to produce a total score range of 5 to 40, with higher scores indicating greater experiences of enacted and internalised stigma. The SSCI-8 has shown good internal consistency, with α = .89 and item-total correlations ≥.45 (Molina et al., 2013).

Consideration of Future Consequences. The Consideration of Future Consequences

Scale (CFC; Strathman et al, 1994) was used to assess the extent to which an individual considers immediate versus long-term consequences of behaviours. An example item is "I think it is more important to take warnings about negative outcomes seriously even if the negative outcome will not occur for many years". The CFC uses a 5-point response scale ranging from 1 = *"Not like me at all"* to 5 = *"Very much like me"*. Scoring requires first reverse-scoring items 3, 4, 5, 9, 10, 11 & 12, then summing all 12 items of the scale for a maximum total score range of 12 to 60. Higher overall scores are indicative of a greater consideration of future consequences, meaning the individual is more likely to consider the non-immediate consequences of engaging in certain behaviours. The CFC has demonstrated good internal consistency with alphas ranging from .80 to .86 (Strathman et al., 1994).

Fatalism. Fatalism was measured using the pre-determinism subscale of the Health Fatalism Scale (pre-determinism subscale; Shen et al., 2009). The pre-determinism subscale measures beliefs around fate, luck, destiny, and pre-determined outcomes of disease or health based on heredity. It comprises ten statements with a 5-point response scale ranging from 1 = *"Strongly Disagree"* to 5 = *"Strongly Agree"*. A sample item within the scale is *"*If someone was meant to have a serious disease, it doesn't matter what doctors and nurses tell them to do, they will get the disease anyway*"*. Item responses are totalled for an overall subscale score ranging from 10 to 50. Higher scores are indicative of greater fatalistic beliefs, meaning participants believe that all events are determined in advance. The pre-determinism subscale has shown good internal consistency with a reported alpha of α = .86 (Shen et al., 2009).

Barriers to Help-Seeking. Help-Seeking was measured using two subscales of the Barriers to Help Seeking Scale: the need for control and self-reliance subscale, and the minimising problems and resignation subscale (Mansfield et al., 2005). The need for control and self-reliance subscale measures an individual's desire to avoid being perceived by others as weak or vulnerable via 10 questions (total score range 10-50), with items such as "I do not want to appear weaker than my peers". Lower total scores on this subscale indicate that avoidance of being perceived as weak or vulnerable was less likely to influence help seeking behaviours. The minimising problems and resignation subscale measures an individual's propensity to dismiss or ignore negative health symptoms or discomfort using a six item subscale (total score range 6-30), with items such as "The problem wouldn't be a big deal; it would go away with time". Each subscale utilised a 5-point response format ranging from 1 = *"Not at All"* to 5 = *"Very Much"* to identify how much each item poses as a barrier to help-seeking behaviour. Lower total scores on the minimising problems and resignation subscale indicate that the individual was less likely to dismiss or ignore negative health symptoms or discomfort. The subscales have shown good reliability, with alphas ranging from α = .75 for the minimising problems and resignation subscale, to .89 for the need to control and self-reliance subscale (Mansfield et al., 2005).

Resilience. The Brief Resilience Scale (BRS; Smith et al., 2008) assesses the ability of the responder to bounce back or recover from stress. It comprises of six items, measured on a 5-point response scale ranging from 1 = *"Strongly Disagree"* to 5 = *"Strongly Agree"*. Example items include *"*I tend to bounce back quickly after hard times" and "It does not take me long to recover from a stressful event*"*. Items 2, 4 and 6 require reverse coding, before summing the total of all items and dividing this total by the number of items answered This results in a total score ranging from 1 to 5, with higher scores indicating greater levels of resilience. The BRS has shown good internal consistency, with alphas ranging from α = .80 - .91 (Smith et al., 2008).

Reliability

Reliability analysis was conducted in SPSS for each of the relevant measures within the current study, and the results are presented below in Table 4.8. All measures presented with acceptable reliability.

Table 4.8

Internal Consistency of Measures at Baseline

Measure	Internal Consistency (α)
AUDIT-C	.79
SSCI-8	.90
Consideration of Future Consequences Scale	.75
Health Fatalism Scale (pre-determinism subscale)	.88
Barriers to Seeking Help Scale (need for control and self-reliance subscale)	.89
Barriers to Seeking Help Scale (minimising problems and resignation subscale)	.85
Brief Resilience Scale	.85

Cancer Survivorship Care Plans and Survivorship Information

Information regarding the participants' receipt of SCPs and survivorship information was only collected at 6-month and 12-month follow-up, as many participants were still staying at the lodge at baseline and had not yet received this information. Receipt of a SCP was assessed via a single, self-reported item asking whether the participant received a written (or digital) SCP from medical staff ("Yes/No" item-response scale). Additionally, participants were provided with a checklist of 18 follow-up care activities, as recommended by the ACSC (Wiley et al., 2015), and asked to indicate whether they had received information relating to these items from their healthcare team in the last 6 months (since completing the last questionnaire). A summary of the items on this checklist is provided in Table 4.9. Each of these items had a yes/no response scale. For analysis, ACSC-recommended information items were used to create two dichotomous variables: whether the participant had received any medical-related information, and whether the participant had received any health behaviour-related information. Items were categorised as medical- or health behaviour-related as shown in Table 4.9.

Table 4.9

Follow-up Cancer Care Information Items in Questionnaire

Have you been given information on any of the following items from the medical staff?	
Medical-related information	Health behaviour-related information
a) Information about short-term side effects from your treatment?	b) Information about how to manage your diet?
c) Information about the likely course of recovery from these side effects?	d) Information about the type and amount of physical exercise you should be doing?
e) Information about late or long-term side effects from your treatment?	f) Information about the availability of counselling (e.g. psychologist, social worker, support group)?
g) Information regarding genetic counselling?	h) Information or advice on where to seek help for financial concerns (e.g. missing work, cost of treatment)?
i) Information about chemoprevention (efforts to delay the development of future cancer)?	j) Instructions regarding future cancer screening for other cancers?
k) The contact details for your oncologist or oncology team?	l) Details of symptoms and signs of recurrence to watch out for?
m) A schedule of follow-up appointments?	n) Recommendations for health behaviours to aid in your recovery and/or cancer management?
o) Advice regarding ongoing adjuvant (secondary) therapy?	p) A list of relevant resources available to you in your community?
q) A schedule of follow-up tests that you require?	r) Advice regarding priorities and goals to aid in your recovery?

Data Analytic Procedures

Data Screening

Prior to the analysis of data, several assumptions were tested, and data checks were performed. First, data were examined for instances of missing or insufficient data. Nine participants withdrew their data after baseline and 6 participants failed to provide data for key variables in this study and were thus removed, leaving a final sample size of 273. Visual inspection of descriptives, scatterplots, and skewness and kurtosis statistics revealed no excessive deviations in normality, linearity, and homoscedasticity. Any variances were considered non-problematic given the robustness of regression analysis and adequate sample size. Multicollinearity was not considered an issue, with tolerance values and variation inflation factors (VIF) within acceptable ranges. The criterion to determine statistical significance was $p < .05$.

Sample Size & Power Analysis

An a-priori analysis was conducted using G*Power 3.1 (Faul et al., 2007). The overall study was powered to address the primary aim of identifying individual characteristics that influence adherence to health-promoting behaviours following a cancer diagnosis. Thus, power analyses were conducted for regression analyses with a maximum of 16 predictor variables (including all potential demographic, clinical, and informational variables). Results indicated that with an $\alpha = .05$, and an expected small to moderate effect size ($f^2 = .15$), a sample size of 143 would be required to achieve power of .80. Thus, the baseline sample size of 273 following data screening provided a sufficient sample to test the hypotheses, allowing room for attrition over the course of the longitudinal study. For all statistical tests in the current studies, a significance level of $p<.05$ was used.

Overarching Data Analytic Strategy

Data were analysed using SPSS v26 (IBM, 2019) and Mplus8 (Muthén & Muthén, 2017). The specific data analytic strategy for each individual study is provided at the beginning of each chapter. Overall, in order to address the research questions, four core analytical approaches were adopted:

1. Descriptive analysis was conducted to create a profile of participants and their behaviours, presented in both Chapter 5 and Chapter 6;
2. Geographical differences in participant profiles and behaviours were examined using independent samples t-tests, tests of two proportions and chi-square analyses, presented in Chapter 5;
3. Health-promoting lifestyle behaviours over the 12-month study period were examined via Repeated Measures ANOVA, Cochran's *Q* analysis, Friedman's tests and McNemar change tests, and presented in Chapter 6; and

4. Attitudinal predictors of baseline (Chapter 5), 6-month and 12-month health-promoting behaviours (Chapter 7) were examined via multiple hierarchical and logistic regression analyses, using a 3-step analytical approach, and detailed within each chapter respectively.

Chapter 5: Study 2 – The Regional Person Living with Cancer that Travels for Treatment: Demographic, clinical, individual, informational and health profiles.

The overall purpose of this program of research was to examine factors that may influence adherence to health-promoting lifestyle behaviours and clinical management in regional people living with cancer. Currently, little is known about the health profile of regional people living with cancer, although regional populations generally show poorer health behaviours and a more vulnerable demographic and clinical profile than their metropolitan counterparts (e.g. lower socio-economic status and poorer health outcomes). This study provides an examination and presentation of the demographic, clinical, attitudinal and health behaviour profile of a sample of at-risk regional people living with cancer at the time of attending a major centre for cancer treatment/care. Further, a large proportion of literature examining the factors that are likely to influence adherence (reviewed in Chapters 1 to 3) focuses on their influence on initial help-seeking behaviours and participation in cancer screening activities. As revealed in Chapter 3, the role of regional-specific attitudinal factors on the effects on longer-term health behaviours following treatment for a serious medical condition has not been examined. This study additionally examines whether individual characteristics are related to health behaviours at initial presentation.

This chapter conducts an examination of the data observed at Time 1 (baseline), and provides a summarised profile of the participants, a regional cancer sample at-risk of premature death and poorer cancer outcomes. This study (Study 2) focuses on data concerning participants' health behaviours over the previous 12 months, obtained at the baseline assessment point when participants first arrived at accommodation in a major centre after travelling to receive treatment. Specifically, it seeks to address three core research questions:

1. What is the baseline profile of regional people living with cancer who travel to

receive treatment with respect to demographics, clinical factors, attitudinal factors, informational factors (receipt of a written or digital SCP or ACSC-endorsed information), and health behaviours/indicators?

2. Do baseline demographic, clinical factors, attitudinal factors, informational factors, and health behaviours/indicators differ across geographic remoteness areas?
3. Are there any attitudinal factors which predict baseline health-promoting lifestyle behaviours/indicators after accounting for demographics and clinical factors?

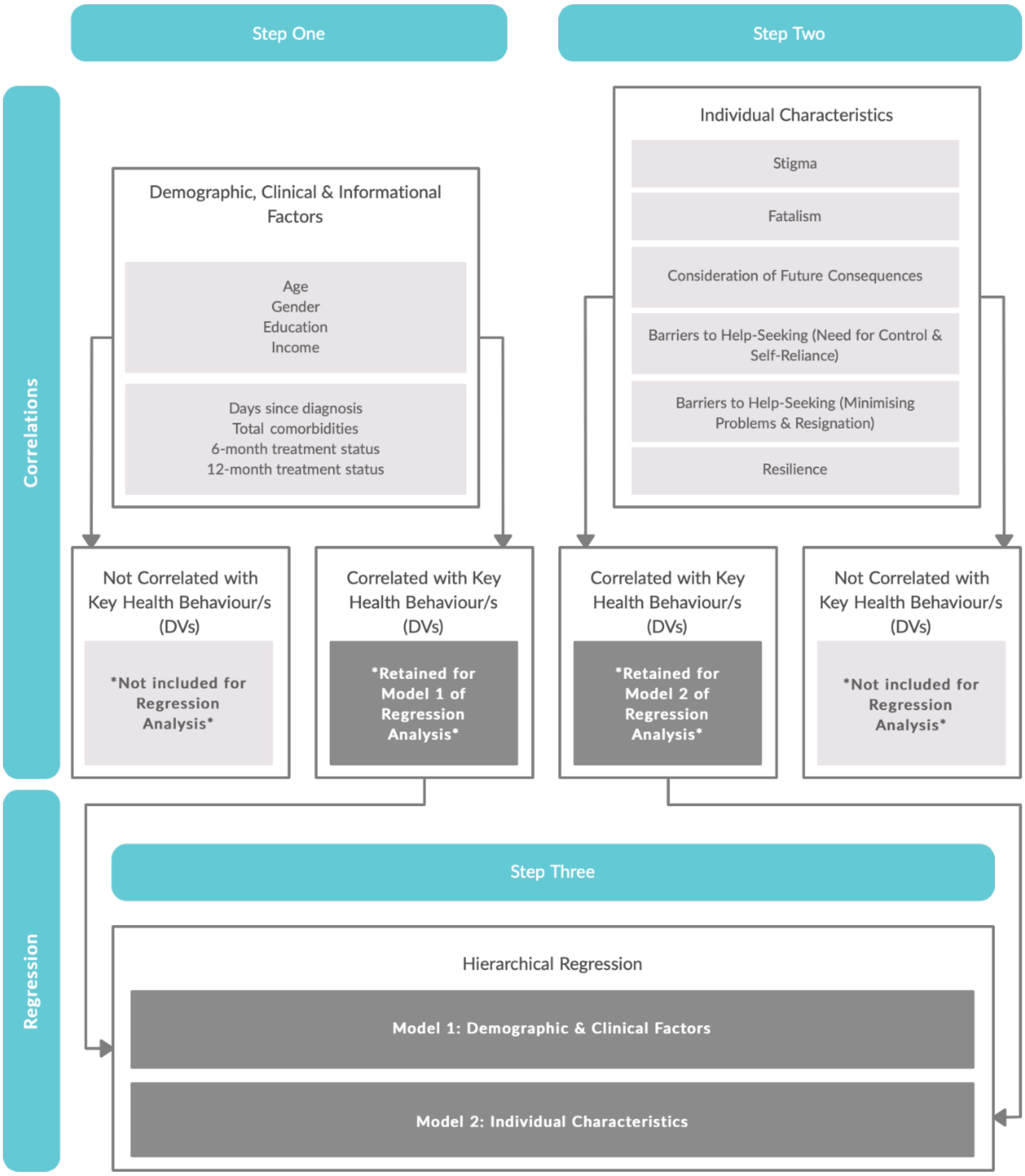
As data regarding the receipt of a SCP or ACSC-endorsed information was collected retrospectively at 6-months, associations between informational factors and baseline health behaviours were not examined.

Data Analytic Strategy

Data for this study were analysed using SPSS Version 26 (IBM, 2019). To answer the first research question regarding the baseline profile of the sample, frequency, and descriptive analyses were carried out both on the sample as a whole, and when split into geographic regions. The second research question was addressed via a series of independent samples t-tests, tests of two proportions, and chi-square analyses to identify any differences in sample profiles between geographic regions. SEIFA percentiles and quartiles were not subject to examination across regions, as these variables are produced using postcodes/geographic location as an indicator of area-level socio-economic disadvantage. The final research question used regression analyses to examine whether demographics, clinical and individual characteristics were predictive of health behaviours over the past 12 months, as reported at baseline. Given the large number of variables measured in this study, and to minimise unnecessary analyses and Type 1 error, a three-step process of analysis was adopted to answer the third research question (see Figure 5.1).

Figure 5.1

Flowchart of Analytical Process



Step One

First, a series of correlational analyses were conducted to examine the relationship between baseline demographic and clinical factors and key health behaviours during the past 12 months. Demographic and clinical factors that were significantly correlated with any health behaviour were subsequently included in Model 1 of hierarchical regression analyses for that behaviour, examining predictors of each of the health behaviour variables (BMI, alcohol consumption, smoking behaviour, fruit and vegetable consumption, and exercise).

Step Two

Second, correlational analyses were conducted to examine the relationships between attitudinal factors (stigma, fatalism, consideration of future consequences, barriers to help-seeking, and resilience) and health behaviours during the past 12 months. Only those individual characteristics significantly related to any health behaviours progressed to the regression stage of analysis and were included in Model 2 of the regression. Any attitudinal variables that were not related to baseline health behaviours were not examined further.

Step Three

Finally, individual hierarchical regression analyses were conducted for all predictor variables showing significant relationships with health behaviours. Any correlated demographic and clinical factors were entered at Model 1, and correlated attitudinal factors were added at Model 2. Analyses were conducted for each health behaviour dependent variable separately. Where multiple attitudinal factors correlated with any given health behaviour, separate regression analyses were conducted to allow exploration of the independent effects of each attitudinal factor. For any cases in which there were no correlated demographic or clinical factors, but individual characteristics were correlated, a standard linear regression was conducted with only individual characteristics entered into the model. Hierarchical multiple regression analyses were conducted for continuous health behaviour variables, and binomial logistic regression analyses were conducted for dichotomous variables.

In addition to reducing the number of variables analysed and given the homogeneity of the group (determined following analysis of the first two research questions), it was determined that the use of continuous variables (e.g. BMI score) rather than categorical variables (e.g. BMI category) would provide a more meaningful analysis of the data where possible. The final outcome health behaviour variables used in the regression analyses are outlined in Table 5.1.

Table 5.1

Health Behaviour and Indicator Variables Used to Represent Australian Cancer Survivorship Centre Endorsed Behaviours

ACSC-Endorsed Behaviour	Variable Analysed
Weight management	BMI score
Healthy Diet	Average Daily Servings of Fruit Average Daily Servings of Vegetables
Physical Exercise	Godin Shepard Leisure Time scores
Smoking Cessation	Yes/No Smoking
Limited Alcohol Consumption	AUDIT-C scores

Note. ACSC = Australian Cancer Survivorship Centre

Results

Baseline Sample Profile and Variations Across Geographic Remoteness

Demographic Characteristics at Baseline. Table 5.2 provides a breakdown of the demographic characteristics of the baseline sample. There were a total of 273 regional people living with cancer in the sample with a mean age of 64.79 years (SD = 10.69). Approximately 57.00% of participants were male, and 4.50% identified as Aboriginal and/or Torres Strait Islander. Participants were mostly born in Australia (78.40%), in a relationship (65.40%), and 45.00% had a 10th grade or lower education. More than half of participants (54.10%) reported an annual household income of $30,000 AUD or less. The sample had a mean SEIFA percentile of 37.09 (SD 22.26), meaning that, on average, participants came from the lowest 37.09% of areas with respect to socio-economic advantage, with almost 40.00% falling within the lowest SEIFA quartile.

Table 5.2

Baseline Sample Demographic Characteristics

Demographic	M	SD
Age (years)	64.79	10.69
Missing	-	
Gender		
Male	154 (57.20%)	
Female	115 (42.80%)	
Missing	*4*	
Aboriginal/Torres Strait Islander		
Yes	12 (4.50%)	
No	255 (95.50%)	
Missing	*6*	
Born in Australia		
Yes	192 (78.40%)	
No	53 (21.60%)	
Missing	*28*	
Relationship Status		
In a Relationship	174 (65.40%)	
Not in a Relationship	92 (34.60%)	
Missing	*7*	
No. of Dependents	0.41	1.02
	Range 0-7	
SEIFA Percentile	37.09	22.26
Lowest Quartile	106 (39.10%)	
Mid to Lowest Quartile	92 (33.90%)	
Mid to Highest Quartile	60 (22.10%)	
Highest Quartile	13 (4.80%)	
Missing	*2*	
Household Annual Income (AUD)		
$30,000 or less	125 (54.10%)	
>$30,000	106 (45.90%)	
Missing	*42*	
Education		
Middle School	122 (45.00%)	
Senior School	40 (14.80%)	
Tertiary/Trade	109 (40.20%)	
Missing	*2*	

Note. N = 273, SEIFA = Socio-Economic Indexes for Areas

Demographic characteristics of the sample were examined across ARIA regions of Inner Regional and Outer Regional to determine whether any differences were evident between groups based on geographic remoteness area. As can be seen in Table 5.3, the sample was relatively homogenous with respect to demographics, with no statistically significant differences identified between inner and outer regional groups.

Table 5.3

Demographic Characteristics of Baseline Sample Examined Across Geographical Remoteness Areas

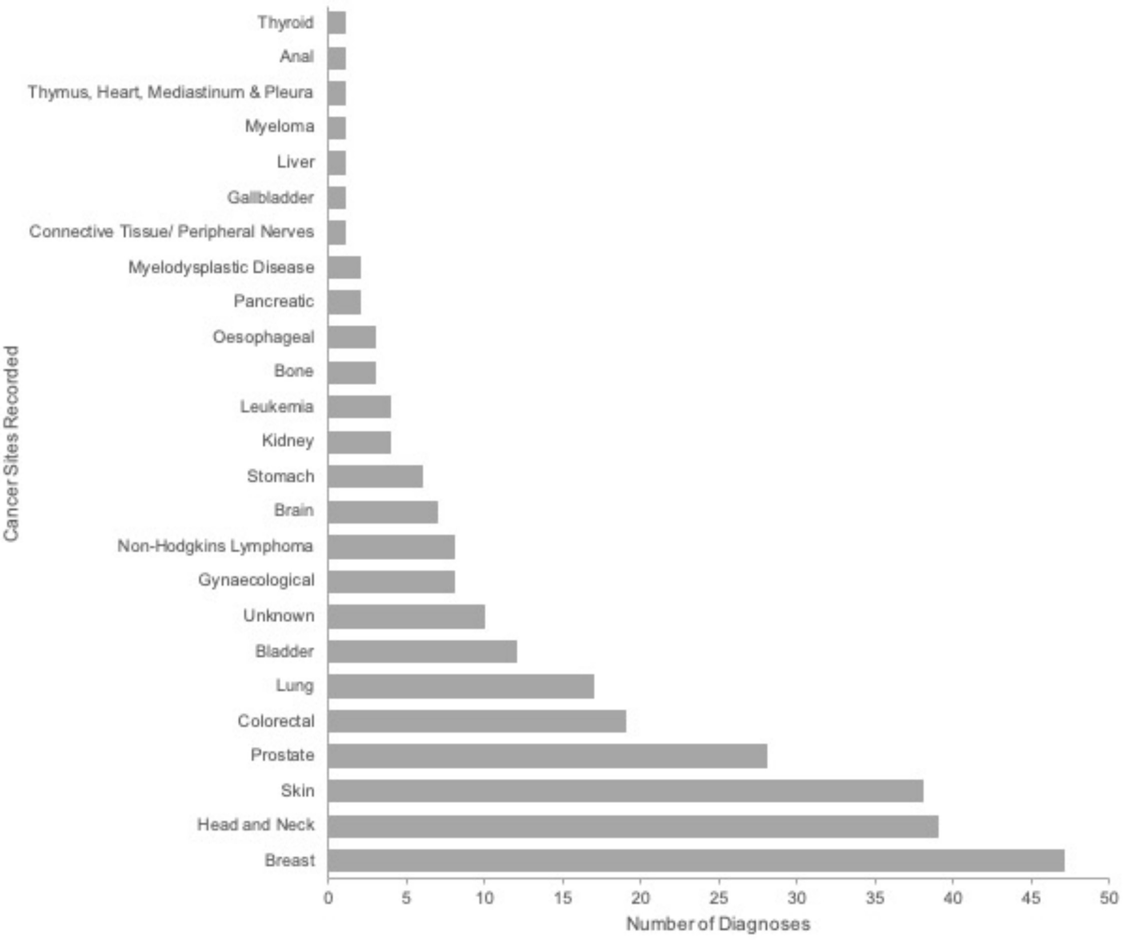
Baseline Sample Demographic Characteristics by Geographic Remoteness							
Demographic	Inner Regional (*n* = 137)		Outer Regional (*n* = 134)		Group Differences		
	M	SD	M	SD	Statistic	*df*	*p*
Age (years)	65.29	10.30	64.32	11.12	.740[a]	269	.46
Missing							
Gender					3.697[b]	1	.06
Male	86 (62.80%)		67 (51.10%)				
Female	51 (37.20%)		64 (48.90%)				
Missing	-		*3*				
Aboriginal/Torres Strait Islander					1.396[b]	1	.24
Yes	4 (3.00%)		8 (6.00%)				
No	129 (97.00%)		125 (94.00%)				
Missing	*4*		*1*				
Born in Australia					3.061[b]	1	.08
Yes	93 (73.80%)		98 (83.10%)				
No	33 (26.20%)		20 (16.90%)				
Missing	*11*		*16*				
Relationship Status					1.901[b]	1	.17
In a Relationship	82 (61.70%)		92 (69.70%)				
Not in a Relationship	51 (38.30%)		40 (30.30%)				
Missing	*4*		*2*				
No. of Dependents	0.37	0.88	0.46	1.14	-.730[a]	269	.47
Household Annual Income (AUD)					.059[b]	1	.81
$30,000 or less	64 (54.70%)		60 (53.10%)				
>$30,000	53 (45.30%)		53 (46.90%)				
Missing	*20*		*21*				
Education					5.257[c]	2	.07
Middle School	53 (38.70%)		68 (50.70%)				
Senior School	19 (14.00%)		21 (15.70%)				
Tertiary/Trade	64 (47.10%)		45 (33.60%)				
Missing	*1*		-				

Note. *N* = 273. Two participants failed to provide their postcode and were thus unable to be included in geographic comparisons.
[a]= Independent Samples T-Test, [b]= Test of Two Proportions, [c]= Chi Square Test.

Clinical Characteristics at Baseline. Figure 5.2 shows a breakdown of the different cancer diagnoses across the sample. The most commonly identified cancers overall were breast (17.80%), head and neck (14.80%), skin (14.40%) and prostate (10.60%).

Figure 5.2

Participant Cancer Sites



Note. N = 273.

A further breakdown of sample clinical characteristics is provided in Table 5.4. More than half of the participants (56.60%) did not know the stage of cancer at diagnosis. Approximately one quarter (24.60%) reported their current cancer diagnosis as a recurrence of previous cancer, and 32.20% reported having a previous diagnosis of another unrelated cancer.

In total, approximately 78.00% of the sample were actively undergoing treatment at the time of recruitment, while the remaining participants were either engaged in follow-up care or were in the diagnostic and treatment planning stage. The number of days since diagnosis for those participants currently undergoing treatment ranged from 0 – 6,107 days (M = 531.27; SD = 1,041.98). With large variation in cancer types across the sample and differing treatment schedules based on the individual, some participants had undergone multiple cancer treatments over a longer period, thus increasing the mean number of days for those participants currently undergoing treatment. The median number of days since diagnosis for participants currently undergoing treatment was 126.50 days.

Table 5.4

Baseline Sample Clinical Characteristics

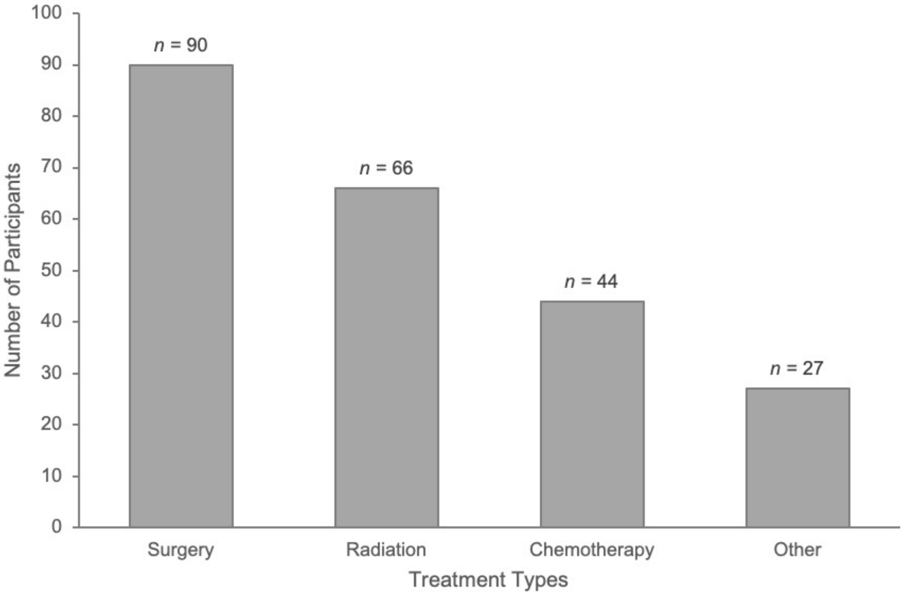
Clinical Characteristic	M	SD
No. Days Since Diagnosis		
Status: In Treatment	513.27	1041.98
	Range (0 – 6107)	
Status: Not in Treatment	1261	1611.18
	Range (22 – 7722)	
Missing	*13*	
Treatment Status		
In Treatment	173 (77.90%)	
Not in Treatment	49 (22.10%)	
Missing	*51*	
Cancer Stage		
Known by Patient	106 (43.40%)	
Unknown by Patient	138 (56.60%	
Missing	*29*	
Cancer Recurrence		
Yes	60 (24.60%)	
No	184 (75.40%)	
Missing	*29*	
Previous Cancer		
Yes	79 (32.20%)	
No	166 (67.80%)	
Missing	*28*	

Note. N = 273.

In total, 170 participants ($n = 170/235$, 72.30%) reported having received at least one form of treatment within the past 12 months. Figure 5.3 visually presents the different types of treatments received by those participants. The most common treatment received was surgery (45.90%), followed by radiation therapy (32.70%), and chemotherapy (21.40%). Other treatments reported (12.10%) included immunotherapy, targeted therapy, hormone therapy, stem cell treatment, precision medicine, and diagnostic surgery.

Figure 5.3

Treatment Received Over the Previous 12 Months

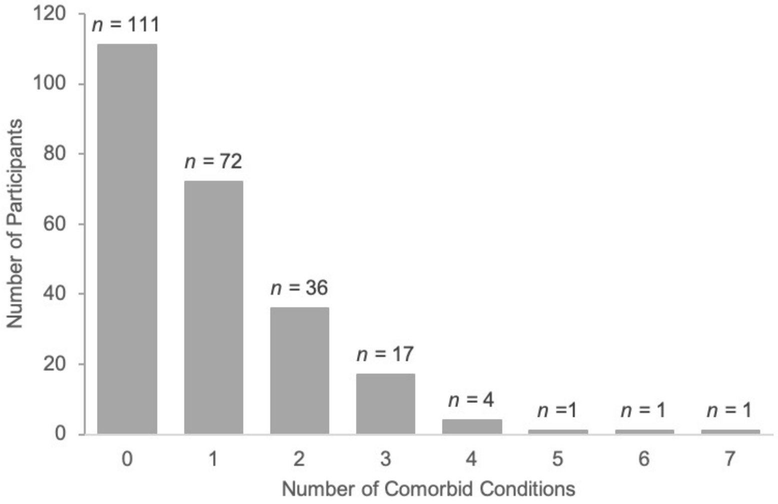


Note. $N = 170$. Other treatments = immunotherapy, targeted therapy, hormone therapy, stem cell treatment, precision medicine and diagnostic surgery.

With respect to comorbidities, participants reported an average of .94 comorbid conditions (M = .94, SD = 1.16). Almost 60.00% of the sample reported having at least one medical diagnosis in addition to cancer, with 29.60% reporting one, 14.80% reporting two and 9.90% of participants reporting three or more comorbid conditions (see Figure 5.4). Additionally, Figure 5.5 provides a visual breakdown of conditions reported by the sample. The most frequently reported comorbid condition was diabetes (16.50%), followed by solid tumour (14.50%).

Figure 5.4

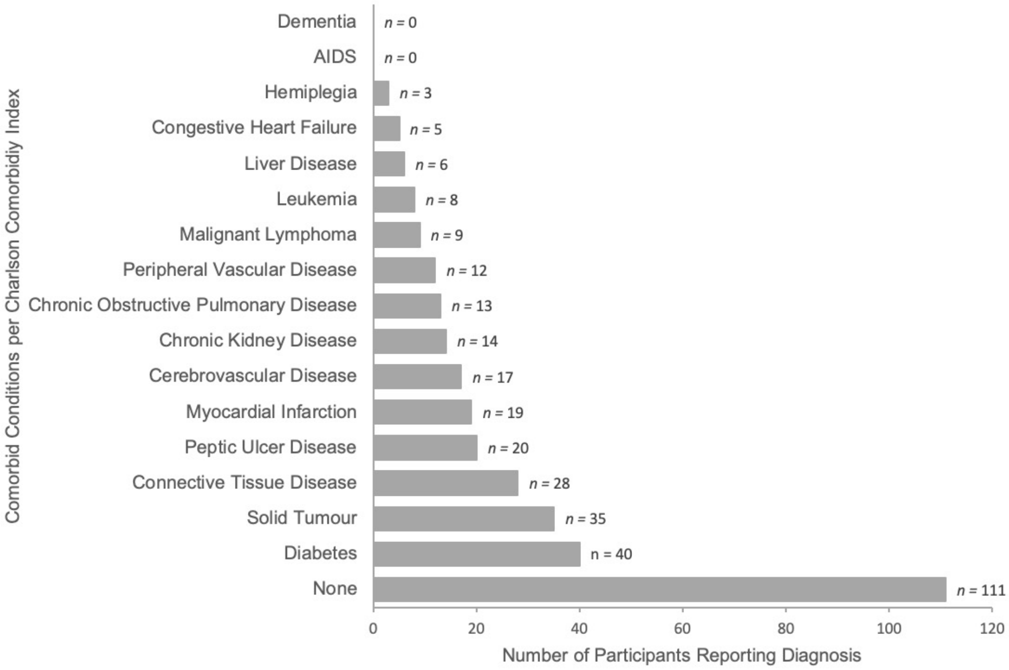
Total Number of Diagnosed Comorbid Conditions Reported



Note. *N* = 243

Figure 5.5

Frequency of Self-Reported Comorbid Diagnoses



Note. *N* = 243

Examination of group differences in clinical characteristics across geographic remoteness areas (see Table 5.5) revealed a significant difference between inner and outer regional groups for the site of cancer. Specifically, post-hoc z-tests of two proportions revealed that the proportion of outer regional participants with a breast cancer diagnosis (26.90%) was significantly greater than the proportion of inner regional participants with a breast cancer diagnosis (9.00%). There were no differences across remoteness areas for any other clinical characteristic examined.

Table 5.5

Clinical Characteristics of Sample Examined Across Geographical Remoteness Areas

Clinical Characteristic	Inner Regional (*n* = 137)		Outer Regional (*n* = 134)		Group Differences		
	M	SD	M	SD	Statistic	*df*	*p*
No. Days Since Diagnosis	694.14	1155.44	677.34	1165.47	.116[a]	257	.91
	Range (0 - 5657)		*Range (5 – 7722)*				
Status: In Treatment	547.46	1026.43	516.49	1072.02			
	Range (0- 4567)		*Range (5 – 6107)*				
Status: Not In Treatment	1339.42	1613.79	1185.72	1638.28			
	Range (52 - 5657)		*Range (22 - 7722)*				
Missing	*5*		*7*				
Site of Cancer					17.493[c]	6	.008
Breast	12 (9.00%)		35 (26.90%)		14.353[d]		<.001
Head and Neck	20 (16.50%)		19 (14.60%)		.009[d]		.92
Skin	22 (16.50%)		16 (12.30%)		.953[d]		.33
Prostate	19 (14.30%)		9 (6.90%)		3.746[d]		.053
Colorectal	9 (6.80%)		10 (7.70%)		.084[d]		.77
Lung	8 (6.00%)		9 (6.90%)		.090[d]		.77
Other Cancers:	43 (32.30%)		32 (24.60%)		1.920[d]		.166
Bladder	9 (6.80%)		3 (2.30%)				
Gynaecological	5 (3.80%)		3 (2.30%)				
Non-Hodgkins Lymphoma	3 (2.30%)		5 (3.80%)				
Brain	6 (4.50%)		1 (0.80%)				
Stomach	2 (1.50%)		4 (3.10%)				
Kidney	3 (2.30%)		1 (0.80%)				
Leukemia	2 (1.50%)		2 (1.50%)				
Bone	2 (1.50%)		1 (0.80%)				
Oesophageal	-		3 (2.30%)				
Pancreatic	1 (0.80%)		1 (0.80%)				
Myelodysplastic Disease	1 (0.80%)		1 (0.80%)				
Connective Tissue/ Peripheral Nerves	1 (0.80%)		-				
Gallbladder	-		-				
Liver	1 (0.80%)		-				
Myeloma	1 (0.80%)		-				
Thymus, Heart, Mediastinum & Pleura	-		1 (0.80%)				

Clinical Characteristic	Inner Regional (*n* = 137)		Outer Regional (*n* = 134)		Group Differences		
	M	SD	M	SD	Statistic	*df*	*p*
Anal	1 (0.80%)		-				
Thyroid	-		1 (0.80%)				
Unknown	5 (3.80%)		5 (3.80%)				
Missing	*4*		*4*				
Treatment Status					.311^{b}	1	.58
In Treatment	92 (79.30%)		80 (76.20%)				
Not in Treatment	24 (20.70%)		25 (23.80%)				
Missing	*21*		*29*				
Cancer Stage					2.854^{b}	1	.09
Known by Patient	48 (38.40%)		58 (49.20%)				
Unknown by Patient	77 (61.60%)		60 (50.80%)				
Missing	*12*		*16*				
Cancer Recurrence					.404^{b}	1	.53
Yes	33 (26.40%)		27 (22.90%)				
No	92 (73.60%)		91 (77.10%)				
Missing	*12*		*16*				
Previous Cancer					1.080^{b}	1	.30
Yes	37 (29.40%)		42 (35.60%)				
No	89 (70.60%)		76 (64.40%)				
Missing	*11*		*16*				
Treatment Received in the 12 Months Prior to Completing Baseline Assessment							
Surgery	49 (46.20%)		40 (44.90%)		.032^{b}	195	.86
Radiation Therapy	39 (35.50%)		27 (29.70%)		.756^{b}	201	.39
Chemotherapy	24 (21.40%)		19 (20.40%)		.031^{b}	205	.86
Other^{e}	15 (13.30%)		12 (11.00%)		.266^{b}	222	.61
Total No. of Comorbid Conditions	1.04	1.21	0.83	1.11	1.413	240	.16
Missing	*12*		*17*				

Note. N = 273. Two participants failed to provide their postcode and were thus unable to be included in geographic comparisons. ^{a}= Independent Samples T-Test, ^{b}= Test of Two Proportions, ^{c}= Chi Square Test, ^{d}=Post-Hoc z test of 2 proportions, ^{e}=Other treatments include: Immunotherapy, Targeted Therapy, Hormone Therapy, Stem Cell Treatment, Precision Medicine, Diagnostic Surgery, or any other treatment not listed.

Individual Characteristics at Baseline

Table 5.6 presents the mean scores of the characteristics of stigma, fatalism, consideration of future consequences, barriers to help-seeking, and resilience.

Table 5.6

Baseline Sample Individual Characteristics

Individual Characteristic	M	SD
Stigma	11.71	5.04
Range	*(8 - 32)*	
Missing	*13*	
Fatalism	26.62	8.78
Range	*(10 - 50)*	
Missing	*24*	
Consideration of Future Consequences	39.08	7.21
Range	*(17 - 60)*	
Missing	*27*	
Need for Control & Self-Reliance	23.24	9.26
Range	*(10 - 50)*	
Missing	*4*	
Minimising Problems & Recognition	14.00	5.79
Range	*(4 - 30)*	
Missing	*4*	
Resilience	22.13	3.98
Range	*(6 - 30)*	
Missing	*8*	

Note. N = 273

Examination of the group differences across geographic regions revealed no statistically significant differences in attitudinal characteristics across inner and outer regional groups (see Table 5.7). This suggests that average levels/ranges of attitudes were similar across all geographic locations.

Table 5.7

Individual Characteristics of Sample Examined Across Geographical Remoteness

Individual Characteristic	Inner Regional (n = 137)		Outer Regional (n = 134)		Group Differences[a]		
	M	SD	M	SD	Statistic	*df*	*p*
Stigma	11.80	5.13	11.61	4.99	.288	257	.77
	Range (8 - 32)		*Range (8 - 32)*				
Missing	*5*		*7*				
Fatalism	26.57	8.89	26.76	8.68	-.168	246	.87
	Range (10 - 50)		*Range (10 - 50)*				
Missing	*9*		*14*				
Consideration of Future Consequences	39.03	7.63	39.16	6.82	-.133	243	.89
	Range (17 - 56)		*Range (25 - 60)*				
Missing	*14*		*12*				
Need for Control & Self-Reliance	23.75	9.52	22.63	8.95	.998	266	.32
	Range (10 - 50)		*Range (10 - 47)*				
Missing	*3*		-				
Minimising Problems & Recognition	14.46	5.73	13.49	5.83	1.374	266	.17
	Range (6 - 29)		*Range (4 - 30)*				
Missing	*3*		-				
Resilience	21.86	4.08	22.39	3.89	-1.097	262	.27
	Range (6 - 30)		*Range (11 - 30)*				
Missing	*5*		*2*				

Note. N = 273. Two participants failed to provide their postcode and were thus unable to be included in geographic comparisons.

[a]= Independent Samples T-Test

Health Behaviours and Health Indicators at Baseline

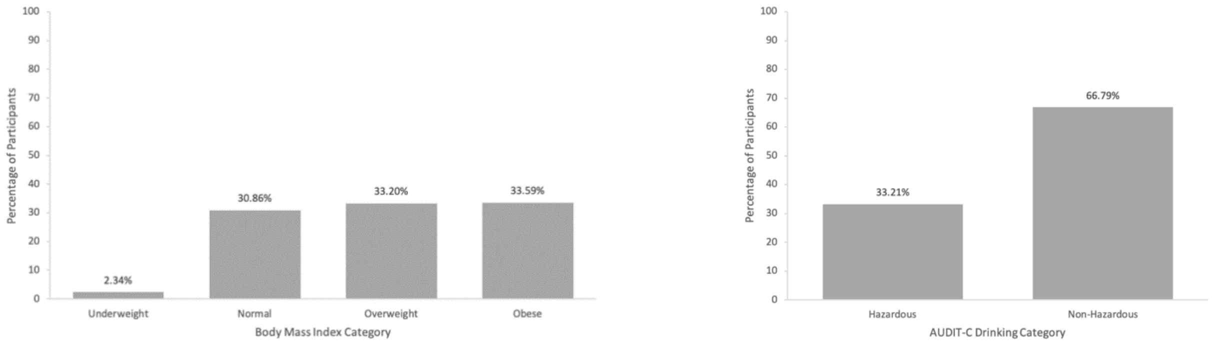
Figure 5.6 provides a visual summary of health behaviours of the sample. The average body mass index (BMI) of participants was 27.95 (SD = 6.49), which falls within the “Overweight” category. As shown in Figure 5.6, approximately two-thirds (66.80%) of participants fell within the “Overweight” or “Obese” categories. With respect to alcohol consumption, approximately one third (33.20%) of participants reported hazardous levels of drinking according to their AUDIT-C scores (M = 2.91 SD = 3.07). Of those participants who had ever smoked (68.30% of the full sample), around 36.00% had smoked cigarettes within the past 12 months. On average, the sample did not meet standard nutritional guidelines for fruit and vegetable intake. Participants reported meeting approximately 84.00% of recommended daily fruit intake and 53.00% of recommended daily vegetable intake. Over one-third of participants (36.60%) were insufficiently active as measured by self-reported weekly physical activity (M = 22.37 SD = 21.91).

Figure 5.6

Visual Summaries of Health Behaviours and Indicators at Baseline

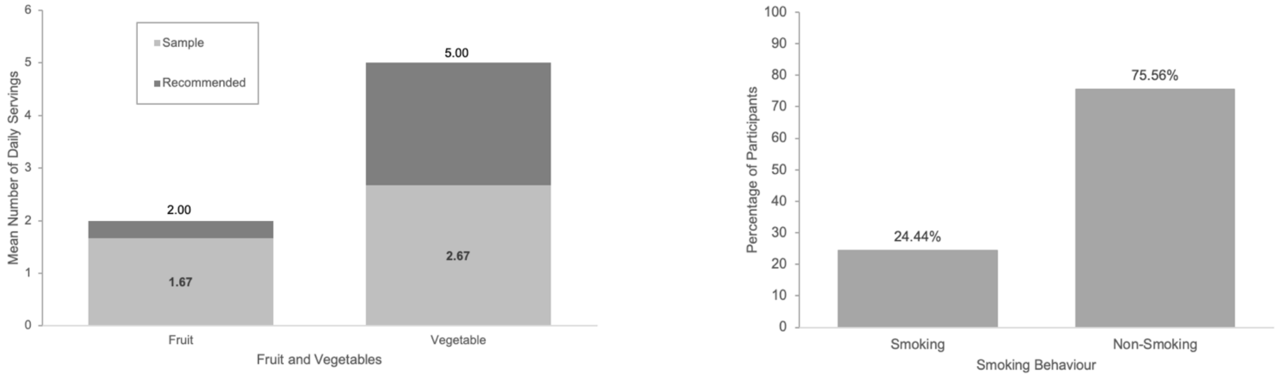
BMI Category

Alcohol Consumption

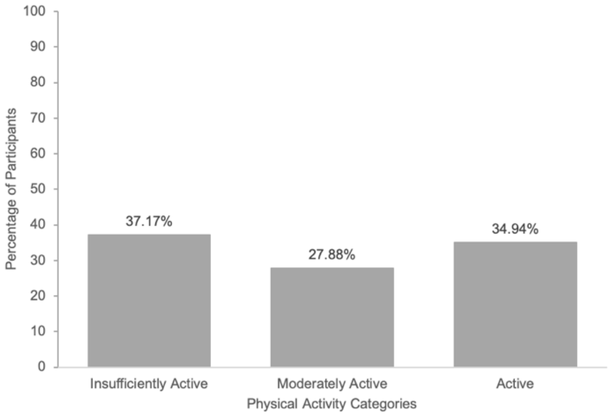


Healthy Diet

Smoking



Physical Activity



Note. N = 273

Health behaviours and health indicators at baseline were examined across geographical remoteness areas. As shown in Table 5.8, there was no statistically significant difference in health behaviours across inner and outer regional groups. This suggests that patterns of smoking, alcohol consumption, exercise, nutrition, and BMI were similar across all geographic locations.

Table 5.8

Baseline Health Behaviours Across Geographical Remoteness Areas

Health Behaviour/Indicator	Inner Regional (*n* = 137)		Outer Regional (*n* = 134)		Group Differences		
	M	SD	M	SD	Statistic	*df*	*p*
Body Mass Index (BMI)	28.43	7.19	27.45	5.62	1.204[a]	253	.23
Missing	*4*		*12*				
BMI Category					.806[c]	2	.67
Underweight	3 (2.30%)		3 (2.50%)				
Normal	42 (31.60%)		36 (29.50%)				
Overweight	41 (30.80%)		44 (36.10%)				
Obese	47 (35.30%)		39 (32.00%)				
Missing	*4*						
Alcohol Consumption (AUDIT-C)	2.99	0.88	2.85	3.29	.367[a]	262	.71
Missing	*3*		*4*				
Hazardous Drinking Level (AUDIT-C)					.008[b]	1	.93
Yes	45 (33.60%)		42 (33.10%)				
No	89 (66.40%)		85 (66.90%)				
Missing	*3*		*7*				
Smoked in Previous 12mths					.290[b]	1	.59
Yes	35 (25.90%)		30 (23.10%)				
No	100 (74.10%)		100 (76.90%)				
Missing	*2*		*4*				
Avg Daily Fruit Intake	1.60	1.17	1.74	1.00	-1.078[a]	268	.28
Missing	*1*		-				
Avg Daily Vegetable Intake	2.70	1.75	2.65	1.44	.254[a]	266	.80
Missing	*1*		*2*				
Physical Activity (GSLT)	23.54	21.51	21.34	22.35	.099[a]	266	.92
Missing	*3*		-				
Physical Activity (GSLT) Category					3.264[c]	2	.20
Insufficiently Active	45 (33.60%)		54 (40.30%)				
Moderately Active	40 (29.90%)		35 (26.10%)				
Active	49 (36.60%)		45 (33.60%)				
Missing	*3*		-				

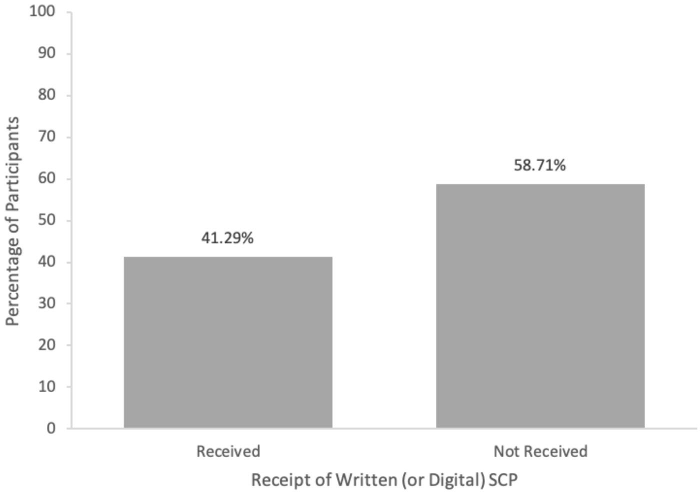
Note. N = 273. Two participants failed to provide their postcode and were thus unable to be included in geographic comparisons.
GSLT = Godin Shepherd Leisure Time scale, AUDIT-C = Alcohol Use Disorders Identification Test,
[a]= Independent Samples T-Test, [b]= Test of Two Proportions, [c]= Chi Square Test.

Survivorship Information

At 6- and 12-months post-recruitment, participants were asked to indicate the types of information they received regarding follow-up care activities. As shown in Figure 5.7, when asked at 6-months post-baseline (Time 2), only 41.29% of participants reported that they had received a written or digital SCP after treatment.

Figure 5.7

Breakdown of Participants Receiving a Written or Digital Survivorship Care Plan

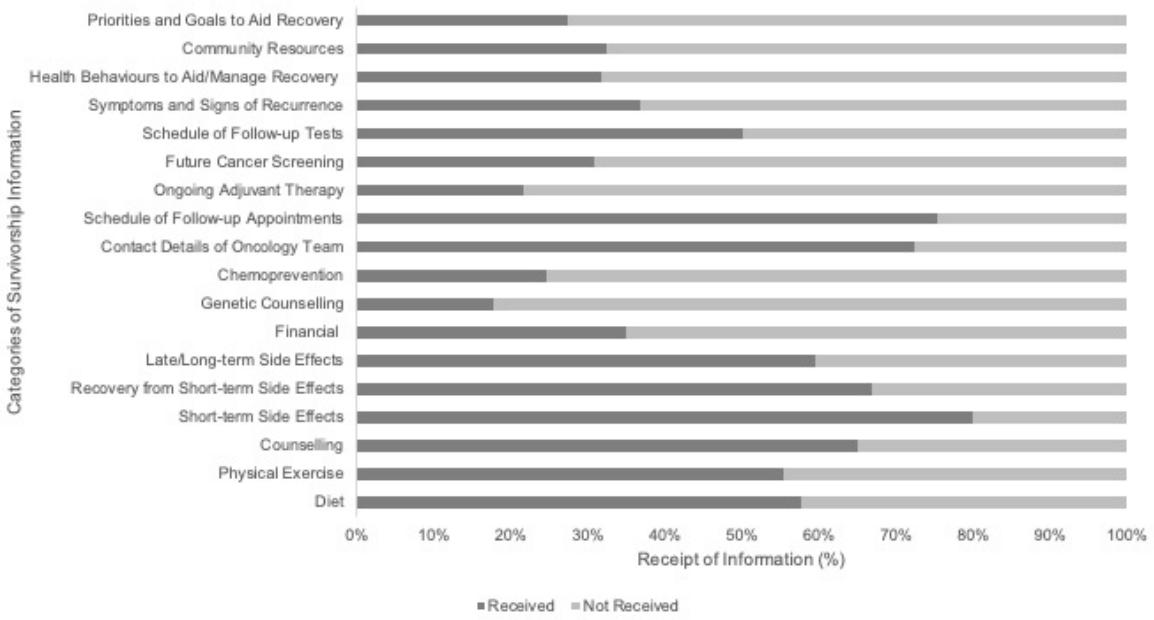


Note. N = 201

Figure 5.8 provides a breakdown of the different types of information recommended by the ACSC, and the percentage of participants who reported having received that information. Participants reported most commonly receiving information on short-term side effects of treatment, receiving a schedule of follow-up appointments, and receiving the contact details of their treating oncologist/oncology team. Only 57.60% of participants reported receiving information about diet, 55.30% received information about physical exercise, and 31.80% received recommendations of health behaviours to aid in cancer recovery and/or cancer management. Approximately one-quarter of participants received advice regarding priorities and goals to aid recovery.

Figure 5.8

Breakdown of Survivorship Information Received



Note. N = 273

Examination of group differences according to geographic remoteness areas revealed that there was no statistically significant difference in receipt of either a SCP or ACSC-recommended information based on level of remoteness. As shown in Table 5.9, neither inner nor outer regional participants were more or less likely to receive survivorship information.

Table 5.9

Receipt of Survivorship Care Plan and Survivorship Information Examined Across Geographical Remoteness Areas

Information Type	Inner Regional (*n* = 137)	Outer Regional (*n* = 134)	Group Differences		
			Statistic	*df*	*P*
Written (or Digital) Survivorship Care Plan			.037	1	.85
Yes	40 (40.80%)	43 (42.20%)			
No	58 (59.20%)	59 (57.80%)			
Missing	*39*	*32*			
Received medical-related information			1.156	1	.28
Yes	80 (83.30%)	78 (77.20%)			
No	16 (11.70%)	23 (22.80%)			
Missing	*41*	*33*			
Received health behaviour-related information			.042	1	.84
Yes	65 (67.70%)	67 (66.30%)			
No	31 (32.30%)	34 (33.70%)			
Missing	*41*	*33*			
Information about managing diet			.174	1	.68
Yes	57 (59.40%)	57 (56.40%)			
No	39 (40.60%)	44 (43.60%)			
Missing	*41*	*33*			
Information about physical exercise			1.238	1	.27
Yes	50 (51.50%)	60 (59.40%)			
No	47 (48.50%)	41 (40.60%)			
Missing	*40*	*33*			
Information about availability of counselling			.008	1	.93
Yes	63 (65.60%)	65 (65.00%)			
No	33 (34.40%)	35 (35.00%)			
Missing	*41*	*34*			
Information about short-term side effects of treatment			.001	1	.97
Yes	78 (80.40%)	81 (80.20%)			
No	19 (19.60%)	20 (19.80%)			
Missing	*40*	*33*			
Information about likely course of recovery from short-term side effects			.123	1	.73

Information Type	Inner Regional (*n* = 137)	Outer Regional (*n* = 134)	Group Differences		
			Statistic	*df*	*P*
Yes	64 (66.00%)	69 (68.30%)			
No	33 (34.00%)	32 (31.70%)			
Missing	*40*	***33***			
Information about late or long-term side effects of treatment			.190	1	.66
Yes	59 (61.50%)	59 (58.40%)			
No	37 (38.50%)	42 (41.60%)			
Missing	*41*	*33*			
Information or advice on where to seek help for financial concerns			.035	1	.85
Yes	33 (34.40%)	36 (35.60%)			
No	63 (65.60%)	65 (64.40%)			
Missing	*41*	*33*			
Information about genetic counselling			.588	1	.44
Yes	15 (15.60%)	20 (19.80%)			
No	81 (84.40%)	81 (80.20%)			
Missing	*41*	*33*			
Information about chemoprevention			.432	1	.51
Yes	26 (26.80%)	23 (22.80%)			
No	71 (73.20%)	78 (77.20%)			
Missing	*40*	*33*			
Contact details of oncologist/oncology team			.030	1	.86
Yes	70 (72.20%)	74 (73.30%)			
No	27 (27.80%)	27 (26.70%)			
Missing	*40*	*33*			
Schedule of follow-up appointments			.980	1	.32
Yes	76 (78.40%)	73 (72.30%)			
No	21 (21.60%)	28 (27.70%)			
Missing	*40*	*33*			
Advice regarding ongoing adjuvant therapy			.130	1	.72
Yes	22 (22.90%)	21 (20.80%)			
No	74 (77.10%)	80 (79.20%)			
Missing	*41*	*33*			
Information regarding future cancer screening for other cancers			1.319	1	.25
Yes	26 (27.10%)	35 (34.70%)			
No	70 (72.90%)	66 (65.30%)			
Missing	*41*	*33*			

Information Type	Inner Regional (*n* = 137)	Outer Regional (*n* = 134)	Group Differences		
			Statistic	*df*	*P*
Schedule of follow-up tests required			.251	1	.62
Yes	50 (52.10%)	49 (48.50%)			
No	46 (47.90%)	52 (51.50%)			
Missing	*41*	*33*			
Details of symptoms and signs of recurrence			.577	1	.45
Yes	33 (34.40%)	40 (39.60%)			
No	63 (65.60%)	61 (60.40%)			
Missing	*41*	*33*			
Recommendations of health behaviours to aid recover and/or cancer management			1.279	1	.26
Yes	27 (28.10%)	36 (35.60%)			
No	69 (71.90%)	65 (64.40%)			
Missing	*41*	*33*			
List of relevant community resources			.061	1	.81
Yes	32 (33.30%)	32 (31.70%)			
No	64 (66.70%)	69 (68.30%)			
Missing	*41*	*33*			
Advice regarding priorities and goals to aid recovery			2.884	1	.09
Yes	21 (21.90%)	33 (32.70%)			
No	75 (78.10%)	68 (67.30%)			
Missing	*41*	*33*			

Note. *N* = 273. Two participants failed to provide their postcode and were thus unable to be included in geographic comparisons.

Associations Between Individual Characteristics and Health Behaviours at Baseline

Step One

In Step One, relationships between key health behaviours, demographics and clinical characteristics at baseline were examined via a series of correlational analyses. As shown in Table 5.10, statistically significant associations were identified between age, gender, education, and total comorbidities with key health behaviours at baseline (alcohol, smoking, vegetable intake, and exercise). Income, days since diagnosis, and receipt of cancer-related treatment in the 12 months prior were not correlated with any of the health behaviours at baseline. The statistically significant relationships and factors which were carried forward to regression analyses are summarised in Table 5.11. According to Cohen's (1988) conventions, there was a weak, negative correlation between smoking and age, and a weak, positive correlation between smoking and education. For alcohol consumption, a strong, negative association with gender and weak positive associations with both education and total comorbidities was evident. Additionally, there were weak positive associations between gender and vegetable intake, and education and exercise.

Table 5.10

Condensed Summary of Correlations Between Health Behaviours, Demographics and Clinical Characteristics at Baseline

Variable	Age^{a,b}	Gender^{b,d}	Education ^{c,e}	Income^{b,d}	Days Since Diagnosis^{a,b}	Total Comorbidities^{a,b}	12-month Treatment^{b,d}
Body Mass Index	-.024	.121	.007	.033	-.044	.067	.021
Alcohol	-.050	-.288***	.134*	.089	-.090	.176***	.030
Smoking	-.138*	-.059	-.122*	-.030	-.058	-.042	.087
Fruit	.115	.089	.036	.037	.013	.015	.087
Vegetables	.106	.137*	.069	.114	.051	.033	-.039
Exercise	-.091	-.022	.215***	.096	-.046	-.058	.040

Note. $^{***}p < .001$, $^{*}p < .05$, ^{a}Pearson's correlation, ^{b}Point-biserial correlation, ^{c}Spearman's correlation, ^{d}Fisher-Exact Test, ^{e}Rank-biserial correlation

Table 5.11

Summary of Significantly Correlated Demographic and Clinical Characteristics with Baseline Health Behaviours

Health Behaviour	Demographic Variables	Clinical Variables
Body Mass Index	-	-
Alcohol	Gender, Education	Total Comorbidities
Smoking	Age, Education	-
Fruit	-	-
Vegetables	Gender	-
Exercise	Education	-

Step Two

In Step Two, associations between baseline health behaviours and individual characteristics were examined and are summarised in Table 5.12. Fatalism, consideration of future consequences, the need for control and self-reliance, and minimising problems and resignation were significantly associated with several key health behaviours (BMI, fruit and vegetable intake, and exercise). However, no health behaviours at baseline were associated with stigma or resilience. According to Cohen’s (1988) conventions, there were weak, negative associations between fatalism and vegetable intake, weak, negative associations with both the need for control and self-reliance and minimising problems and resignation, and weak to moderate, positive associations between consideration of future consequences and vegetable intake. For fruit intake, there were weak, negative associations with the need for control and self-reliance and weak, negative associations with minimising problems and resignation. For exercise, there was a weak, negative association with fatalism. Finally, a weak, negative association between the need for control and self-reliance subscale and BMI was identified. A summary of all statistically significant relationships with individual characteristics is provided in Table 5.13.

Table 5.12

Condensed Summary of Correlations Between Health Behaviours and Individual Characteristics at Baseline

Variable	Stigma[a,b]	Fatalism[a,b]	Consideration of Future Consequences[a,b]	Need for Control and Self-Reliance [a,b]	Minimising Problems and Resignation[a,b]	Resilience[a,b]
Body Mass Index	-.056	-.015	-.019	-.140*	-.074	.032
Alcohol	-.039	-.076	.037	-.001	.029	.049
Smoking	.039	.123	-.059	.067	.092	-.020
Fruit	.065	-.103	.075	-.190***	-.151*	.071
Vegetables	-.064	-.152*	.248***	-.130*	-.180***	.053
Exercise	-.021	-.125*	.038	-.027	-.017	.015

Note. $^{***}p < .001$, $^{*}p < .05$, [a]Pearson's correlation, [b]Point-biserial correlation

Table 5.13

Summary of Significantly Correlated Individual Characteristics with Health Behaviours

Health Behaviour	Individual Characteristics
Body Mass Index	Need for Control and Self-Reliance
Alcohol	-
Smoking	-
Fruit	Need for Control and Self-Reliance, Minimising Problems and Resignation
Vegetables	Fatalism, Consideration of Future Consequences, Need for Control and Self-Reliance, Minimising Problems and Resignation
Exercise	Fatalism

Step Three

BMI, fruit and vegetable intake and exercise were the only health behaviours that had statistically significant correlations with any predictor variables. For each of these health behaviours a separate regression was conducted with significantly correlated demographic and clinical variables entered into Model 1, and significantly correlated individual characteristics entered into Model 2. A separate analysis was conducted for each of the associated attitudinal variables. For example, four separate analyses were conducted to predict daily vegetable intake, with gender entered into Model 1, and fatalism, consideration of future consequences, need for control and self-reliance, and minimising problem and recognition each entered into Model 2 of individual analyses. A summary of all analyses conducted is provided in Table 5.14.

Table 5.14

Summary of Regression Analyses Conducted for the Prediction of Health Behaviours

Health Behaviour	Model 1 Predictors	Model 2 Predictors
BMI	Need for Control and Self-Reliance	-
Fruit	Need for Control and Self-Reliance	-
Fruit	Minimising Problems and Resignation	-
Veg	Gender	Fatalism
Veg	Gender	Consideration of Future Consequences
Veg	Gender	Need for Control and Self-Reliance
Veg	Gender	Minimising Problems and Resignation
GSLT	Education	Fatalism

Body Mass Index (BMI)

The Need for Control and Self-Reliance. As no demographic or clinical factors showed associations with BMI at baseline, a standard linear regression was conducted with the need for control and self-reliance entered as the only predictor. The overall model was not significant, R^2= .009, F(1,248) = 2.366, p=.13, meaning that the need for control and self-reliance did not predict BMI scores.

Average Daily Servings of Fruit

No demographic or clinical factors were correlated with daily servings of fruit at baseline, therefore separate standard linear regression analyses were conducted for each of the measures of Barriers to Help-Seeking.

Barriers to Help-Seeking (Need for Control and Self-Reliance). The need for control and self-reliance significantly predicted daily fruit intake at baseline, accounting for 4.40% of the variance, $R^2 = .044$, $F(1,265) = 12.259$, $p<.001$. Those with a greater need for control and self-reliance were likely to consume fewer servings of fruit.

Barriers to Help-Seeking (Minimising Problems and Resignation). The minimising problems and resignation subscale also significantly predicted daily fruit intake, accounting for 3.30% of the variance, $R^2 = .033$, $F(1,265) = 9.133$, $p = .003$. Those participants with a greater tendency towards minimising problems and resignation were also likely to consume fewer servings of fruit. These results are presented in Table 5.15.

Table 5.15

Results of Regression Analysis Predicting Daily Fruit Intake From the Need for Control and Self-Reliance, and Minimising Problems and Resignation

Variable	*B* [95% CI]	*p*	β	*sr*²
	Need for Control & Self-reliance (N=267)			
Need for Control & Self-Reliance	-.022 [-.034, -.010]	.001	-.210	.044
	Minimising Problems & Resignation (N=268)			
Minimising Problems & Resignation	-.030 [-.050, -.011]	.003	-.151	.033

Average Daily Servings of Vegetables

For each of the regression analyses conducted for the average daily servings of vegetables, gender was entered into Model 1 of the hierarchical linear regression analysis, with fatalism, consideration of future consequences, the need for control and self-reliance and minimising problems and resignation entered into Model 2 in separate regression analyses. Gender was a significant predictor of the average daily servings of vegetables, such that females were likely to consume a greater amount of vegetables than males.

Fatalism. The addition of fatalism in Model 2 significantly added to the prediction of vegetable intake ($\Delta R^2 = .017$, $\Delta F\ (1,237) = 4.336$, $p = .038$), with the overall model accounting for 7.10% of the variance in vegetable intake, $R^2 = .071$, $F(2,237) = .024$, $p < .001$. Fatalism accounted for a 1.70% increase in the variance in vegetable consumption, with those with higher levels of fatalism likely to consume fewer vegetables.

Consideration of Future Consequences. The addition of consideration of future consequences in Model 2 significantly added to the prediction of vegetable intake ($\Delta R^2 = .062$, $\Delta F\ (1,237) = 16.704$, $p < .001$), with the overall model accounting for 11.80% of the variance, $R^2 = .118$, $F(2,237) = 15.800$, $p < .001$. Consideration of future consequences accounted for a 6.20% increase in variance, with those more likely to consider the future consequences of behaviour likely to consume a greater number of vegetables than those with lower levels of consideration.

Need for Control and Self-Reliance. The addition of the need for control and self-reliance in Model 2 significantly added to the prediction of vegetable intake, $\Delta R^2 = .020$, $\Delta F\ (1,256) = 5.541$, $p = .019$. The overall model was significant, $R^2 = .062$, $F(2,256) = 8.502$, $p < .001$, explaining 6.20% of the variance in vegetable intake. The need for control and self-reliance accounted for a 2.00% increase in variance. Those with higher levels of need for control and self-reliance were likely to consume fewer vegetables.

Minimising Problems and Resignation. The addition of minimising problems and resignation in Model 2 significantly added to the prediction ($\Delta R^2 = .039$, $\Delta F\ (1,258) = 10.776$, $p = .001$), with the overall model accounting for 7.00% of the variance in vegetable intake, $R^2 =$

.070, $F(2,258) = 9.756$, $p<.001$. Minimising problems and resignation accounted for a 3.90% increase in variance, indicating that participants with a greater tendency towards minimising problems and resignation were likely to consume fewer vegetables. A summary of all regression analyses for the prediction of daily vegetable intake is provided in Table 5.16.

Table 5.16

Results of Regression Analyses Predicting Daily Vegetable Intake From Gender, Fatalism, Consideration of Future Consequences and Barriers to Help-Seeking

Variable	*B* [95% CI]	*p*	β	sr^2
	Fatalism (N=240)			
Model 1				
Gender	.677 [.31, 1.040]	.000	.232	.054
Model 2				
Gender	.707 [.346, 1.068]	.000	.242	.058
Fatalism	-.022 [-.042, -.001]	.038	-.131	.017
	Consideration of Future Consequences (N=240)			
Model 1				
Gender	.682 [.322, 1.041]	.000	.236	.056
Model 2				
Gender	.641 [.293, .990]	.000	.221	.049
CFC	.049 [.026, .073]	.000	.250	.062
	Need for Control & Self-reliance (N=259)			
Model 1				
Gender	.590 [.244, .936]	.001	.205	.042
Model 2				
Gender	.572 [.228, .915]	.001	.198	.039
Need for Control and Self-Reliance	-.022 [-.040, -.004]	.019	-.143	.020
	Minimising Problems & Resignation (N=261)			
Model 1				
Gender	.528 [.170, .886]	.004	.177	.031
Model 2				
Gender	.515 [.163, .867]	.004	.173	.030
Minimising Problems and Resignation	-.050 [-.080, -.020]	.001	-.197	.039

Baseline Exercise Levels

Fatalism. A hierarchical linear regression model was conducted to predict baseline exercise levels. In Model 1 of the hierarchical linear regression analysis, education accounted for 5.30% of the variance in exercise, $R^2 = .053$, $F(1,241) = 13.420$, $p<.001$, such that participants with higher levels of education were more likely to engage in exercise than those with lower levels of education. With the addition of fatalism in Model 2, the overall model was significant, $R^2 = .092$, $F(2,240) = 12.164$, $p<.001$, contributing to 9.20% of the variance in exercise (see Table 5.17). Fatalism significantly improved the overall model's prediction of exercise by 3.90%, $\Delta R^2 = .039$, $\Delta F\ (1,240) = 10.385$, $p=.001$, such that those with higher levels of fatalism were likely to engage in lower levels of exercise than those with lower levels of fatalism.

Table 5.17

Results of a Regression Analysis Predicting Exercise From Education and Fatalism

Variable	*B* [95% CI]	*p*	β	sr^2
Model 1				
Education	6.817 [3.151, 10.482]	.000	.230	.053
Model 2				
Education	5.856 [2.212, 9.500]	.002	.197	.038
Fatalism	-.629 [-1.013, -.244]	.001	-.201	.039

Note. $N = 243$

Summary of Study Findings

In summary, regional people living with cancer who traveled to metropolitan areas to receive cancer care and treatment were primarily older (M = 64.79 years, SD = 10.69), male (57.20%), Australian born (78.40%), middle school educated (45.00%), in a relationship

(65.40%), and did not identify as Aboriginal/Torres Strait Islander (95.50%). Seventy-three percent of participants fell within the mid to lowest and lowest SEIFA quartiles, with participants, on average, living within the lowest 37.09% of areas in terms of socio-economic disadvantage. The most common cancers reported were breast, head and neck, skin, prostate, and colorectal cancer. Seventy-eight percent were actively in treatment at the time of recruitment. Almost one-quarter reported their current cancer as a recurrence of a previous cancer and one-third reported having had a previous other cancer. Less than half of participants knew details of their cancer stage at the time of diagnosis and only 41.00% reported having received a SCP within 6 months of receiving treatment/care.

In terms of individual characteristics, there is little opportunity for the comparison of individual characteristic scores within rural samples across current literature. However, comparisons with other samples were made where possible in order to better understand where the sample falls with respect to these individual characteristics. For fatalism, consideration of future consequences and barriers to help-seeking, the closest comparison is offered by Goodwin, et al. (2019), whose study examined the impact of attitudinal and cognitive traits on colorectal cancer screening compliance in a sample of Australian adults (n = 490, mean age = 61.26 years, 29.00% male). As presented in Table 5.18 this study's sample reported slightly higher mean scores for fatalism and barriers to help-seeking and slightly lower mean scores for consideration of future consequences than the sample in Goodwin, et al. (2019); aligning with existing literature that suggests regional/rural individuals show greater levels of fatalism and barriers to help-seeking and lower levels of consideration of future consequences.

Table 5.18

Comparisons of Fatalism, Consideration of Future Consequences and Barriers to Help-Seeking Subscale Scores Between the Current Study and Goodwin, et al. (2019)

	Current Sample	Goodwin et al., 2019
Sample Characteristics	AUS regional sample (N=273), *M*=64.79 years (SD 10.69), 57.00% male	AUS adults (N=490), *M*=61.26 years (SD 7.05), 29.00% male
Health Fatalism Scale		
Predeterminism subscale	26.62 (8.78)	23.20 (8.70)
Consideration of Future Consequences Scale	39.08 (7.21)	41.76 (7.20)
Barriers to Help Seeking Scale		
Need for Control and Self-Reliance	23.24 (9.26)	19.00 (8.50)
Minimising Problems and Resignation	14.00 (5.79)	12.24 (5.34)

The current sample showed a mean stigma score on the SSCI-8 of 11.71 (SD 5.04), similar to the findings of a study of 223 Iranian women with a breast cancer diagnosis, which reported a mean score of 11.75 (SD 5.57; Daryaafzoon et al., 2020). However this sample was significantly younger than the current study's sample, with a mean age of 47.10 years (SD 9.10), and the all-female participants were recruited through treatment centres in Tehran, Iran with no reporting or examination of geographical residence. No study samples were identified to compare resilience scores, with the current sample scoring a mean 22.13 (SD 3.98) out of a total possible score of 30.

With respect to baseline health-promoting behaviours, these regional people living with cancer displayed poor engagement in health-promoting behaviours, similar to those reported by the AIHW (2019). Two-thirds of the sample were categorised as overweight or obese, one-third reported hazardous levels of alcohol consumption, the majority did not meet daily fruit and vegetable recommendations and approximately one-quarter were insufficiently active.

Examination of the demographic, clinical, and individual characteristics and health behaviours of the sample revealed a largely homogenous group, with minimal geographical differences across remoteness areas. There was a significantly greater proportion of participants with a breast cancer diagnosis in outer regional than in inner regional groups, which may be attributable to poorer access to screening services in more geographically remote areas. No other differences were detected across inner and outer groups with respect to demographic, clinical, individual characteristics, and informational factors. Examination of individual characteristic predictors of engagement in health-promoting behaviours at the time of seeking cancer treatment revealed that individual characteristics played a limited role in predicting health-behaviour. Barriers to help-seeking, consideration of future consequences, and fatalism were the only individual characteristic factors found to be associated with baseline health behaviours. Higher level of the need for control and self-reliance, and minimising problems and resignation predicted consumption of fewer servings of fruit and vegetables only. Higher levels of fatalism predicted the consumption of fewer vegetables as well as poorer levels of exercise, and higher levels of consideration of future consequences predicted lower vegetable consumption only. Importantly, fruit and vegetable intake was poor across the entire sample.

Discussion

The purpose of this study was to produce a descriptive health profile of a regional cancer population who travel to attend major treatment centres in urban areas and who are known to be at-risk of premature death and poorer cancer outcomes. In the first instance, it sought to examine the sample in terms of demographic, clinical, and individual characteristics, and to determine levels of information receipt in the 6 months following treatment. Second, this chapter examined whether demographic, clinical, individual characteristic and informational factors differed across geographic remoteness areas. Finally, it sought to identify any individual characteristic predictors of health-promoting lifestyle behaviours (in the 12 months prior) reported at baseline recruitment.

Profiling an At-Risk Regional Cancer Population

Overall, this sample of regional people living with cancer attending Cancer Council Queensland lodges in major centres to receive cancer treatment were a homogenous group, showing very little variation in terms of demographics, clinical characteristics, and attitudinal characteristics. Their overall profile of demographic and health disadvantage aligned closely with available evidence describing regional Australians generally (AIHW, 2019).

Importantly, the findings of this study show that this at-risk group of people living with cancer entered into cancer treatment exhibiting some very poor health behaviours; participants self-reported smoking, high alcohol use, and many were overweight/obese. The nutritional and physical activity behaviours reported by this sample are consistent with those reported in non-metropolitan Australians more broadly (AIHW, 2019), which not only place individuals at heightened risk of developing serious health conditions in the first place, but now with a cancer diagnosis, could limit the opportunities for recovery during treatment and survivorship. Specifically, making positive improvements in each of these health behaviours will play a critical role in cancer treatment effectiveness, recovery, and long-term wellness for these individuals (Rausch et al., 2012; Sabaté, 2003, Wiley et al., 2015). The trajectory of these health behaviours over the following years will be crucial to the person’s wellbeing and survivorship.

It is alarming to note that after having attended major centres for cancer treatment, only 41.00% of participants reported having received a SCP, with many also failing to receive information about specific recommended health behaviours. This is concerning given that individuals are often expected to make considerable changes to their health behaviours throughout the survivorship period to promote a full recovery. It is also concerning for this population in particular given that upon leaving the CCQ lodges, they are returning to regional and rural areas where access to doctors, health services, and ongoing support is often reduced. As found in Study 1 (Chapter 3), understanding how receipt of survivorship information influences health-promoting behaviours following a cancer diagnosis and treatment is critical, especially for those people whose access to treatment centres and ongoing support following treatment in major centres is greatly reduced upon returning home to regional areas (Schootman et al., 2013) and this will be examined in Study 4.

The Influence of Attitudes on Baseline Health Behaviours

At the time of attending major centres for cancer treatment/care, individual characteristics appeared to play a limited role in predicting health behaviours. Fatalism, barriers to help-seeking (stoicism), and consideration of future consequences were the only factors found to predict health behaviour, and only to predict lower levels of fruit (barriers to help-seeking) and vegetable (barriers to help-seeking, consideration of future consequences, and fatalism) consumption, and lower levels of exercise (fatalism). The effects that were found were also reasonably small in magnitude.

These findings are not surprising, given that this was an examination of individual relationships with health behaviours prior to the introduction of a specific health threat (in this case prior to a cancer diagnosis). According to the HBM (Rosenstock, 1966), factors such as individual characteristics may play a moderating role in health-promoting behaviour engagement if the individual believes that there a significant and severe threat to their health, and assesses the benefits of performing that behaviour to outweigh the costs and barriers. In the absence of a specific health threat, it is only possible to examine the predictive role of individual characteristics on health behaviours generally, rather than its predictive role in the presence of a health threat. These findings do, however, suggest that individual characteristic factors may not play a significant role in the general health behaviours of regional populations, and that other factors such as accessibility, infrastructure and environment (Olsen et al., 2019) may play a more prominent role. Study 4 will examine whether such effects are more pronounced following a clear health threat (following cancer diagnosis and treatment).

Summary

This study examined the baseline characteristics and health behaviour profile of an at-risk regional cancer population at the time of attending major centres for cancer treatment/care. The findings suggest that this purposive sample of regional people living with cancer are particularly vulnerable with respect to sociodemographics, display poor engagement in healthy lifestyle behaviours prior to diagnosis and, unfortunately, the majority are not sent home with the information needed (SCPs) to fully understand the healthy behaviours required to promote a full cancer recovery. Therefore, at the time of attending for cancer treatment/care, participants are showing a health profile consistent with an increased risk of poor outcomes and survival. However, individual factors played a limited role in predicting engagement in baseline health behaviours. Positive changes in these behaviours will be important to promoting positive recovery and decreasing the risk of ongoing health complications following cancer treatment. Study 3 (Chapter 6) will therefore examine the 12-month period following diagnosis and treatment with respect to engagement in health-promoting lifestyle behaviours, and adherence to follow-up appointments, tests, and adjuvant treatments.

Chapter 6: Study 3 - An Examination of Health-Promoting Behaviours of Regional People Living with Cancer Over a 12-month Period

Study 2 (Chapter 5) revealed that regional people living with cancer displayed poor engagement in health-promoting behaviours in the 12 months prior to attending metropolitan areas for cancer care/treatment. The group showed high levels of overweight/obesity, hazardous alcohol consumption and tobacco smoking as well as poor diet, placing them at heightened risk of poorer cancer outcomes. According to the HBM, a serious health issue – such as a cancer diagnosis - may provide a ‘cue to action’, motivating the individual to make positive health behaviour changes (Rosenstock, 1966; Austin et al., 2002). Thus, Study 3 (Chapter 6) explores participant engagement in each of these health-promoting behaviours as well as cancer-specific medical care, over the 12 months following attendance at a major centre for cancer treatment/care.

Data obtained from each of the three time points (baseline, 6-months and 12-months) was examined to understand participant engagement in recommended health-promoting behaviours and adherence to recommended follow-up medical care following the return home to regional areas. In doing so, this study (Study 3) provides a descriptive behavioural profile of the sample over the 12-month period. Specifically, it sought to identify whether participants showed significant improvements in ‘health-promoting’ behaviours (e.g. reduced their alcohol intake) following treatment and returning home, or whether they continued with existing levels of poor health behaviours (e.g. continued with poor fruit and vegetable intake) despite the cancer treatment. Study 3 also aimed to examine whether participants engaged in recommended medical care during these 12 months (e.g. attended follow-up medical appointments as advised). A summary of key health-promoting behaviours and follow-up medical care behaviours examined is provided in Table 6.1 and specific definitions and measures are provided in Chapter 4.

Table 6.1

Summary of Key Health Behaviours/Indicators Examined

Health-Promoting Lifestyle Behaviours/Indicators	Follow-up Medical Behaviours
Body Mass Index	Appointment Adherence
Alcohol Consumption	Test Adherence
Smoking Behaviour	Treatment Adherence
Daily Fruit Intake	
Daily Vegetable Intake	
Exercise Levels	

Data Analytic Strategy

Data were analysed using SPSS Version 26 (IBM, 2019) and Mplus 8 (Muthén & Muthén, 2017). Change in behaviours was examined in several ways. First, frequency and descriptive analyses were carried out to examine health behaviours at each time point. Second, changes in health behaviours across the three time points (baseline, 6- and 12-months) were examined. Continuous variables (BMI scores, AUDIT-C scores, number of servings of fruits and vegetables, and exercise scores) were examined via Repeated Measures Analysis of Variance (RM ANOVA). Given that a large number of participants failed to provide data across all three time-points, these analyses were also conducted in Mplus 8 using multilevel modelling to confirm the RM ANOVA findings (example syntax provided in Appendix C). This analysis is analogous to a repeated-measures ANOVA in that it tests differences among the means at the different timepoints by specify a model whereby means are constrained to be equal across timepoints. When the Wald test is significant this indicates that the null hypothesis of the means being equal can be rejected as it is too improbable (Hoffman, 2015). The benefits of conducting the analysis this way using Mplus software is that is uses a full information maximum likelihood (FIML) technique for dealing with data that is missing at random. This is a principled missing data method whereby missing values are not directly replaced (i.e., imputed), rather they combine available information from the observed data with statistical assumptions in order to estimate parameters statistically. Principle methods not only increase statistical power through utilising all of the available data, but provide better, less bias parameter estimates by considering the conditions under which missing data occurred (Dong & Peng, 2013). Categorical variables were examined via Cochran's *Q* analysis and ordinal categories via Friedman's test, using SPSS Version 26, to determine whether there were any statistically significant changes in the proportions of participants within each category over time. Where significant differences were identified, post-hoc analyses with Bonferroni adjustment were conducted to determine where differences existed between the three time points.

As recruitment occurred during participants' attendance at major cities for cancer-related care, follow-up medical care behaviours (to be conducted following completion of treatment) were measured at the 6- and 12-months timepoints. Participants were asked to self-report whether a) they had attended all scheduled or recommended appointments, b) undertaken any scheduled or recommended tests, and c) undertaken additional scheduled or recommended treatment. Participants who indicated “Not Applicable” were coded to have met behaviour recommendations for the purposes of analysis, along with those who reported "Yes", while participants who indicated "No" were deemed to have not met behaviour recommendations. Change between the two time points was analysed using McNemar Change Tests using SPSS Version 26.

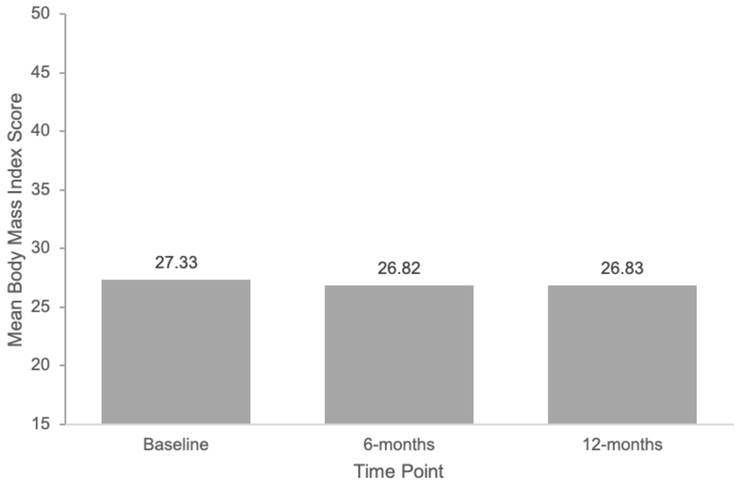
Health Behaviours/Indicators Over the 12-Month Period

Body Mass Index

In total, 151 participants provided BMI data across all three timepoints. As shown in Figure 6.1, mean BMI scores decreased slightly from baseline (*M* = 27.33, SD = 5.40) to 6-months (*M* = 26.82, SD = 5.56) and remained similar at 12-months (*M* = 26.83, SD = 5.39).

Figure 6.1

Changes in BMI Over the 12-Month Study Period



Note. N = 151.

Repeated measures ANOVA revealed that there was a statistically significant difference in BMI scores across the three time points, $F(2, 300) = 4.399$, p=.013, partial η^2 = .028. Pairwise comparisons (Table 6.2) showed that there was a significant decrease in BMI scores both from baseline to 6-months and baseline to 12-months. However, there was no difference in BMI scores from 6-months to 12-months.

Table 6.2

Pairwise Comparisons for Body Mass Index

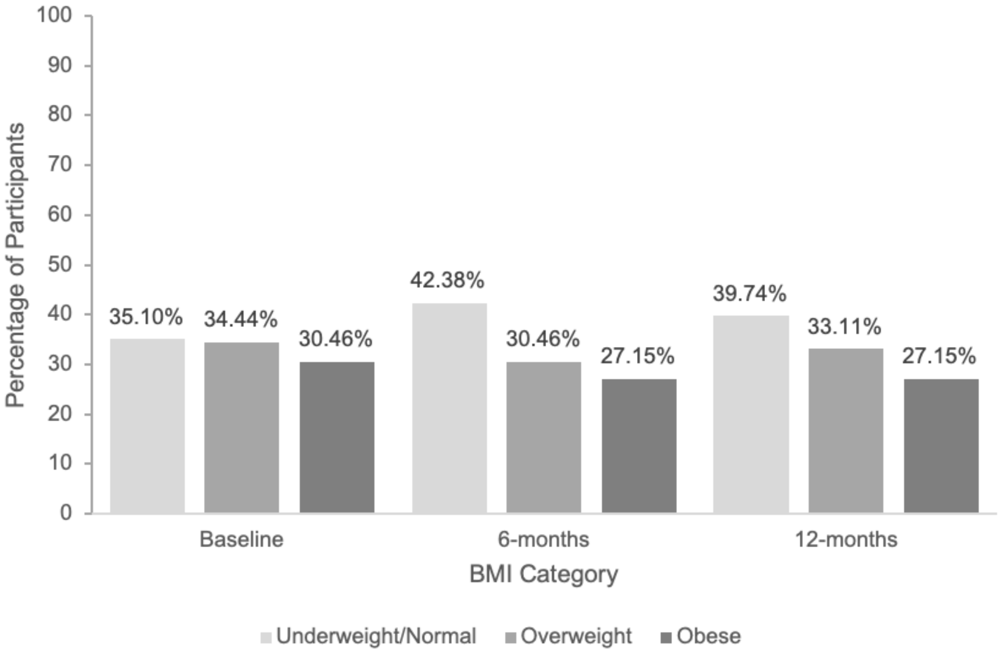
Comparison		Mean Difference	*SE*	*p*	95% Confidence Interval	
					Lower	Upper
Baseline	6-months	.504	.191	.027	.042	.966
	12-months	.499	.195	.035	.026	.972
6-months	Baseline	-.504	.191	.027	-.966	-.042
	12-months	-.005	.199	1.000	-.488	.478
12-months	Baseline	-.499	.195	.035	-.972	-.026
	6-months	.005	.199	1.000	-.478	.488

Note. N = 151

In addition to examining raw scores, BMI was also examined via changes in BMI categories. Significant differences were identified in the proportions of participants falling within each of the categories across the 12-month period, $\chi^2(2) = 8.227$, p=.016. Post-hoc analysis showed that these differences existed between baseline and 6-months (*p*=.003, partial $\eta^2 = .057$), but not between baseline and 12-months (p=.09) or 6-months and 12-months (*p*=.55). As can be seen in Figure 6.2, the proportion of participants falling within the “overweight” and “obese” BMI categories decreased from baseline to 6-months. In contrast, the proportion of participants in the "underweight/normal" category increased.

Figure 6.2

Participants Within Each BMI Category Over the 12-Month Study Period



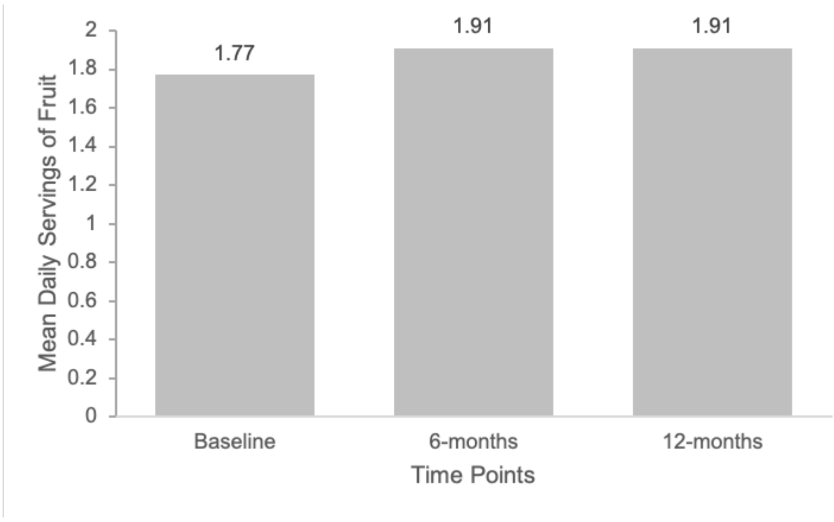
Note. N = 151.

Nutrition-Related Behaviours

*Changes in Daily Fruit Intake***.** In total, 161 participants reported their average daily servings of fruit consumed at each of the three time points. Mean patterns of daily fruit intake are shown in Figure 6.3, with servings increasing slightly from baseline (M = 1.77, SD = 1.12) to 6-months (M = 1.91, SD = 1.06) and then remaining stable at 12-months (M = 1.91, SD = 1.07). However, repeated measures ANOVA found that this increase was not statistically significant, $F(2,320) = 2.611$, p=.08, partial $\eta^2 = .016$.

Figure 6.3

Mean Average Daily Servings of Fruit Over the 12-Month Study Period

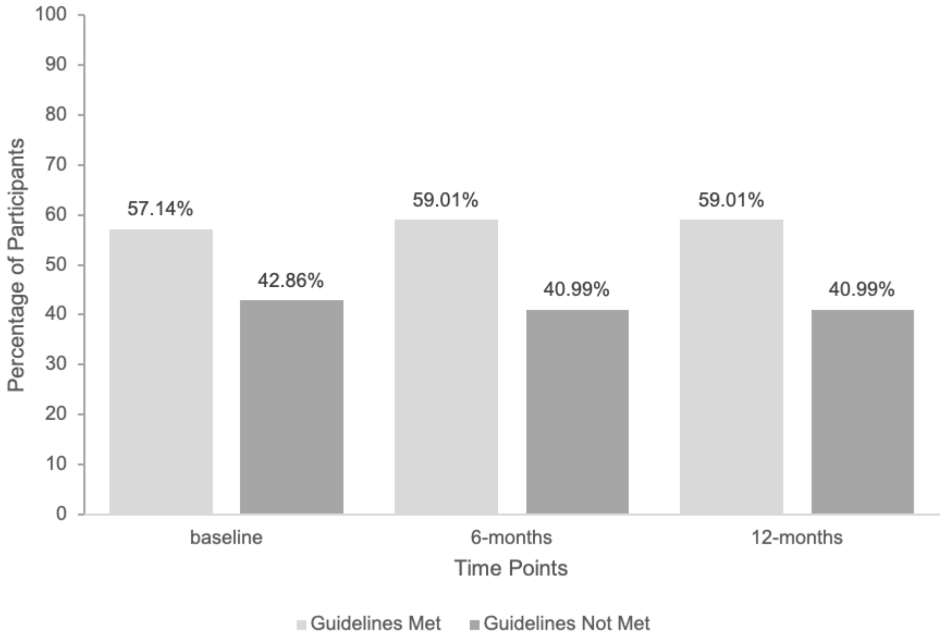


Note. N = 161.

The Proportion of Participants Meeting Recommended Daily Fruit Intake Guidelines. The proportion of participants meeting recommended daily fruit intake guidelines of two servings per day is presented in Figure 6.4. At baseline, 57.10% (n = 93/163) of participants met the daily nutritional guidelines of two servings of fruit. The proportion of participants meeting guidelines increased slightly to 58.30% (n = 95/163) at 6-months and then remained the same (n = 95/163, 58.30%) at 12-months.

Figure 6.4

Proportion of Participants Meeting Daily Fruit Recommendations Over the 12 Months



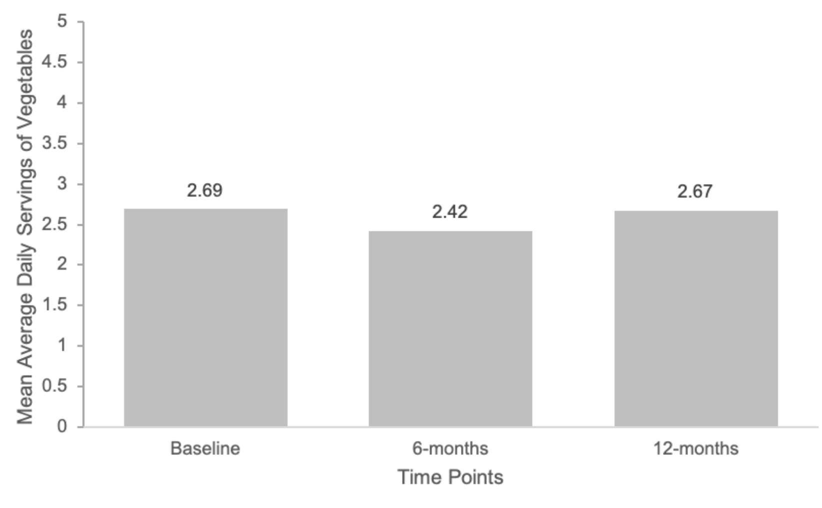
Note. *N* = 161.

Cochran's *Q* test found no statistically significant difference in the proportion of participants meeting versus not meeting guidelines across time points, $\chi 2$ (2) = .409, $p = .82$. That is, the proportion of participants who did and did not meet the national guidelines did not significantly change throughout the 12 months.

Changes in Daily Vegetable Intake. One hundred and sixty-two participants reported their average daily servings of vegetables. Figure 6.5 presents the mean average daily serving of vegetables throughout the 12-month study period. Average daily servings decreased slightly from baseline (*M* = 2.69, SD = 1.49) to 6-months (*M* = 2.42, SD = 1.39) before increasing again at 12-months (*M* = 2.67, SD = 1.46).

Figure 6.5

Mean Average Daily Servings of Vegetables Over the 12-Month Study Period



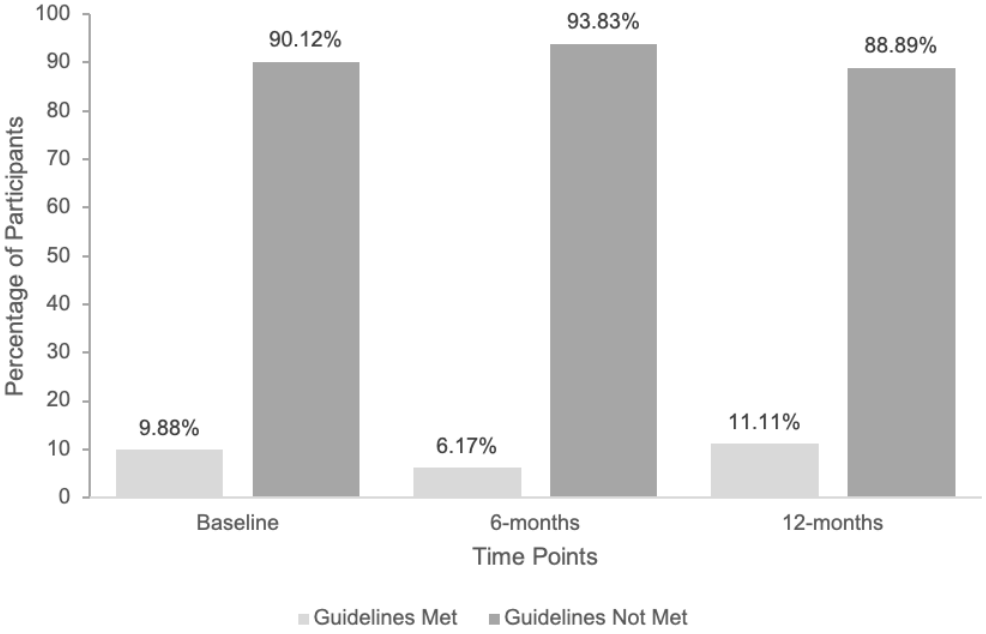
Note. *N* = 162.

Repeated Measures ANOVA with Greenhouse-Geisser correction ($\varepsilon = .959$) revealed a statistically significant difference across time points, $F(1.918, 308.877) = 4.479$, $p=.013$, partial $\eta^2 = .027$. Post-hoc analysis with a Bonferroni adjustment showed that daily vegetable intake decreased significantly from baseline to 6-months ($M = 0.264$, 95%CI [.009, .518], $p=.040$), and increased significantly from 6- to 12-months ($M = 0.243$, 95%CI [.030, .455], $p=.019$). However, there was no statistically significant difference in daily vegetable intake between baseline and 12-months ($M = 0.021$, 95%CI [-.220, .263], $p=1.00$).

Changes in Meeting Recommended Daily Vegetable Intake Guidelines. The proportion of participants meeting daily vegetable recommendations of five servings per day are shown in Figure 6.6. At baseline, 90.12% participants did not meet the recommended five servings of vegetables, increasing at 6-months to 93.83%. At 12-months, the percentage of participants not meeting these recommendations had decreased to 88.89%.

Figure 6.6

Proportion of Participants Meeting Daily Vegetable Recommendations Over 12 Months



Note. $N = 161$.

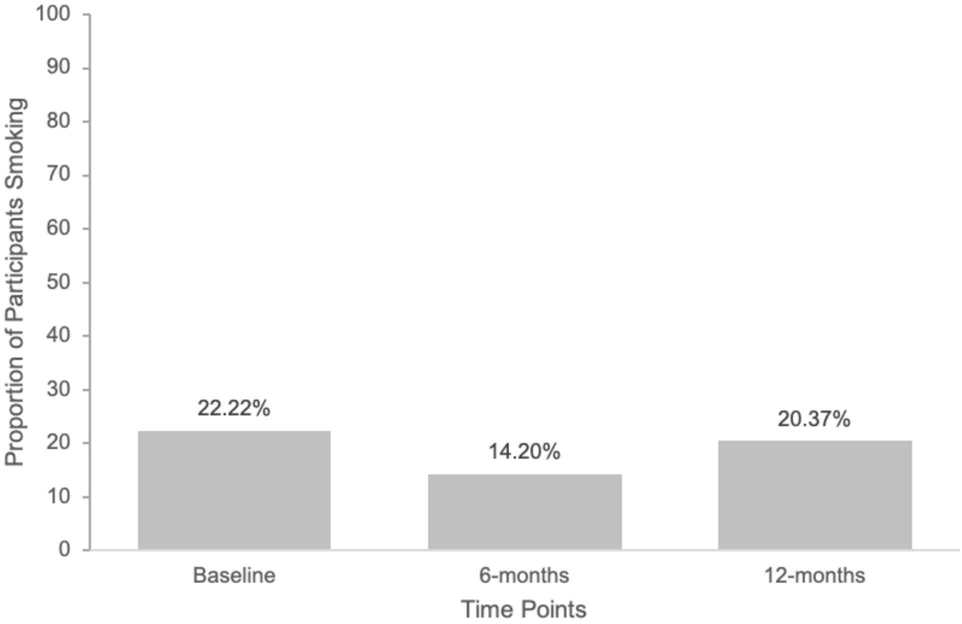
Cochran's *Q* test found no statistically significant difference in the proportion of participants meeting daily vegetable guidelines over the 12-month period, $\chi 2\ (2) = 4.160$, $p = .13$. The proportion of participants not meeting recommendations was high at baseline and did not change throughout the study period.

Smoking Behaviours

The Proportion of Participants Engaging in Smoking Behaviours. Smoking behaviours over the 12-month study period are presented in Figure 6.7. Of the 162 participants providing data at all three time points, 22.22% reported smoking within the past 12 months at baseline. At 6-months, the proportion of participants smoking had reduced to 14.20%. At 12-months, the proportion of participants smoking increased to 20.37%.

Figure 6.7

Proportion of Participants Smoking Over the 12-Month Study Period



Note. N = 162.

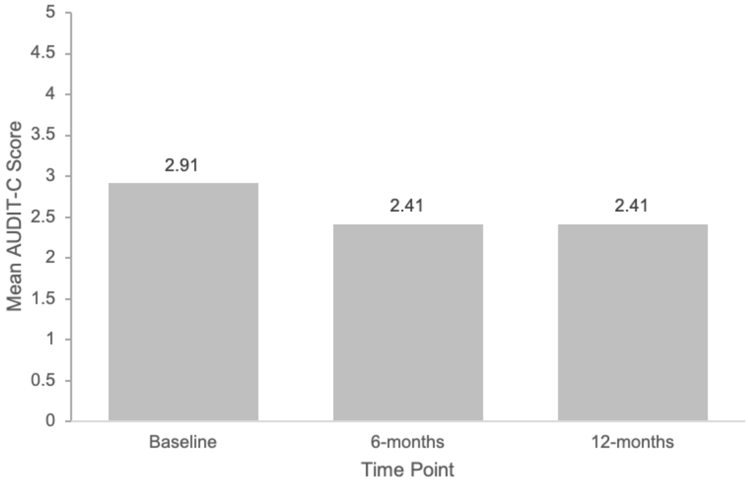
Cochran's *Q* test indicated the percentage of participants smoking was statistically different across timepoints, $\chi 2$ (2) = 14.632, *p* = .001. Post-hoc analysis showed that, compared to baseline, there was a significant decrease in the proportion of participants who reported smoking at 6-months (*p* = .001). Likewise, there was a significant increase in proportions who reported smoking between 6- and 12-months (*p* = .015). However, there was no difference between baseline and 12-months, *p* = 1.00.

Alcohol Consumption (AUDIT-C)

Changes in Alcohol Consumption. Mean AUDIT-C scores for 149 participants who provided measures of alcohol consumption across the 12-month period are presented in Figure 6.8. Mean AUDIT-C scores decreased from baseline (*M* = 2.91, SD = 3.22) to 6-months (*M* = 2.41, SD = 2.89) and remained stable at 12-months (*M* = 2.41, SD = 2.81).

Figure 6.8

Mean AUDIT-C Scores Over the 12-Month Study Period



Note. N = 149.

Repeated measures ANOVA with Greenhouse-Geisser correction showed significant differences in AUDIT-C scores across time points, $F(1.922, 286.33) = 8.876$, $p<.001$, partial $\eta^2 = .056$. As shown in Table 6.3, post-hoc analysis with a Bonferroni adjustment revealed that AUDIT-C scores were significantly lower from baseline to 6-months, and from baseline to 12-months. However, AUDIT-C scores did not significantly differ between 6- and 12-months.

Table 6.3

Pairwise Comparisons for Alcohol Consumption

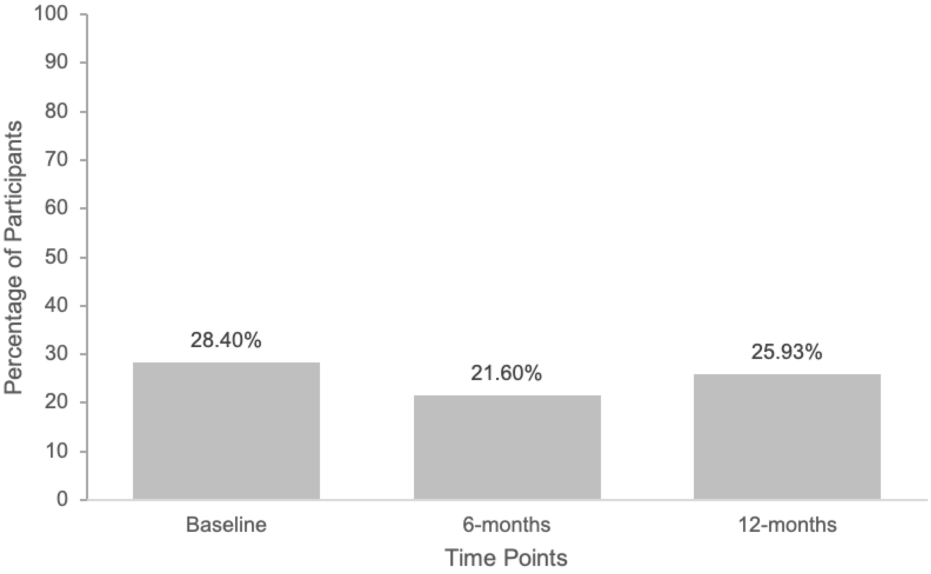
Comparison		Mean Difference	*SE*	*p*	95% Confidence Interval	
					Lower	Upper
Baseline	6-months	.507	.142	.002	.162	.852
	12-months	.500	.147	.003	.145	.855
6-months	Baseline	-.507	.142	.002	-.852	-.162
	12-months	-.007	.124	1.000	-.306	.292
12-months	Baseline	-.500	.147	.003	-.855	-.145
	6-months	.007	.124	1.000	-.292	.306

Note. N = 149

Proportions of Participants Demonstrating Hazardous Levels of Alcohol Consumption. Figure 6.9 shows the proportion of participants meeting hazardous and non-hazardous levels of drinking based on AUDIT-C scores. At baseline, 30.87% (*n* = 46/149) participants reported hazardous levels of drinking and this dropped to 23.49% (*n* = 35/149) at 6-months. By 12-month follow-up, 28.19% (*n* = 42/149) of participants reported drinking at hazardous levels.

Figure 6.9

Proportion of Participants Categorised With Hazardous Alcohol Consumption Over the 12-Month Study Period



Note. N = 149.

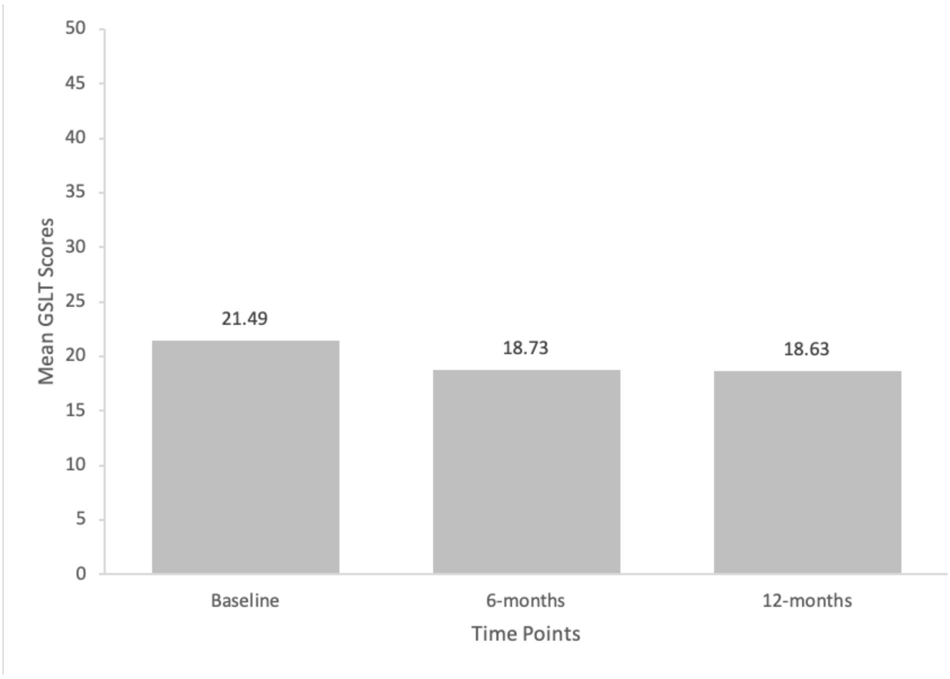
The proportion of participants drinking at hazardous levels differed across timepoints, $\chi2$ (2) = 6.000, p = .05. Post-hoc analysis showed that the proportion of participants reporting hazardous levels of drinking significantly decreased from baseline to 6-months, p = .016. There were no significant differences in proportions between 6-months and 12-months (p = .11) or baseline and 12-months (p = .39).

Exercise (Godin Shepard Leisure Time Activity Questionnaire)

Changes in Exercise Levels. One hundred and forty-one participants reported their average weekly exercise via the Godin Shepard Leisure Time Activity Questionnaire (GSLT). Figure 6.10 presents mean GSLT scores the 12-month study period. Average GSLT scores decreased slightly from baseline (*M* = 21.49, SD = 16.14) to 6-months (*M* = 18.73, SD = 16.09) to 12-months (*M* = 18.63, SD = 17.41). Repeated measures ANOVA revealed that there was no statistically significant difference in GSLT scores across the three time points, $F(2, 280) = 2.361$, p=.09, partial $\eta^2 = .017$.

Figure 6.10

Mean Exercise Scores Over the 12-Month Study Period

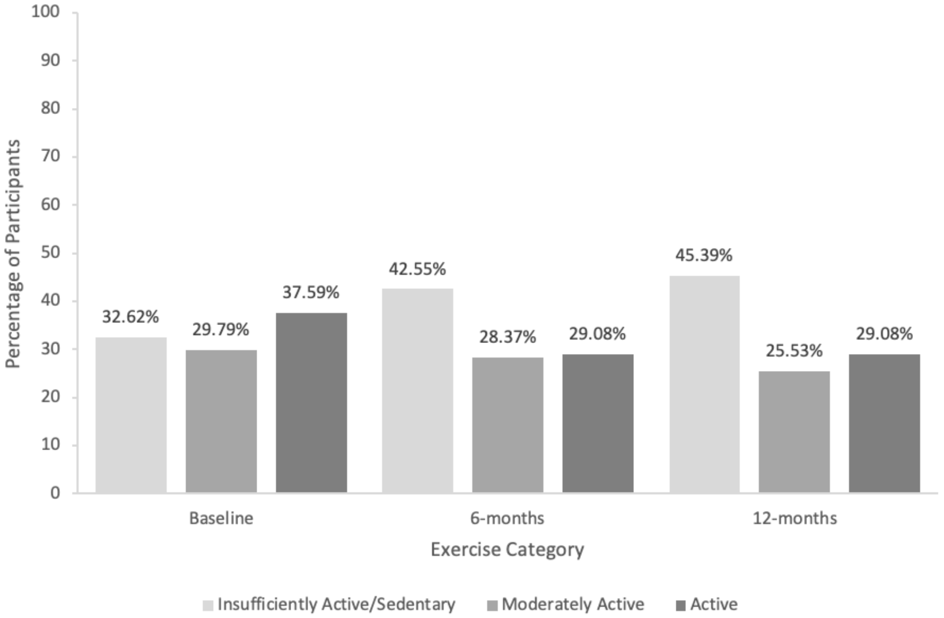


Note. N = 141.

The proportion of participants in Exercise Categories. In addition to examining raw scores, exercise was also examined via changes in GSLT categories, and is presented in Figure 6.11. Significant differences in the proportions of participants falling within each of the categories across the 12-month period were identified, $\chi^2(2) = 7.869$, p=.020. However, post-hoc analysis did not show any differences between baseline and 6-months (*p*=.08), baseline and 12-months (p=.07) or 6-months and 12-months (*p*=.91).

Figure 6.11

Participants Within Each Exercise Category Over the 12-Month Study Period



Note. *N* = 141.

Supplementary Analyses Conducted in MPlus 8

Supplementary to analyses conducted in SPSS v26, a series of analyses were conducted in MPlus8 using multilevel modelling. As shown in Table 6.4, the findings from these analyses aligned with those found using repeated-measures ANOVA in SPSS, with no major variations in outcomes.

Table 6.4

Findings of Multilevel Modelling Examining Changes in Continuous Health Behaviours

Time Comparison	Fruit	Vegetable	BMI	Alcohol	Exercise
T1 mean	1.67	2.67	27.95	2.91	22.37
(SD)	(1.08)	(1.60)	(6.48)	(3.06)	(21.87)
n	271	269	256	265	269
T2 mean	1.90	2.41	26.89	2.27	21.45
(SD)	(1.04)	(1.43)	(5.50)	(2.82)	(22.52)
n	203	205	193	197	203
T3 mean	1.87	2.65	27.02	2.39	20.43
(SD)	(1.07)	(1.45)	(5.82)	(2.82)	(22.04)
n	175	175	164	160	163
Wald, (*p*)					
$T1_{mean} - T2_{mean} - T3_{mean}$	442.11	294.87	2810.29	58.28	62.47
	(<.001)	(<.001)	(<.001)	(<.001)	(<.001)
$T1_{mean} - T2_{mean}$	9.21	6.36	10.17 (.001)	23.65	1.04
	(.002)	(.012)		(<.001)	(.307)
$T2_{mean} - T3_{mean}$	0.03	7.92	0.34	0.06	0.46
	(.828)	(.005)	(0.560)	(.809)	(.499)

Note. N = 141

BMI = Body mass index, **bold** = significant at p = <.01

Medical Adherence Behaviours Over a 12-Month Period

Table 6.5 provides a summary of the frequency and percentage of participants providing self-reported adherence to scheduled or recommended follow-up care at 6- and 12-months. While a large proportion of participants reported adhering to scheduled or recommended appointments (96.50% at 6-months and 95.40% at 12-months) and tests (77.30% at 6-months and 83.60% at 12-months), only 38.20% reported adhering to scheduled/recommended treatment at 6-months, and 35.30% at 12-months.

Table 6.5

Participant Adherence to Scheduled and/or Recommended Follow-up Care

Activity	6-months	12-months
Appointments		
Adherent	153 (96.20%)	152 (95.60%)
Non-Adherent	5 (3.10%)	3 (1.90%)
Not Applicable	1 (0.60%)	4 (2.50%)
Tests		
Adherent	121 (76.70%)	130 (82.30%)
Non-Adherent	23 (14.60%)	11 (7.00%)
Not Applicable	14 (8.90%)	17 (10.80%)
Treatment		
Adherent	51 (37.20%)	49 (35.80%)
Non-Adherent	65 (47.40%)	61 (44.50%)
Not Applicable	21 (15.30%)	27 (19.70%)

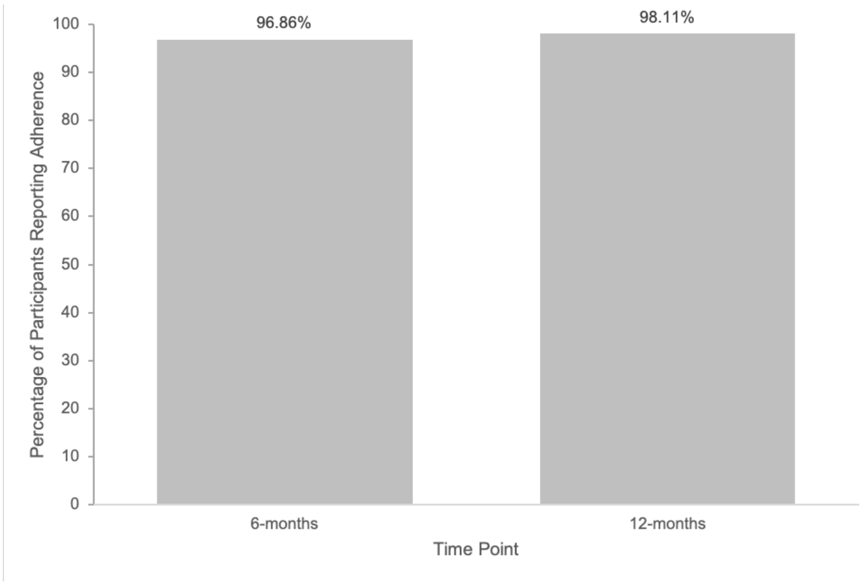
Changes in the proportion of participants reporting adherence to medical-related recommendations (appointments, tests and treatment) versus non-adherence over the 12-month period were examined. Related-Samples Exact McNemar Change Test (McNemar, 1947) with continuity correction (Edwards, 1948) was conducted for changes in behaviours at both 6-months and 12-months.

Adherence to Scheduled/Recommended Appointments

One hundred and fifty-nine participants provided self-report adherence data for attendance at scheduled/recommended appointments at both 6-months and 12-months. As shown in Figure 6.12, at 6-months, 96.86% of the 159 participants providing 6-month and 12-month data reported adhering to all scheduled and recommended appointments. At 12-months, this increased to 98.11% of participants. No significant differences were detected in the proportion of participants adhering versus not adhering to appointments over the 12 months, $\chi 2(1) = .125$, $p=.73$.

Figure 6.12

Proportion of Participants Reporting Adherence to Appointments Over the 12-Month Study Period



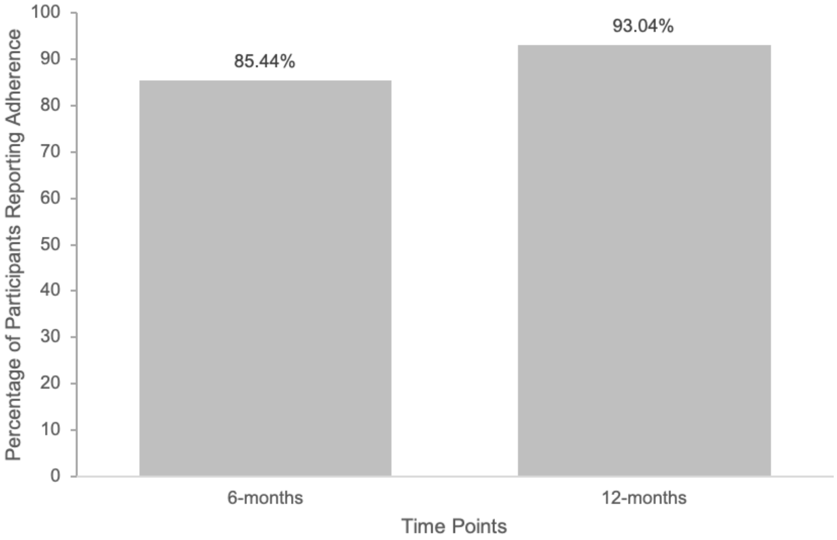
Note. N = 159.

Adherence to Scheduled/Recommended Tests

As shown in Figure 6.13, at 6-months, 85.40% of the 158 participants providing 6-month and 12-month data reported adhering to all scheduled and recommended tests. At 12-months, this decreased to 7.00% of participants. The proportion of adherent participants across time points was significantly different, $\chi^2(1) = 4.321$, p=.038. A greater proportion of participants were non-adherent to scheduled/recommended tests at 6-months than at 12-months.

Figure 6.13

Proportion of Participants Reporting Adherence to Tests Over the 12-Month Study Period



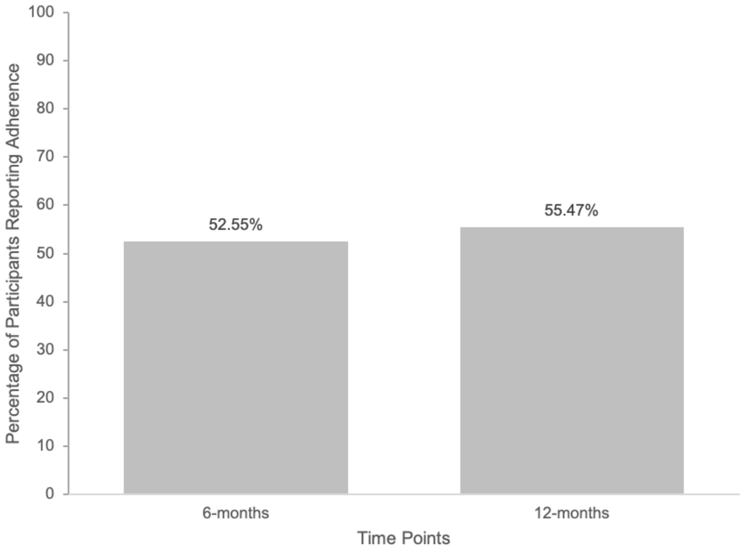
Note. N = 158.

Adherence to Scheduled/Recommended Ongoing or Adjuvant Treatment

Figure 6.14 presents participant reporting of adherence to scheduled/recommended treatments. At 6-months, only 52.55% of participants reported adherence to treatment recommendations; increasing slightly at 12-months, with 55.47% of participants reporting adherence. Among the 137 participants included in this analysis, the proportion of adherent versus non-adherent participants did not significantly differ across time points, $\chi^2(1) = .161$, p=.69.

Figure 6.14

Proportion of Participants Reporting Adherence to Treatment Over the 12-Month Study Period



Note. N = 137.

Summary of Study Findings

Table 6.6 provides a summary of the findings with respect to changes in health behaviours over the 12-month period following attendance at a major centre for cancer treatment/care. While participants show improvement in a number of health behaviours at the 6-month mark (BMI, smoking, alcohol consumption and hazardous drinking), by 12-months most of these behaviours have returned to baseline levels.

Table 6.6

Summary of Changes in Health Behaviours Over the 12-Month Study Period

Health Behaviours	Mean Sample Value			Change from Baseline to 12-months
	Baseline	6-months	12-months	
BMI	27.33	26.82	26.83	-.50
Statistical Change		decrease	no change	decrease
Fruit Servings	1.77	1.91	1.91	.14
Statistical Change		no change	no change	no change
Vegetable Servings	2.69	2.42	2.67	-.02
Statistical Change		decrease	increase	no change
Smoking	22.22%	14.20%	20.37%	-1.85%
Statistical Change		decrease	increase	no change
Alcohol (AUDIT-C)	2.91	2.41	2.41	-.5
Statistical Change		decrease	no change	decrease
Hazardous Drinking	30.87%	23.49%	28.19%	-2.68%
Statistical Change		decrease	no change	no change
Exercise (GSLT)	21.49	18.73	18.63	-2.86
Statistical Change		no change	no change	no change

With respect to adherence to clinical management regimes, adherence to scheduled and/or recommended appointments was very high at both 6-months and 12-months follow up. Adherence to scheduled and/or recommended tests increased significantly between 6- and 12-months, although was relatively high at both time points. Adherence to scheduled and/or recommended treatment was low at both 6- and 12-months. A summary of these findings can be seen in Table 6.7.

Table 6.7

Summary of Changes in Participant Adherence to Scheduled and/or Recommended Follow-up Care Over the 12-Month Study Period

	Self-Reported Adherence		Change in Adherence
Follow-up Care	6-months	12-months	
Appointments	96.86%	98.11%	1.25%
Not Applicable	1 (0.60%)	4 (2.50%)	no change
Tests	85.40%	93.00%	7.60%
Not Applicable	14 (8.90%)	17 (10.80%)	increase
Treatment	52.55%	55.47%	2.92%
Not Applicable	21 (15.30%)	27 (19.70%)	no change

Discussion

The primary aim of Study 3 (Chapter 6) was to examine participants' health behaviours and adherence to medical management recommendations over the 12-month period following cancer treatment/care at a major centre; that is, how their health behaviours changed in the presence of a serious health threat. Specifically, it aimed to determine whether participants showed improvements in health-promoting lifestyle behaviours over the 12-month period, and to describe participant adherence to follow-up medical management activities during this time.

Health Behaviours Over the 12-month Study Period

Study 2 (Chapter 5) described the baseline profile of regional people living with cancer, and highlighted that this sample came into the CCQ lodges and cancer treatment centres with quite poor health profiles; they smoked, drank alcohol, were overweight/obese, and had nutritional and physical activity behaviours consistent with those reported for non-metropolitan Australians nation-wide (AIHW, 2019). The results of this study (Study 3) showed that participants were able to make some positive changes with respect to weight management, tobacco smoking, and alcohol consumption in the first six months after cancer treatment/care. Such positive changes are promising and provide hope for individuals in the cancer recovery process. These results are also consistent with the HBM (Rosenstock, 1966) which posits that the presence of a significant and severe health threat may provide impetus for health behaviour change and suggest that even those who experience a serious health threat from a position of demographic and health disadvantage can make positive health changes.

Unfortunately, despite a generally positive trend in health behaviour change in the first 6 months, by 12 months following cancer care, almost all health behaviours had returned to baseline levels. That is to say, smoking behaviours had increased significantly from 6- to

12-months, as did alcohol consumption and the proportion of participants engaging in hazardous levels of drinking. Although AUDIT-C scores for alcohol consumption showed a decrease overall from baseline to 12-months, the proportion of individuals engaging in hazardous levels of drinking did not change from baseline to 12-months, meaning that positive changes in hazardous drinking observed from baseline to 6-months were reversed from 6- to 12-months. Fruit consumption levels remained unchanged from 6- to 12-months, with no difference from baseline to 12-months.

Interestingly, the number of servings of vegetables consumed each day by participants reduced from baseline to 6-months. Although there are no general guidelines that discourage the consumption of vegetables throughout treatment, it is possible that this decrease could be attributed to factors such as dietary requirements throughout the treatment and recovery process; for example, individuals may be unable to consume solid foods due to the side-effects of treatment, or may in general find eating more difficult (i.e. gastro-intestinal side-effects or general discomfort). The possibility that treatment- or recovery-related factors influencing lower consumption of vegetables at 6-months is further supported by the subsequent increase in vegetable consumption from 6- to 12-months. Similar factors may be at play for physical activity; it is likely that side effects of treatment such as reduced energy might impact on an individual's ability to engage in physical activity, although it would be hoped that by 12-months this would begin to diminish for at least some. It would be important for future research to identify the reasons for some of the changes in behaviours.

Further, even for those behaviours that had improved, many remained less than optimal for maximum treatment effectiveness, recovery, and long-term wellbeing. Such findings are not surprising and align with previous research showing improved, but still sub-optimal, engagement in cancer screening activities in survivor populations (Bellizzi et al., 2005; Cho et al., 2010; Eakin et al., 2007).

The effective ‘reversal’ of most positive changes in health-promoting behaviours from 6- to 12-months could potentially highlight an important intervention or support point. According to the HBM, a major component of health behaviour change is that the benefits of such change outweigh the barriers, in the context of a perceived health threat. Dixon and Welch (2000) found that regional individuals were more likely to see health services as curative in nature, and to associate the absence of disease with health. It is possible that, while individuals are likely to be acutely affected by immediate side-effects from treatment over the first 6 months, as these side-effects subside or lessen during recovery this may result in a lower perceived health threat and ultimately less emphasis on health behaviour change as critical. Likewise, as participants show positive health behaviour change in the immediate period following cancer treatment/care, ensuring adequate support, information, and rationale are provided for making and sustaining these changes beyond the immediate recovery period may assist in greater improvements, and longer-lasting behaviour change. It is, however, first important to attempt to uncover the factors driving the health behaviours in order to identify targets for intervention and change.

Adherence to Follow-up Clinical Management Recommendations

The findings with respect to self-reported adherence to follow-up appointments, tests, and treatments revealed very high adherence to follow-up appointments and tests, and alarmingly poor adherence to follow-up treatment recommendations. Regional people living with cancer face significant additional logistical challenges in accessing specialist services (Crawford-Williams et al., 2018; Ireland et al., 2017; Spees et al., 2015), and the findings of this study highlight specific areas where geographical factors may play a particularly critical role in the ongoing access to follow up treatments after the main receipt of cancer care.

Of particular concern, is the number of participants who reported not to have undertaken scheduled or recommended adjuvant treatment over the 12 months following receiving treatment/care in a major centre. Findings show that approximately 47% of participants at 6 months and 45% of participants at 12 months had not undertaken recommended treatment. Failure to undertake follow-up treatment may negatively impact cancer recovery, outcomes, and survival (Chia et al., 2006; Eakin et al., 2007; Fishbein et al., 2017; Gugssa Boru et al., 2017; Heckman, 2007; Khanam et al., 2014; Putman, 2004; Sabaté, 2003; Schectman et al., 2002; Schootman et al., 2013). There are a number of factors that could contribute to such a high prevalence of nonadherence. This sample comprises regional people living with cancer who travel to major centres in order to receive cancer treatment/care, and whose treatment team is therefore located in major centres. Thus, it is not unforeseeable that in many cases adjuvant treatments would also need to be completed in major centres. For example, while follow-up tests or appointments could potentially involve shorter travel distances to nearby centres with the necessary equipment that do not require individuals to stay in or near the facilities for an extended period of time, in many cases additional treatment is likely to involve both of these.

From a HBM perspective, engaging in shorter-length activities (such as appointments and tests), while not without logistical challenges (i.e. service accessibility, travel requirements, and service wait-times), may be perceived more achievable than additional treatment. Despite its obvious benefits, it is possible that the individual, familial, and financial impacts (among others) of travel and needing to access accommodation near treatment centres for a lengthy period of time, combined with the experience of treatment and recovery are perceived to be greater than the benefits of accessing such treatment. At least, this may serve to delay accessing adjuvant treatment until such time as it is no longer avoidable (Cramb et al., 2011; Strasser, 2003; Tropman et al., 2017; Weaver & Gjesfjeld, 2014). Further, Youl et al. (2019) reported that treatment decision-making for regional people living with cancer, who are broadly characterised as lower SES and with lower levels of education, is influenced by the financial costs of treatment and education levels (with lower levels of education associated with lower likelihood to engage in the treatment decision-making process). Thus, regional residency may disproportionately affect individuals with respect to adherence to adjuvant treatment, however the potential contributors to nonadherence are varied and not well understood within this context.

Summary

A healthy transition into survivorship is largely dependent on reducing health risks where possible to ensure positive recovery and long-term wellness. Engaging in healthy lifestyle behaviours and adhering to follow-up clinical management activities play a key role in this transition (Akinyemiju et al., 2017; Danaei et al., 2005; Wiley et al., 2015). This study provided an in-depth profile of engagement in health-promoting lifestyle behaviours and follow-up clinical management activities for a group of at-risk regional people living with cancer over the 12 months following cancer treatment/care.

While the findings of Study 2 (Chapter 5) suggested that individual characteristics played a limited role in driving engagement in health behaviours prior to cancer treatment/care, the role of such factors in shaping health behaviours in the presence of a cancer diagnosis is not yet understood. This study (Study 3) provided a profile of regional people living with cancer in the 12 months post-treatment, showing considerable positive change in health-promoting behaviours within the first 6 months, followed by a reversal of these changes in the second 6 months. While this highlighted potential areas for intervention, it is important that viable targets for intervention be identified. Study 4 (Chapter 7) will now examine the demographic, clinical, informational, and individual characteristic predictors of improvement in health-promoting behaviours at both 6- and 12-months post-treatment.

Chapter 7: Study 4 - Predictors of Engagement in Follow-Up Care and Health Behaviours for Regional People Living with Cancer

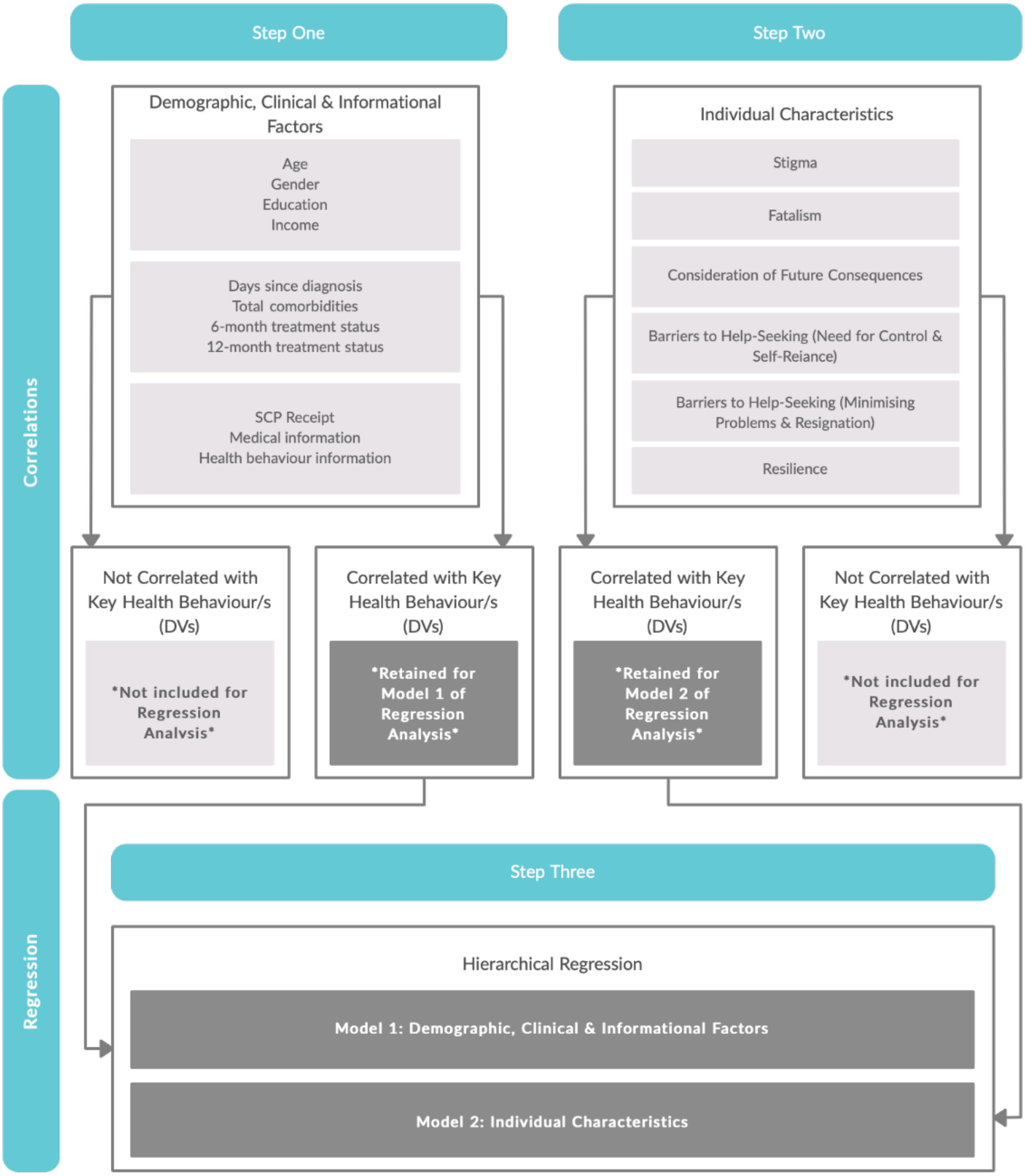
Study 3 (Chapter 6) provided an overview of the health-promoting behaviours and engagement in follow-up clinical management in the 12 months following receiving cancer treatment/care in a major centre. Overall, regional people living with cancer showed positive improvement in a number of health behaviours at 6-months, followed by a return to baseline, sub-optimal levels by 12-months. This chapter explores predictors of participant engagement in health-promoting behaviours at both 6- and 12-months post-treatment to determine which factors were driving health-promoting behaviours and adherence to follow-up clinical management. Demographic, clinical, informational, and individual characteristics obtained at baseline and engagement in health-promoting behaviours at 6- and 12-months were examined. Additionally, whether the participant had undergone any treatment within the previous 6 months was included under clinical factors, as the receipt of treatment may impact on subsequent health behaviours within the period. Specifically, this chapter aims to identify whether individual characteristics predicted engagement in health behaviours (following the participants' return home) above and beyond the impact of demographic, clinical, and informational factors, which have previously demonstrated to affect health behaviours.

Data Analytic Strategy

Predictors of the key health-promoting behaviours were examined at both 6- and 12-month follow-up time points. Given the large number of variables measured in this study, the same three-step process utilised in Chapter 5 was utilised to examine and analyse the data to minimise unnecessary analyses and Type 1 error. Each step is detailed below and summarised for clarity in Figure 7.1.

Figure 7.1

Flowchart of Analytical Process



Step One

First, a series of correlational analyses were conducted to examine the relationship between health behaviours at both 6- and 12-month time points and baseline demographic, clinical, and informational factors. Baseline demographic, clinical, and informational factors that were significantly correlated with any of the health behaviour dependent variables were selected for inclusion in Model 1 of the regression analyses. Variables were only carried through for a regression using the health behaviour dependent variable with which they were correlated. Any demographic, clinical, and informational variables that were not significantly correlated with health behaviours at 6- and 12-month time points were not examined further.

Step Two

Second, the relationship between individual characteristics (stigma, fatalism, consideration of future consequences, barriers to help-seeking, and resilience) and health behaviours were also examined via correlational analysis. Those individual characteristics which were significantly related to any of the health behaviour dependent variables were selected for inclusion in Model 2 of the regression analyses. Any individual characteristics that were not significantly related to health behaviours at 6- and 12-month time points were not examined further.

Step Three

Third, individual hierarchical regression analyses were conducted for all health behaviours that showed significant relationships with any of the individual characteristic predictor variables. This analysis was conducted for each health behaviour dependent variable separately. For these analyses, any significantly correlated demographic, clinical, and informational factors were entered at Model 1, and any significantly correlated individual characteristics were added individually at Model 2. For any health behaviour in which there were no significantly correlated demographic, clinical, or informational variables, but individual characteristics were significantly correlated, a standard linear regression was conducted with only one model for individual characteristics. Where there were multiple individual characteristics significantly correlated with a single health behaviour, these were entered in separate regression analyses to allow an exploration of the independent effects of each individual characteristic variable. Hierarchical multiple regression analyses were conducted for continuous health behaviour variables, and binomial logistic regression analyses were conducted for dichotomous variables.

Associations Between Baseline Demographic, Clinical and Informational Factors and Health Behaviours at 6-months

Step One

A series of correlational analyses were conducted to examine associations between demographic, clinical, and informational factors and key health behaviours. As shown in Table 7.1, age, gender, education, total comorbidities, and 6-month treatment status all showed significant associations with key health behaviours at 6-months. Income, days since diagnosis, and variables concerning receipt of health-related information were not significantly correlated with any health behaviours at 6-months. A summary of relationships and factors carried forward to regression analyses is provided in Table 7.2. In particular, weak to moderate, positive correlations were identified between gender, and education and several health behaviours (smoking, alcohol consumption, consumption of fruit, consumption of vegetables, exercise, and adherence to treatment).

Table 7.1

Summary of Correlations Between Health Behaviours, Demographics, Clinical Characteristics and Receipt of Information at 6 Months

Variable	Age^{a,b}	Gender^{b,d}	Education ^{c,e}	Income^{b,d}	Days Since Diagnosis^{a,b}	Total Comorbidities^{a,b}	6-month Treatment^{b,d}	Received SCP^{b,d}	Received medical information^{b,d}	Received behavioural information^{b,d}
BMI	-.057	.125	.071	.063	-.100	.060	-.120	.098	.015	-.110
Audit C	.053	-.298***	.123	.053	-.021	-.206***	-.090	.004	-.084	-.004
Smoking	-.034	-.138	-.179*	-.088	.075	.036	-.033	-.100	.003	.081
Fruit	.092	.164*	-.015	-.060	.066	.040	-.013	.008	.024	-.086
Veg	.141*	.160*	.108	.078	-.077	-.012	-.095	.075	-.094	-.042
GSLT	-.062	-.057	.212***	-.061	-.017	-.130	-.022	-.070	-.010	-.100
Appointment Adherence	.026	.099	-.011	.059	-.009	.024	-.009	-.007	-.011	.067
Test Adherence	.028	.061	.029	-.009	.044	-.005	.160*	-.130	.059	.078
Treatment Adherence	-.045	.196***	.006	-.029	-.142	.066	.332***	-.010	-.015	.045

Note. $^{***}p < .001$, $^{*}p < .05$, ^{a}Pearson's correlation, ^{b}Point-biserial correlation, ^{c}Spearman's correlation, ^{d}Fisher-Exact Test, ^{e}Rank-biserial correlation

Table 7.2

Summary of Significantly Correlated Demographic, Clinical and Informational Variables with 6-month Health Behaviours

Health Behaviour	Demographic Variables	Clinical Variables	Informational Variables
BMI	-	-	-
Audit C	Gender	Total Comorbidities	-
Smoking	Education	-	-
Fruit	Gender	-	-
Veg	Age, Gender	-	-
GSLT	Education	-	-
Appointment Adherence	-	-	-
Test Adherence	-	6-month Treatment	-
Treatment Adherence	Gender	6-month Treatment	-

Step Two

Second, the correlational relationships between 6-month health behaviours and individual characteristic factors were examined and are summarised in Table 7.3 and Table 7.4. Significant associations between individual characteristics and specific health behaviours were identified for fatalism, consideration of future consequences, and the two measures representing barriers to help-seeking (need for control and self-reliance, and minimising problems and resignation). There were no significant associations for stigma or resilience with any of the 6-month health behaviours. Specifically, there were weak, negative associations between the need for control and self-reliance and fruit consumption and vegetable consumption (both the need for control and self-reliance and minimising problems and resignation). Weak, positive associations were identified between the need for control and self-reliance and smoking, and fatalism and smoking. Weak to moderate positive associations were identified between consideration of future consequences and vegetable consumption.

Table 7.3

Summary of Correlations Between Health Behaviours and Individual Characteristics at 6 Months

Variable	Stigma[a,b]	Fatalism[a,b]	Consideration of Future Consequences[a,b]	Need for Control & Self-Reliance [a,b]	Minimising Problems & Resignation [a,b]	Resilience[a,b]
BMI	.034	.038	-.007	-.077	-.009	.084
Audit C	.020	.022	.043	.031	.120	.034
Smoking	.047	.184*	-.108	.147*	.116	.050
Fruit	.017	-.067	.140	-.145*	-.059	.013
Veg	-.033	-.040	.282***	-.221***	-.155*	-.025
GSLT	.098	-.118	.102	-.042	-.049	-.081
Appointment Adherence	-.011	.002	-.061	.019	.055	.096
Test Adherence	-.009	-.001	.064	-.068	.004	-.009
Treatment Adherence	.011	-.018	.064	-.056	.042	-.002

Note. $^{***}p < .001$, $^{*}p < .05$, [a]Pearson's correlation, [b]Point-biserial correlation

Table 7.4

Summary of Significantly Correlated Individual Characteristics with 6-month Health Behaviours

Health Behaviour	Individual Characteristics
BMI	-
Audit C	-
Smoking	Fatalism, Need for Control & Self-Reliance
Fruit	Need for Control & Self-Reliance
Veg	Consideration of Future Consequences, Need for Control & Self-Reliance, Minimising Problems & Resignation
GSLT	-
Appointment Adherence	-
Test Adherence	-
Treatment Adherence	-

Step Three

Finally, Table 7.5 summarises the regression analyses that were conducted based on the results of Step 1 and 2 findings. Regressions were conducted for all health behaviours measured at 6-months that showed significant correlations with either demographic, clinical, informational and at least one of the individual characteristics. Each regression analysis aimed to determine the predictive ability of individual characteristic factors on 6-month health behaviours above and beyond the impact of demographic, clinical, and informational factors. Each individual characteristic factor was entered into separate regression analyses to indicate its unique effect.

Table 7.5

Summary of Hierarchical Regression Analyses Conducted

Health Behaviour	Demographic, Clinical and Informational Variables entered (Model 1)	Individual Characteristics entered (Model 2)
Smoking	Education	Fatalism
Smoking	Education	Need for Control & Self-Reliance
Fruit Intake	Gender	Need for Control & Self-Reliance
Vegetable Intake	Age, Gender	Consideration of Future Consequences
Vegetable Intake	Age, Gender	Need for Control & Self-Reliance
Vegetable Intake	Age, Gender	Minimising Problems & Resignation

Smoking Behaviours at 6-month Follow-up

Table 7.6 presents the results of two separate hierarchical logistic regression analyses, examining the influence of fatalism and the need for control and self-reliance on smoking behaviours at 6-months, after accounting for education.

Table 7.6

Results of Regression Analyses Predicting Smoking at 6-months From Education, Fatalism and the Need for Control and Self-Reliance

Note. NCS = Need for Control and Self-Reliance

Variable	*b*	*SE (b)*	*p*	*Exp(B)* *[95% CI]*
		Fatalism (N=186)		
Model 1				
Education	-1.361	.215	.000	.256 [.168, .391]
Model 2				
Education	-.815	.237	.001	.443 [.278, .705]
Fatalism	-.037	.008	.000	.963 [.947, .979]
		Need for Control & Self-Reliance (N=201)		
Model 1				
Education	-1.409	.215	.000	.244 [.161, .372]
Model 2				
Education	-.896	.236	.000	.408 [.257, .647]
NCS	-.040	.009	.000	.961 [.943, .978]

Note. NCS = Need for Control and Self-Reliance

Fatalism. Together, education and fatalism predicted smoking behaviour at 6-months with 86.00% accuracy, $\chi 2$ ($df = 2$, $N = 186$) = 101.330, $p<.001$, Cox and Snell $R^2 = .420$, Nagelkerke $R^2 = .560$. The addition of fatalism to the model improved prediction, $\chi 2$ ($df = 1$, $N = 186$) = 23.622, $p<.001$. As fatalism increased, the likelihood of engaging in smoking at 6-month follow-up decreased by 3.70%.

Need for Control and Self-Reliance. Likewise, education and the need for control and self-reliance also significantly predicted smoking behaviour at 6-months with 86.10% accuracy, $\chi 2$ ($df = 2$, $N = 201$) = 109.485, $p<.001$, Cox and Snell $R^2 = .420$, Nagelkerke $R^2 = .560$. The addition of the need for control and self-reliance to the model improved prediction $\chi 2$ ($df = 1$, $N = 201$) = 21.984, $p<.001$. As the need for control and self-reliance increased, the likelihood of engaging in smoking at 6-month follow-up decreased by 3.90%.

Daily Fruit Intake at 6-months

Need for Control and Self-Reliance. Hierarchical linear regression was conducted for the prediction of daily fruit intake at 6-month follow-up, with results presented in Table 7.7. On its own in Model 1, gender accounted for 3.40% of the variance in 6-month daily fruit intake, such that females were more likely to consume servings of fruit than males, $R^2 = .034$, $F(1,197) = 6.983$, $p = .009$. In Model 2, the combination of gender and the need for control and self-reliance was also a significant predictor, $R^2 = .053$, $F(2,196) = 5.446$, $p = .005$, explaining 5.30% of the variance. However, the need for control and self-reliance did not significantly add to the prediction of fruit intake, $\Delta R^2 = .018$, $\Delta F\ (1,196) = 3.810$, $p = .052$, meaning the need for control and self-reliance did not predict fruit intake at 6-month follow-up.

Table 7.7

Results of a Regression Analysis Predicting 6-month Fruit Intake From Gender and the Need for Control and Self-Reliance

Variable	*B* [95% CI]	*p*	β	sr^2
Model 1				
Gender	.377 [.096, .659]	.009	.185	.034
Model 2				
Gender	.368 [.088, .647]	.010	.180	.032
NCS	-.015 [-.029, .000]	.052	-.136	.018

Note. *N* = 199, NCS = Need for Control and Self-Reliance.

Daily Vegetable Intake at 6-month Follow-up

Consideration of Future Consequences. In Model 1 of the hierarchical linear regression analysis, age and gender accounted for 7.60% of the variance in 6-month daily vegetable intake, $R^2 = .076$, $F(2,184) = 7.553$, $p = .001$, such that older females were likely to consume greater quantities of vegetables than younger males. When consideration of future consequences was added to the regression at Model 2, it significantly added to the prediction ($\Delta R^2 = .144$, $\Delta F\ (1,183) = 17.741$, $p < .001$) with the overall model accounting for 15.80% of the variance in daily vegetable intake, $R^2 = .158$, $F(3,183) = 11.407$, $p<.001$. As can be seen in Table 7.8, age, gender, and consideration of future consequences each significantly predicted 6-month vegetable intake levels, with consideration of future consequences accounting for an 8.20% increase in variance. That is, those who were more likely to consider the future consequences of their behaviour were likely to consume greater amounts of vegetables.

Table 7.8

Results of Regression Analysis Predicting Vegetable Intake at 6-months From Age, Gender, Consideration of Future Consequences and Barriers to Help-Seeking

Variable	*B* [95% CI]	*p*	β	*sr*^{2}
	Consideration of Future Consequences (N=187)			
Model 1				
Age	.027 [.007, .046]	.007	.199	.038
Gender	.687 [.278, 1.096]	.001	.241	.055
Model 2				
Age	.028 [.010, .047]	.003	.211	.042
Gender	.647 [.255, 1.039]	.001	.227	.049
CFC	.054 [.029, .080]	.000	.286	.082
	Need for Control & Self-reliance (N=202)			
Model 1				
Age	.024 [.006, .043]	.010	.184	.032
Gender	.576 [.176, .976]	.005	.200	.038
Model 2				
Age	.023 [.005, .041]	.013	.173	.028
Gender	.551 [.158, .943]	.006	.191	.035
NCS	-.031[-.051, -.010]	.003	-.202	.041
	Minimising Problems & Resignation (N=202)			
Model 1				
Age	.024 [.006, .043]	.020	.184	.032
Gender	.576 [.176, .976]	.005	.200	.038
Model 2				
Age	.023 [.004, .041]	.025	.172	.028
Gender	.572[.174, .968]	.005	.199	.038
MPR	-.034 [-.068, -.001]	.046	-.138	.019

Note. CFC = Consideration of Future Consequences, NCS = Need for Control and Self-Reliance, MPR = Minimising Problems and Resignation

Barriers to Help-Seeking. In Model 1, age and gender accounted for 5.80% of the variance in vegetable intake, R^2= .058, $F(2,199) = 6.139$, p=.003. Older females were likely to consume greater quantities of vegetables than younger males.

Need for Control and Self-Reliance. In Model 2, the need for control and self-reliance added to the overall model's prediction (ΔR^2= .085, ΔF (1,198) = 8.951, p=.003), with the overall model accounting for 15.80% variance in vegetable intake levels, R^2= .158, F(3,198) = 7.240, p<.001. Those with higher levels of the need for control and self-reliance related to the need for control and self-reliance were likely to consume fewer vegetables than those with lower levels**.**

Minimising Problems and Resignation. When added in Model 2, minimising problems and resignation also added to the overall model's prediction (ΔR^2= .063, ΔF (1,198) = 4.029, p=.046), accounting for 7.70% of the variance in total, R^2= .077, F(3,198) = 5.498, p=.001. Specifically, those with higher levels of minimising problems and resignation were likely to consume fewer vegetables than those with lower levels.

Associations between Health Behaviours at 12-months and Demographic, Clinical and Informational Factors

The process adopted for the analysis of health behaviours at the 6-month follow-up time point was repeated for health behaviours measured at the 12-month follow-up time point.

Step One

A series of correlational analyses were conducted to examine associations between demographic, clinical, and informational factors and key health behaviours at 12-months (see Table 7.9 and Table 7.10). Significant associations were identified between a number of demographic and clinical factors (gender, education, days since diagnosis, and 6- and 12-month treatment status), and several health behaviours (alcohol consumption, smoking, vegetable consumption, exercise, appointment adherence, and treatment adherence). In particular, gender showed weak to moderate associations with both alcohol and vegetable consumption, and education showed a weak to moderate association with smoking and exercise. Days since diagnosis was moderately, negatively associated with appointment adherence. No informational factors were associated with any of the health behaviours at 12-months. Factors carried forward to regression analyses are summarised in Table 7.11.

Table 7.9

Summary of Correlations Between Health Behaviours, Demographics and Clinical Characteristics at 12 Months

Variable	Age[a,b]	Gender[b,d]	Education [c,e]	Income[b,d]	Days Since Diagnosis[a,b]	Total Comorbidities[a,b]	6-month Treatment[b,d]	12-month Treatment[b,d]
BMI	-.007	.127	.012	-.012	-.029	.120	-.135	-.015
Audit C	.034	-.285***	.069	.106	-.059	-.154	-.100	-.163*
Smoking	-.071	-.155	-.150*	.011	.031	.000	-.013	-.074
Fruit	.087	.127	.004	-.020	-.071	.055	.113	.015
Veg	.059	.290***	-.025	.083	-.114	.141	-.081	.087
GSLT	-.090	-.059	.253***	-.028	-.036	-.107	.097	-.055
Appointment Adherence	-.095	.120	-.049	-.002	-.292***	.059	.107	.114
Test Adherence	-.058	.049	.003	.023	-.010	.070	-.013	.108
Treatment Adherence	-.084	.151	-.072	-.006	-.147	.071	.189***	.272***

Note. $^{***}p < .001$, $^{*}p < .05$, [a]Pearson's correlation, [b]Point-biserial correlation, [c]Spearman's correlation, [d]Fisher-Exact Test, [e]Rank-biserial correlation

Table 7.10

Summary of Point-Biserial Correlations Between Health Behaviours and Receipt of Information at 12 Months

Variable	Received SCP at 6-months	Received SCP at 12-months	Received medical information at 6-months	Received medical information at 12-months	Received behaviour information at 6-months	Received behaviour information at 12-months
BMI	.066	-.021	-.018	-.067	-.003	-.076
Audit C	.059	-.004	-.089	-.074	.028	-.067
Smoking	-.121	-.119	.011	-.055	-.049	-.073
Fruit	.112	.010	-.017	-.046	-.033	-.041
Veg	.131	.084	-.105	-.005	-.035	-.051
GSLT	-.057	-.087	-.052	-.041	.031	-.016
Appointment Adherence	.069	.166	.048	.042	-.096	-.012
Test Adherence	.115	.132	-.004	.040	-.131	.046
Treatment Adherence	.073	.004	-.091	.092	-.136	-.035

Note. $^{***}p < .001$, $^{*}p < .05$

Table 7.11

Summary of Significantly Correlated Demographic, Clinical and Informational Variables with 12-month Health Behaviours

Health Behaviour	Demographic Variables	Clinical Variables	Informational Variables
BMI	-	-	-
Audit C	Gender	12-month treatment	-
Smoking	Education	-	-
Fruit	-	-	-
Veg	Gender	-	-
GSLT	Education	-	-
Appointment Adherence	-	Days since diagnosis	-
Test Adherence	-	-	-
Treatment Adherence	-	6-month treatment, 12-month treatment	-

Step Two

Second, the correlational relationships between health behaviours at 12-months and individual characteristics were examined and are summarised in Table 7.12 and Table 7.13. The need for control and self-reliance, fatalism, and consideration of future consequences each showed significant associations with key health behaviours, including smoking, exercise, and adherence to tests. There were no statistically significant associations between stigma, resilience, and minimising problems and resignation with health behaviours at 12-months. The need for control and self-reliance showed weak to moderate positive associations with smoking behaviour and weak to moderate negative associations with exercise. There was a weak to moderate negative association between fatalism and exercise, and a weak to moderate positive relationship between consideration of future consequences and test adherence.

Table 7.12

Summary of Correlations Between Health Behaviours and Individual Characteristics at 12 Months

Variable	Stigma^{a,b}	Fatalism^{a,b}	Consideration of Future Consequences^{a,b}	Need for Control & Self-Reliance ^{a,b}	Minimising Problems & Self-Reliance ^{a,b}	Resilience^{a,b}
BMI	.094	.106	.051	-.087	-.101	.065
Audit C	.006	-.017	.003	.013	.122	-.025
Smoking	-.014	.094	-.023	.154*	.147	-.026
Fruit	-.011	-.016	.078	-.131	-.087	-.030
Veg	-.050	.031	.148	-.062	-.015	-.064
GSLT	-.087	-.212***	.099	-.158*	-.121	-.118
Appointment Adherence	-.151	-.023	.074	-.118	-.130	.098
Test Adherence	.038	-.025	.160*	-.090	-.077	-.028
Treatment Adherence	-.007	.052	-.013	.125	.072	-.109

Note. $^{***}p < .001$, $^{*}p < .05$ ^{a}Pearson's correlation, ^{b}Point-biserial correlation

Table 7.13

Summary of Significantly Correlated Individual Characteristics with 12-month Health Behaviours

Health Behaviour	Individual Characteristics
BMI	-
Audit C	-
Smoking	Need for Control & Self-Reliance
Fruit	-
Veg	-
GSLT	Fatalism, Need for Control & Self-Reliance
Appointment Adherence	-
Test Adherence	Consideration of Future Consequences
Treatment Adherence	-

Step Three

Table 7.14 summarises the regression analyses that were conducted as a result of the findings in Step 1 and 2. Regressions were conducted for all health behaviours at 12-months that showed significant correlations with at least one individual characteristic. Each individual characteristic was entered into separate regression analyses to indicate its unique effect. Therefore, each regression analysis explored the predictive ability of each individual characteristic on health behaviours at 12-month follow-up, above and beyond the impact of any significantly correlated demographic, clinical and informational factors. Results of these analyses are presented below.

Table 7.14

Summary of Regression Analyses Conducted

Health Behaviour	Demographic, Clinical and Informational Variables (Model 1 Hierarchical Regression)	Individual Characteristics (Model 2 Hierarchical Regression)
Smoking	Education	Need for Control & Self-Reliance Fatalism
Exercise	Education	
	Education	Need for Control & Self-Reliance
Test Adherence	-	Consideration of Future Consequences

Smoking Behaviour at 12-month Follow-up

Need for Control and Self-Reliance. As shown in Table 7.15, education was entered at Model 1 of the analysis and was significant, accounting for 24.10% of the variance in smoking behaviours with 61.00% accuracy, χ^2 (df =1, N = 172) = 47.510, p<.001, Cox and Snell R^2 = .241, Nagelkerke R^2 = .322, , indicating that a higher level of education was associated with reduced likelihood of smoking at 12 months follow-up. In Model 2, need for control and self-reliance was added to the model, significantly improving the prediction of smoking behaviour by 3.20%, χ^2 (df =1, N = 172) = 7.362, p=.007. The overall model was significant, accounting for 27.30% of the variance and 78.50% accuracy, χ^2 (df =2, N = 172)

= 54.872, p=.007, Cox and Snell R^2 = .273, Nagelkerke R^2 = .364. As levels of the need for control and self-reliance increase, participants were 2.40% less likely to smoke.

Table 7.15

Results of Regression Analysis Predicting Smoking at 12 Months From Education and Need for Control and Self-Reliance

Variable	*b*	*SE (b)*	*p*	*Exp(B)* *[95% CI]*
Model 1				
Education	-.924	.160	.000	.397 [.290, .543]
Model 2				
Education	-.630	.191	.001	.533 [.366, .775]
NCS	-.024	.009	.009	.976 [.959, .994]

Note. N = 172, NCS = Need for Control and Self-Reliance

Exercise Levels at 12-month Follow-up

Fatalism. In Model 1 of the hierarchical linear regression analysis, education accounted for 4.60% of the variance in exercise levels at 12-months, R2= .046, F(1,151) = 7.201, p=.008, such that participants with higher levels of education were more likely to participate in exercise. The addition of fatalism in Model 2 did not significantly add to the prediction of exercise (***Δ***R2= .009, ***Δ***F (1,150) = 1.360, p=.25), meaning fatalism did not predict exercise levels at 12-month follow-up.

Need for Control and Self-Reliance. In Model 1, education accounted for 5.90% of the variance in exercise levels, R2= .059, F(1,164) = 10.241, p=.002, in that those with higher levels of education were more likely to engage in exercise. With the addition of the need for control and self-reliance in Model 2, the overall model was significant, R2= .066, F(2,163) = 5.760, p=.001. However, the need for control and self-reliance subscale did not significantly improve the overall model's prediction of exercise levels, ***Δ***R2= .007, ***Δ***F (1,163) = 1.263, p=.263, meaning that the need for control and self-reliance did not predict exercise levels at

12-month follow-up. Results of the two hierarchical multiple regression analyses are provided in Table 7.16.

Table 7.16

Results of Regression Analysis Predicting Exercise at 12 Months From Education, Fatalism and the Need for Control and Self-Reliance

Variable	*B* [95% CI]	*p*	β	sr^2
	Fatalism (N=153)			
Model 1				
Education	6.326 [1.668, 10.985]	.008	.213	.045
Model 2				
Education	5.890 [1.298, 16.128]	.022	.199	.038
Fatalism	-.293 [-.788, .203]	.250	-.094	.009
	Need for Control & Self-reliance (N=166)			
Model 1				
Education	7.313 [2.801, 11.824]	.002	.242	.059
Model 2				
Education	7.124 [2.603, 11.645]	.002	.236	.056
NCS	-.258 [-.710, .195]	.263	-.085	.007

Note. NCS = Need for Control and Self-Reliance

Adherence to Tests at 12-month Follow-up

Consideration of Future Consequences. As no demographic, clinical, or informational factors were correlated with test adherence behaviours, a standard binary logistic regression analysis was conducted with consideration of future consequences as the only predictor in the model. The omnibus model was not significant, $\chi 2$ (*df* = 1, N = 156) = 1.519, *p*=.22 meaning that consideration of future consequences did not predict adherence to tests at 12-month follow-up, *Exp(B)* [95% *CI*] = 1.005 [.997, 1.013], *b* = .005, *SE (b)* = .004, *p*=.219.

Summary of Study Findings

To summarise the findings of this study, Table 7.17 provides details of all predictive relationships identified. As can be seen in the table, only smoking and vegetable consumption were predicted by individual characteristics at 6-months, and only smoking at 12-months. The most common predictor of health behaviours across time points was barriers to help-seeking (the need for control and self-reliance and minimising problems and resignation). There were no individual characteristic predictors of adherence to clinical management recommendations.

Table 7.17

Summary of Identified Predictors of 6- and 12-Month Post-Treatment Health Behaviours

Health Behaviour	Demographic, Clinical and Informational Predictors	Individual Characteristic Predictors	Direction of Relationship
6-Month Predictors			
Smoking	Education	Fatalism	↑ fatalism = ↑ smoking
Smoking	Education	NCS	↑ NCS = ↑ smoking
Vegetables	Age, Gender	CFC	↑ CFC = ↑ servings
Vegetables	Age, Gender	NCS	↑ NCS = ↓ servings
Vegetables	Age, Gender	MPR	↑ MPR = ↓ servings
12-Month Predictors			
Smoking	Education	NCS	↑ NCS = ↓ smoking

Note. NCS = Need for Control and Self-Reliance, MPR = Minimising Problems and Resignation, CFC = Consideration of Future Consequences, ↑ = increase, ↓ = decrease.

Discussion

Study 4 (Chapter 7) aimed to identify the role of individual characteristics on engagement in follow-up care and health-promoting lifestyle behaviours of regional people living with cancer following cancer treatment/care at a major centre. In particular, it sought to determine whether individual characteristics predicted engagement in follow-up cancer care and health-promoting lifestyle behaviours above and beyond the influence of demographic, clinical, and informational factors. Given that regional populations are frequently distinguished from their metropolitan counterparts based on such characteristics as independence, self-reliance, fatalism and resilience (Bettencourt et al., 208; Cloke &

Milbourne, 1992; Strasser, 2003), and evidence supports that these same characteristics play an influential role in protective health behaviour engagement more broadly (LaToya et al., 2002), it is plausible that they may also play a role in health behaviours during cancer survivorship. Although, this has not been explicitly examined to date.

The findings of this study show limited support for the role of individual characteristics in post-treatment behaviours for regional people living with cancer who seek treatment/care in major centres. For smoking, the strongest relationship between individual characteristics and health-promoting behaviours existed with respect to barriers to help-seeking (specifically the need for control and self-reliance), although the direction of relationships changed from 6- to 12-months. At 6-months, a greater need for control and self-reliance was predictive of higher smoking behaviours, while at 12-months it was predictive of smoking cessation. These inconsistent findings allude to either an insignificant role of barriers to help-seeking or point to a more complex understanding required of health behaviour engagement, and a likely interplay of multiple factors in determining factors associated with smoking or relationships with individual characteristics in regional people living with cancer (Crawford-Williams et al., 2018; Pozet et al., 2008; Underhill et al., 2009). It is possible that the distress of receiving a serious diagnosis such as cancer, amplified by the additional barriers experienced by regional populations in accessing specialist health services (McDougall et al., 2019; Myint et al., 2019; Youl et al., 2019), may play a modifying role on otherwise strong cues to action following a significant health threat (Rosenstock, 1966). Thus, individuals with a greater need for control and self-reliance may continue smoking behaviours as a means of stress relief.

In addition to barriers to help-seeking, fatalism was associated with a greater likelihood of smoking, but only at 6-months post-treatment. It is possible that an individual’s belief that they are unable to control or impact their health outcomes in the presence of a serious health threat may serve as a deterrent to positive health behaviours, especially addictive behaviours such as smoking (Niederdeppe & Levy, 2007). The relationship between fatalism and smoking however, no longer existed at the 12-month mark; perhaps a by-product of the reduction in immediate perceived health threat and a sense that the treatment had worked (Rosenstock, 1966). Once recovery had become apparent, it is possible that fatalism no longer played an important role in driving smoking behaviour.

In addition to smoking, individual characteristics predicted the self-reported average servings of vegetables consumed each day, but only at 6-months post-treatment. In the presence of a heightened perceived threat (a cancer diagnosis), regional people living with cancer who displayed greater consideration of future consequences were likely to consume a greater average number of servings of vegetables per day. Interestingly, this finding is in contrast to that of Study 2 (Chapter 5), where the average number of servings of vegetables across the sample decreased significantly from baseline to 6-months. Even in the face of potential treatment side effects, or whatever was leading to reduced vegetable intake for the rest of the sample, those high in consideration of future consequences were able to consume more vegetables. This highlights a possible target for intervention that may not be limited to vegetable intake.

Finally, greater levels of barriers to help-seeking (both a greater need for control and self-reliance, and greater tendency for minimising problems and resignation) also predicted the consumption of fewer servings of vegetables per day at 6-months. It is possible that a greater tendency to dismiss symptoms of illness or disease and to hold health as a lower priority may result in reduced prioritisation of healthy eating such as the consumption of vegetables.

Summary

The initial improvement in health-promoting behaviours at 6-months and subsequent decline by 12-months after cancer treatment/care (refer to Study 3, Chapter 6) highlighted potential moments for intervention for regional people living with cancer. However, viable targets for such intervention had not yet been identified. This study (Study 4) explored predictors of engagement in health behaviours at 6- and 12- months post cancer treatment/care at a major centre, with a primary focus on individual characteristics commonly associated with regional populations but not yet examined for their role in engagement in post-treatment health management.

The findings suggest that individual characteristics play a minimal role in predicting health behaviours in the 12 months following cancer treatment/care. While this sample of regional people living with cancer showed a clear pattern of improvement and decline over the 12 months, for the greater part, these changes in behaviour were not consistently driven by individual characteristics commonly associated with regional populations and may not represent a meaningful target for intervention. Chapter 8 will now provide an overall discussion of the findings from this program of research, including its strengths and limitations, implications, recommendations for future research and conclusions.

Chapter 8: Discussion and Conclusions

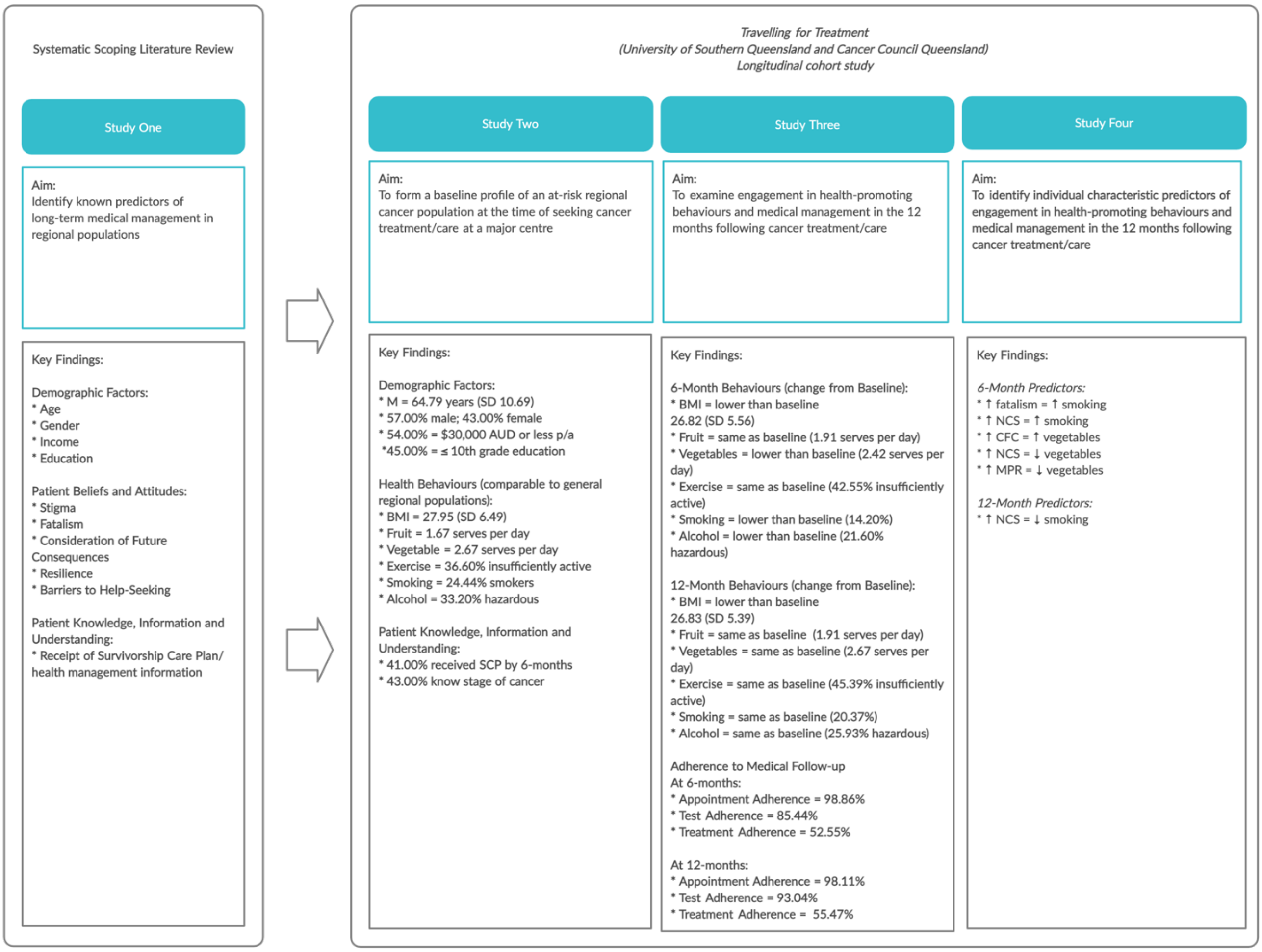
As highlighted throughout this thesis, engagement in health-promoting behaviours in the post-treatment period, including healthy lifestyle behaviours and ongoing medical management, play an essential role in treatment success, optimal recovery, and the long-term wellbeing of individuals with a cancer diagnosis. However, there is currently a limited understanding of how people living with cancer engage with these behaviours during the survivorship period, especially within the context of regional living. Regional people living with cancer are particularly vulnerable to poor cancer outcomes (Cancer Council Queensland, 2018; Cramb et al., 2011; Duncan et al., 2019;Hartley, 2004; Phillips, 2009; Pozet et al., 2008), yet the key drivers of this health disparity are not fully understood, nor is it well understood what happens for them following treatment. This program of research examined a group of at-risk regional people living with cancer in Queensland, Australia from the time of seeking cancer treatment/care at a major centre and for a period of 12 months following the participants' return home to regional areas. In doing so, this research developed an in-depth profile of these individuals with respect to demographic, clinical, and individual characteristics, as well as the health-promoting behaviours and receipt of health information (i.e. receipt of a SCP) of this group of regional people living with cancer when first entering the study (and treatment) and over the 12 month follow-up period. More importantly, this research examined whether demographic, clinical, individual, or informational factors acted as predictors of engagement in health-promoting behaviours during the post-treatment survivorship period for regional people living with cancer. In doing so, it aimed to identify potential areas for effective intervention for improving these behaviours for this at-risk population. This chapter provides an overall discussion and interpretation of the findings of the program of research. A summary of the main takeaways from each study will be presented, followed by a broader interpretation of the findings. The strengths and limitations of this research will then be discussed, in addition to the implications of the research and future directions.

Summary of Main Findings

As detailed in Chapter 2 and summarised in Figure 8.1, this thesis comprised of four studies: a systematic scoping literature review, and three studies conducted within the Travelling for Treatment longitudinal cohort study. The key findings for each of these studies are summarised in Figure 8.1 and below.

Figure 8.1

Summary of Study Aims and Key Findings within this Program of Research



Systematic Scoping Literature Review

Study One

Aim:
Identify known predictors of long-term medical management in regional populations

Key Findings:

Demographic Factors:
* Age
* Gender
* Income
* Education

Patient Beliefs and Attitudes:
* Stigma
* Fatalism
* Consideration of Future Consequences
* Resilience
* Barriers to Help-Seeking

Patient Knowledge, Information and Understanding:
* Receipt of Survivorship Care Plan/ health management information

Travelling for Treatment
(University of Southern Queensland and Cancer Council Queensland)
Longitudinal cohort study

Study Two

Aim:
To form a baseline profile of an at-risk regional cancer population at the time of seeking cancer treatment/care at a major centre

Key Findings:

Demographic Factors:
* M = 64.79 years (SD 10.69)
* 57.00% male; 43.00% female
* 54.00% = $30,000 AUD or less p/a
*45.00% = ≤ 10th grade education

Health Behaviours (comparable to general regional populations):
* BMI = 27.95 (SD 6.49)
* Fruit = 1.67 serves per day
* Vegetable = 2.67 serves per day
* Exercise = 36.60% insufficiently active
* Smoking = 24.44% smokers
* Alcohol = 33.20% hazardous

Patient Knowledge, Information and Understanding:
* 41.00% received SCP by 6-months
* 43.00% know stage of cancer

Study Three

Aim:
To examine engagement in health-promoting behaviours and medical management in the 12 months following cancer treatment/care

Key Findings:

6-Month Behaviours (change from Baseline):
* BMI = lower than baseline 26.82 (SD 5.56)
* Fruit = same as baseline (1.91 serves per day)
* Vegetables = lower than baseline (2.42 serves per day)
* Exercise = same as baseline (42.55% insufficiently active)
* Smoking = lower than baseline (14.20%)
* Alcohol = lower than baseline (21.60% hazardous)

12-Month Behaviours (change from Baseline):
* BMI = lower than baseline 26.83 (SD 5.39)
* Fruit = same as baseline (1.91 serves per day)
* Vegetables = same as baseline (2.67 serves per day)
* Exercise = same as baseline (45.39% insufficiently active)
* Smoking = same as baseline (20.37%)
* Alcohol = same as baseline (25.93% hazardous)

Adherence to Medical Follow-up
At 6-months:
* Appointment Adherence = 98.86%
* Test Adherence = 85.44%
* Treatment Adherence = 52.55%

At 12-months:
* Appointment Adherence = 98.11%
* Test Adherence = 93.04%
* Treatment Adherence = 55.47%

Study Four

Aim:
To identify individual characteristic predictors of engagement in health-promoting behaviours and medical management in the 12 months following cancer treatment/care

Key Findings:

6-Month Predictors:
* ↑ fatalism = ↑ smoking
* ↑ NCS = ↑ smoking
* ↑ CFC = ↑ vegetables
* ↑ NCS = ↓ vegetables
* ↑ MPR = ↓ vegetables

12-Month Predictors:
* ↑ NCS = ↓ smoking

The scoping literature review (Study 1), described in Chapter 3, identified key gaps within the current literature relating to adherence to long-term medical management in regional chronic health populations, subsequently used to inform the remaining studies in this program of research. First, while patient attitudes and beliefs had been of particular interest to researchers, individual characteristics commonly cited as distinct to regional populations (such as stigma, fatalism, consideration of future consequences, attitudes towards help-seeking, and resilience) had not yet been examined for their role in adherence to long-term medical management for regional people. Additionally, patient knowledge, information, and understanding played a prominent role within the literature, highlighting the importance of receiving information and rationale for ongoing medical management. Thus, the results of this study supported the novel benefits of examining individual characteristics associated with regional populations in Study 2, 3 and 4, while also examining and accounting for key demographic factors (age, gender, income, education) and patient information (receipt of a SCP).

Study 2 aimed to understand the baseline profile of an at-risk regional cancer population at the time of seeking cancer treatment/care at a major centre; that is, to understand the starting point of this group with respect to health, socio-economic, and individual characteristics. Overall, participants were older with a low annual household income and just over one-third came from the areas with the lowest socio-economic advantage. Participants showed poor receipt of information/knowledge about their cancer diagnosis, with almost just over half of participants not aware of their cancer stage at diagnosis, and only around 40.00% reporting receipt of a SCP by 6 months post-treatment/care. In terms of health behaviours, participants showed patterns of poor weight management, high rates of hazardous drinking and smoking, poor nutrition, and insufficient physical activity levels at the time of seeking cancer treatment. Individual characteristics commonly considered to be prominent among regional populations (e.g. fatalism, barriers to help-seeking, resilience) played a very limited role in explaining health status and health behaviours at baseline. With an overall baseline profile that placed individuals at high risk of poor health outcomes more broadly, it was subsequently imperative to determine whether these behaviours improved following cancer diagnosis and treatment in Study 3.

Study 3 examined health behaviours, information receipt and engagement in follow-up medical care over the subsequent 12-months from baseline. It was positive to note some improvements in health behaviours, as recommended by governing bodies during the post-treatment period (ACSC, 2017; CCA, 2015), by the 6-month follow-up point (see Figure 8.1). Unfortunately though, by 12-month follow-up, almost all health behaviours had returned to unhealthy baseline levels, placing this group of already at-risk survivors at higher risk of poor outcomes. Also, while participants showed high levels of adherence to follow-up medical appointments and tests, only around half of the sample at both 6-months and 12-months reported having undergone additional recommended treatment. Thus, it was clear from Study 3 that many regional people living with cancer continued to display poor health behaviours and adherence to ongoing treatment over the 12-month period and were, therefore, at significant risk of poor cancer-related outcomes.

The final study (Study 4) examined whether individual characteristics commonly associated with regional populations were responsible for driving engagement in health-promoting behaviours and medical follow-up at both 6- and 12-months post-treatment/care. Overall, the examined individual characteristics had very little influence on the prediction of health-promoting behaviours and adherence to follow-up medical care in the post-treatment period. Only smoking and vegetable consumption were found to be predicted by individual characteristics, but these findings were inconsistent, and these behaviours were still problematic for this sample.

Overall Interpretation of the Findings

There were four main messages to be drawn from this program of research. These include discussion around health-promoting behaviours in regional cancer survivorship, adherence to follow-up clinical management, the role of individual characteristics in these behaviours, and the provision of information and SCPs.

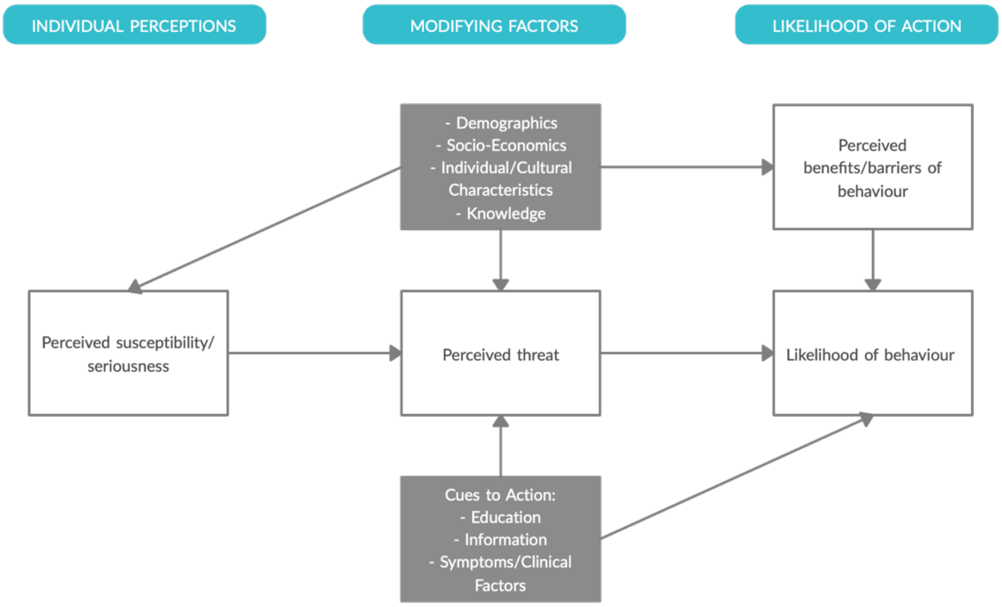
Health-Promoting Behaviours in Regional Cancer Post-Treatment Period

This program of research provided unique insight into the health-promoting behaviours of regional people living with cancer in the period immediately following a cancer diagnosis. To date, there is limited evidence available concerning engagement in these behaviours for this group. Still, comparisons can be made with both the general population and with other chronic health populations. Regional Australians generally show poor engagement in health-promoting lifestyle behaviours, with higher rates of overweight/obesity, smoking, hazardous alcohol consumption, poorer dietary intake, and lower levels of physical activity than their urban counterparts (AIHW, 2019). These behaviours have also been linked to an increased likelihood of poor health, higher rates of disability and death, and a shorter lifespan (AIHW, 2017). For individuals with a chronic health condition such as cancer, poor engagement in health-promoting lifestyle behaviours is of particular concern, as these individuals are already at significant health risk based on diagnosis. Unfortunately, evidence from regional populations with asthma and diabetes shows that regional people living with these conditions display poor engagement in the long-term management of their condition and subsequently experience poorer outcomes (Franks et al., 2005; Tan et al., 2016; Wan et al., 2007). Given that people living in regional areas experience significantly poorer cancer outcomes and survival than those living in major centres (Hartley, 2004; Phillips, 2009; Pozet et al., 2008), understanding whether engagement in health-promoting behaviours following a cancer diagnosis is also problematic for this population, and potentially placing regional people living with cancer at greater health risk, is a logical and important step in addressing disparities.

Consistent with the available literature, the findings of this research show that, at the time of cancer diagnosis and receipt of treatment/care in major centres, regional people living with cancer show similarly poor engagement in health-promoting behaviours as found in regional populations more broadly (AIHW, 2019). That is, they are not dissimilar in their health behaviours to non-cancer regional populations. As purported by the HBM (see Figure 8.2; Rosenstock, 1966) however, the threat of a cancer diagnosis appears to act as a ‘cue to action’, providing impetus for behaviour change in this group. Subsequently, in the 6 months immediately following treatment/care, participants do show some improvement in health-promoting behaviours, although many of these behaviours remain at sub-optimal levels (e.g. despite reductions in the number of drinks, almost one-quarter of participants were still drinking at hazardous levels).

Figure 8.2

Overview of the Health Belief Model (Rosenstock, 1966)



Unfortunately, in line with existing theoretical evidence highlighting the difficulties of maintaining health behaviour change (Kwasnicka et al., 2016), participants on average were able to make only small improvements in some key health behaviours at 6-months before a return to former (baseline) levels by 12-months. As can be seen in Figure 8.2, from an HBM perspective, this suggests that by 12-months post-treatment/care the immediate threat of the cancer diagnosis may have decreased to a point whereby it no longer serves as a strong ‘cue to action’ for continued behaviour change. When considering potential modifying factors at play according to the model, it is possible that the combination of the completion of initial treatment, reduction in specific symptoms or clinical indicators, the physical transition back to regional areas, and/or the gradual return to ‘normal life’ over the 12 month period signifies a reduced threat to the individual, thus reducing the likelihood of continued behaviour change. Additionally, the change in environment from major centres, where they receive ongoing support and encouragement to make necessary changes for optimal cancer outcomes, to their regional communities where support and accessibility is reduced, may create additional barriers to maintaining behavioural change.

The findings from this research confirm that health-promoting behaviours are, in fact, problematic within this group of already at-risk regional people living with cancer during the post-treatment period. It also highlights a potential missed opportunity to work towards achieving optimal cancer recovery and long-term wellbeing for these individuals, failing to capitalise on successful treatment/care through positive health-promoting behaviours. Subsequently, regional people living with cancer face long-term negative consequences that may impact their health outcomes.

Importantly, these findings highlight an opportunity for intervention. That is, the incentive for change following a cancer diagnosis provides an ideal opportunity to encourage and support individuals to make and maintain optimal positive behaviour change through targeted interventions in the immediate post-treatment period. However, the findings suggest that there is likely a complex set of moderating factors at play for regional people living with cancer and that interventions to increase health-promoting behaviours should not focus on modification of individual characteristics (such as fatalism, consideration of future consequences, stigma, resilience. and barriers to help-seeking) to promote and maintain behavioural changes long term. Instead, priority should be placed on ensuring individuals have access to the necessary resources and support to overcome barriers to engagement in positive health behaviours (Russell et al., 2019), beyond the period of initial treatment/care in major centres, as they transition back to regional areas.

Adherence to Follow-up Clinical Management

This program of research revealed that a concerning number of regional people living with cancer failed to adhere to recommended or scheduled ongoing/adjuvant treatment over the 12 months following initial cancer care. While self-reported adherence to follow-up appointments and tests was very high, just under half of the participants had not received further treatment as recommended by their treatment team. As previously discussed, failure to adhere to long-term management regimes, including ongoing treatment, reduces the clinical benefit gained from treatment, inhibits a positive cancer recovery and increases the risk of further complications (Sabaté, 2003; Spees et al., 2015; Wiley et al., 2015).

The fact that participants reported high adherence to appointments and tests shows their willingness to engage in follow-up care, further supported by their efforts to improve health-promoting behaviours despite a significant reduction in supports during their transition back to regional areas. In comparison, the low rates of adherence to treatment suggest that there are likely other important factors at play that serve to disrupt treatment adherence for this group specifically. This supports the findings in existing literature, that a complex relationship exists between multiple factors including the general health of individuals, as well as clinical characteristics of their diagnosis, system- and community-level factors, and geographic remoteness (Crawford-Williams et al., 2018; Ireland et al., 2017; Myint et al., 2019). As discussed in Chapter 6, given that many regional people living with cancer (such as those in this program of research) are required to travel to major centres for treatment, it is likely that the same treatment team would also conduct additional treatment within the same major centre. While follow-up appointments and tests could potentially be carried out at facilities closer to the individual’s home or could be completed in a single visit to the treatment centre, additional treatment is likely to require repeated visits or long-term stays nearby treatment facilities. Such requirements may have financial, familial, employment, and health implications, among many other potential impacts that deter them from undertaking this treatment. Indeed, such barriers to treatment have commonly been reported by regional individuals when seeking cancer treatment (Clavarino et al., 2002; Drury & Inma, 2010; Emery, et al., 2013; Segel & Lengerich, 2020; Spees et al., 2015), and it seems like they may also become relevant in follow-up treatment/care even after initial treatment has been received. This may be particularly relevant during the immediate post-treatment period where the individual may still be recovering financially from the initial costs of treatment and travelling for treatment which can be extensive. This may ultimately impact the long-term recovery of regional people living with cancer and should be considered in survivorship care planning. Alternatively, or additionally, system- and community-level factors such as service delays, wait-lists, community support services, and clinical factors such as prognosis may further complicate adjuvant treatment decision-making and warrant consideration when providing recommendation for follow-up tests and treatments (Gordon et al., 2009, Haigh et al., 2018). Closer examination of potential factors at play, specifically concerning receipt of adjuvant or ongoing cancer treatment for regional people living with cancer will be an important future step in addressing disparities in cancer outcomes.

The Role of Individual Characteristics in Health Behaviour

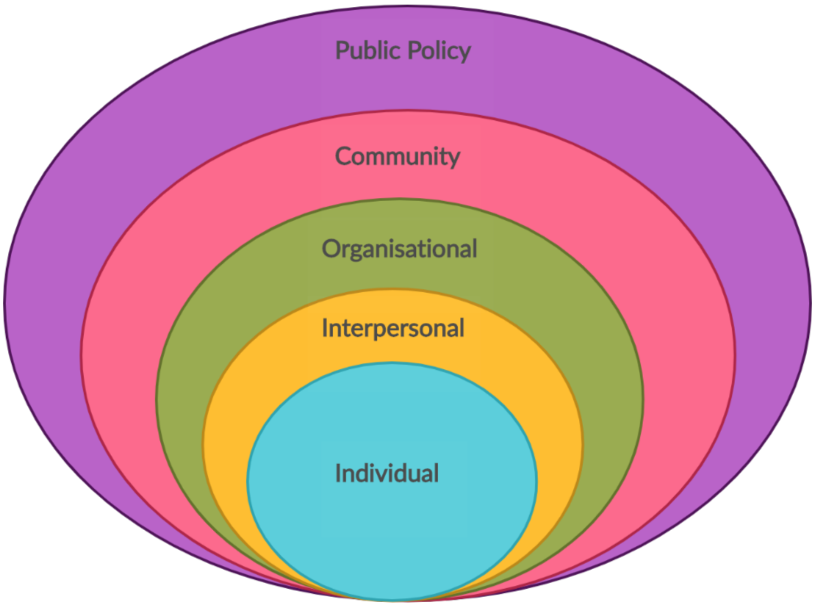
Evidence presented throughout Chapters 1,2, and 3 suggests that individual factors, such as patient attitudes and beliefs, are likely to play an important role in engagement to long-term health management for regional people living with a chronic health condition. As such, characteristics considered to be 'distinctly rural' (Bettencourt et al., 2007; Cloke & Milbourne, 1992; Dixon & Welch, 2000; Strasser, 2003; Weaver & Gjesfjeld, 2014) were examined within this context in an effort to identify whether these characteristics contribute to health behaviours in the regional cancer survivor context. Contrary to existing literature, these characteristics did not appear to play a significant role in engagement in health promoting behaviours in this program of research, despite their frequently-reported influence on general health help-seeking, and preventive health behaviours (Bettencourt et al., 2007; Cramb et al., 2011; Dixon & Welch, 2000; Strasser, 2003; Tropman et al., 2017; Weaver & Gjesfjeld, 2014). That is, this group of regional people living with cancer showed a willingness to engage in follow-up care and to make positive health behaviour changes in response to their cancer diagnosis, but – consistent with other existing literature - factors beyond individual characteristics appeared to have a greater impact on whether the individual was able to implement and carry out those behaviours (Crawford-Williams et al., 2018; Ireland et al., 2017; Myint et al., 2019).

From a theoretical perspective, the findings of this research point to other factors stemming from outside the individual that may be influencing their engagement in health-promoting behaviours and long-term medical management. The results suggest that addressing issues relating to post-treatment engagement in health-promoting behaviours and medical management may be better guided by models that adopt a broader approach to understanding and effecting health behaviour change, such as Bronfenbrenner's Socio-Ecological Model of Health (SEM; Bronfenbrenner, 1977). As presented in Figure 8.3, the

SEM suggests that an individual's behaviour is influenced by relationships between multiple levels of factors within the environment around them, including the individual, their relationships, their communities, and the systems and policies within which these exist.

Figure 8.3

Bronfenbrenner's (1977) Socio-Ecological Model of Health



While this program of research focused specifically on the individual-level factors of influence on health behaviour, the SEM, in conjunction with finding a limited role of individual characteristics on engagement in health-promoting behaviours and long-term medical management in the post-treatment period, suggests that effecting post-treatment health behaviour change and maintaining these changes long-term in regional people living with cancer will require a broader focus on the communities and systems within which regional people return to following treatment, rather than the individual themselves. This is important because it suggests that interventions that focus on individual characteristics as a target for behaviour change will likely have a limited impact on reducing the poor cancer outcomes and survival observed in this group. In other words, while these individual characteristics may shape rural people and distinguish them from their metropolitan counterparts in some ways, they do not necessarily shape their health management behaviours in the post-treatment period of cancer survivorship.

Information & Survivorship Care Plans

In addition to an in-depth examination of health management behaviours of regional people living with cancer, this program of research sought to quantify the receipt of information and, specifically, the receipt of SCPs by regional patients. After completing treatment and returning home to regional areas, the onus is typically on the regional individual to coordinate ongoing care, recognise, and advocate for support and to undertake an active role in monitoring signs and symptoms, making health-promoting changes in their behaviour, and adhering to health management regimes upon return to regional areas (Eakin et al., 2007). The scoping review, conducted in Study 1 of this research, found that patient understanding of their condition, their treatment/care needs, the risks of non-adherence, and the rationale for treatment were critical to positive engagement in health management activities for regional patients. Thus, the receipt of information contained within the SCP may play a crucial role in the regional individual's ability to undertake the necessary activities for optimal cancer recovery and long-term wellbeing (Lin et al., 2018). However, to date, little is known about the provision and uptake of these plans. Thus, this program of research provides essential knowledge of the current provision and uptake of the SCP in an at-risk regional cancer population receiving cancer treatment/care in a major centre.

This research highlighted the limited knowledge and understanding displayed by regional people living with cancer with respect to details of their cancer diagnosis and treatment/care, and the lack of receipt and/or understanding of this information via a SCP. Only 43.00% of participants were aware of their stage of cancer at diagnosis, and only 41.00% reported having received a SCP. Although the results of this research did not show a clear relationship between receipt of a SCP (or lack of) and subsequent health behaviours and adherence to clinical management, it is evident that a more comprehensive examination of the receipt and use of SCPs is critical in order to determine whether individuals recognise what this document is, understand the information provided (and that the information provided is useful to them) and can effectively utilise SCPs to assist with long-term management of their health. These findings align with those of a systematic review by Jacobsen et al (2018), which highlighted the lack of evidence with respect to health outcomes from SCP receipt and recommended that future research focus on ways to evaluate SCP efficacy. Based on the findings of this research, it appears that a large proportion of at-risk regional people living with cancer return to regional areas where they then also experience reduced access to their treatment team and supports received during treatment (Spees, et al., 2015), and the onus is on them to coordinate their ongoing care (Eakin et al., 2007), without access to comprehensive information needed to do so. The potential implications of this are enormous, and yet to be examined comprehensively.

Strengths and Limitations

This program of research is the first of its kind to provide an in-depth assessment of health management behaviours in a cohort of at-risk regional people actively dealing with a cancer diagnosis, treatment, and recovery. Such participants are both challenging to recruit and difficult to retain throughout this experience, thus making this a unique and valuable contribution to the understanding of the regional cancer journey. This study recruited participants via six separate CCQ lodges located across Queensland. The geographical diversity of this sample allows for greater confidence that the findings from this study can be generalised to a growing population of at-risk regional cancer survivors. The longitudinal design over three time points also strengthens the ability of the evidence to support causal conclusions regarding the role of individual characteristics on long-term cancer management; something that does not currently exist for regional cancer populations.

Further, this design has allowed for in-depth representation of a critical transitional time in the cancer journey for at-risk regional people living with cancer, facilitating the identification of key areas where improved supports and service provision for regional people are necessary. The larger sample size offers flexibility in testing and greater precision of parameter estimates, supporting the appropriateness of the findings to inform targeted intervention, and to provide the impetus for further research and/or policy change. Further, this study utilised self-report methods via interviews and questionnaires. This multi-method approach to data collection allowed for the examination of a large number of sociodemographic, patient-related characteristics, clinical characteristics, and informational factors, which contributed to a more in-depth analysis of the post-treatment experience. As a result, this study was able to examine the unique contribution of individual characteristics on engagement in post-treatment health management behaviours by first testing and controlling for other contributing factors.

Notwithstanding these strengths, there are some limitations to this program of research. First, while the inclusion of some objective measures of health behaviours, such as accelerometer data (to measure sedentary behaviours and physical activity) and Medicare data (to measure medical appointments, medications, and procedures) would further strengthen this research, it was not within the scope of this project. Additionally, in a sample of unwell individuals actively engaged in cancer diagnosis, treatment and recovery, already difficult to recruit and retain, and already engaging in intensive longitudinal data collection as part of the Travelling for Treatment program, the burden on patients to include these extra measures was considered too high.

Second, while self-reported data may be affected by issues of social-desirability, participants still reported less than optimal health behaviours across all timepoints. Therefore, if social-desirability were an issue, it would subsequently result in more conservative findings rather than inflation of findings. However, to minimise the likelihood of such problems, several approaches were implemented. Questions perceived by the research team to potentially incite socially desirable responses (such as measures of values, beliefs, and attitudes) were included in questionnaire format rather than within the interview. Participants were invited to complete the questionnaires within their own time and in an environment that they found comfortable, reducing any pressure to complete the questionnaire quickly or to perceive judgement from others while completing the questionnaire. Additionally, questions in both interviews and questionnaires were written and asked in neutral language wherever possible. Finally, interviewers were provided ongoing training throughout the recruitment period to ensure the use of non-judgemental visual and audible responses during interviews.

Third, it is important to consider that, while individual characteristics examined throughout this thesis largely showed to play a limited role in determining post-treatment health behaviours, it is possible that the experience of cancer diagnosis and treatment could influence these characteristics over time and as such, this may have affected the prediction of post-treatment behaviours in this study. In order to fully understand the role of individual characteristics (or lack thereof) in survivorship, these should be measured and monitored at multiple timepoints throughout the survivorship period. Such an approach would assist in determining if changes in individual characteristics brought about by the cancer experience alters its relationship to post-treatment health behaviours.

Implications and Future Directions

This program of research highlighted missed opportunities for intervention during the post-treatment period for regional people living with cancer, that could potentially play a significant role in reducing cancer disparities. First, the health behaviour profile of this group suggests that there is currently a significant, missed opportunity to assist regional people living with a cancer diagnosis in making greater behavioural health changes following cancer treatment/care, and importantly, in maintaining those behaviours over a longer period. In particular, participants show some improvements at 6-months post-treatment/care, suggesting that the ‘cue to action’ provided by a cancer diagnosis is an ideal time to capitalise on building more meaningful behaviour changes through additional support and/or intervention. Likewise, as the immediate threat of diagnosis weakens, individuals would benefit from continued support to prevent relapse to pre-cancer risky health behaviours. Interventions or support would be well targeted during this period. Of particular importance, however, the findings suggest that individual characteristics that are commonly used to describe regional populations and found to influence health help-seeking and preventive health behaviours, do not play a significant role in post-treatment behaviours for regional people living with cancer. Thus, interventions that focus on the individual (specifically on their values, attitudes, and beliefs) are unlikely to have a meaningful impact on post-treatment behaviours. In fact, these individuals display a willingness to engage in both positive health behaviour change and follow-up medical management, but this engagement appears to be impacted by a complex relationship of factors as they transition back to regional areas, that extend well beyond the individual. Therefore, any interventions seeking to improve post-treatment behaviours should focus on addressing the critical differences in health settings between major centres and rural communities through systems-based approaches.

Specifically, this body of work highlights the need to consider the ways in which health and support services are provided to regional people living with cancer in the post-treatment period. While they have access to a broad range of support services while in major centres for treatment/care, attention must be directed towards extending these services into the post-treatment period as they transition outside of the urbanised healthcare setting and return to their regional communities. Efforts must be directed to finding ways to optimise information provision, and to ensure continued support through linking to local community services and clinicians, to enhance engagement in optimal health-promoting behaviours, and to support continued engagement in follow-up cancer care in the long term.

These findings also provide the impetus for two key areas of future research. First, if geographical disparities in cancer outcomes and survival are to be successfully addressed, it is vital that future research addresses health behaviours in the post-treatment period, and specifically the factors influencing poor health behaviours and adherence to ongoing/adjuvant treatment in regional cancer populations. Failure to undertake further treatment, or significant delays in undertaking further treatment, will significantly impact on cancer outcomes, wellbeing, and survival. Identifying key driving factors and providing evidence that may inform intervention, policy, or systemic change should be prioritised. As discussed earlier, such intervention would benefit from a system- or community-level approach as opposed to an individual-level approach. It may take the form of community health activities, community development and increasing awareness of the challenges faced by regional cancer survivors in the post-treatment period.

Second, issues around knowledge, information, and understanding were repeatedly identified throughout this thesis, particularly concerning SCPs. Future research should seek to examine not only whether people receive a SCP, but whether they understand what this document is, and whether this information assists them in the coordination of their ongoing care and optimal recovery, especially when returning to regional areas. The successful implementation of these plans is especially important for regional people, who are reliant upon this information to play an active role in their cancer recovery and long-term wellbeing. However, regional people may require additional components within the SCP to ensure a positive transition upon returning home. This may include, for example, information on how to access available resources and support services within their communities and/or details for local contacts who can assist them in obtaining the information and knowledge required for a healthy transition. A more thorough understanding of how these plans are currently being utilised may provide an opportunity to identify ways to optimise these plans for regional people and to facilitate more effective implementation into routine care. Addressing these issues may improve patient knowledge and understanding of what is required for optimal recovery and wellbeing in survivorship.

Conclusions

This program of research has contributed to the knowledge and understanding of engagement in health management behaviours for regional people living with cancer in the 12 months following cancer diagnosis and receiving treatment/care in a major centre. Overall, regional people living with cancer who receive treatment/care in major centres before returning to regional areas show some improvement in health behaviours in the short-term but are unable to maintain these positive changes long-term. Likewise, they show positive engagement in follow-up medical appointments and tests but struggle to complete follow-up treatment – an area of great concern that should urgently be examined further. It is clear that regional people living with cancer are willing to engage in post-treatment health management, however, appear to lack the necessary knowledge, information, and understanding to engage properly; and support required to make and maintain meaningful change and thus to engage in all essential components of survivorship care outlined by the IoM (2006). Future research must focus on identifying ways to extend support services beyond initial treatment/care, assisting regional people living with cancer to transition into survivorship positively.

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Appendix A: Scoping Review Protocol

OVERVIEW

Regional Queenslanders are 11-31% more likely to die within 5 years of cancer diagnosis than the Queensland average and this pattern of variation appears similar nationally (Cramb, Mengersen, & Baade, 2011). Additionally, regional Queenslanders tend to show increased rates of problematic lifestyle behaviours that might represent potential problems in adherence to clinical management regimes associated with improved survival after treatment (Cramb, Mengersen, & Baade, 2011; NHPA, 2013).

Clinical management regimes incorporate recommendations for health behaviours and medical activities known to promote positive recovery and to protect against future sequelae (Wiley, Kinnane, Piper, Jefford & Nolte, 2015). Adherence to these behaviours is considered so important in maximising positive outcomes for survivors and preventing relapse or further deterioration in health that they have been integrated into Australian NHMRC directives for cancer care and Cancer Survivorship Care Plans (Tan et al., 2016).

For the purposes of this review, formal clinical management behaviours refer to medical-related recommended behaviours as outlined in standard Cancer Survivorship Care Plan guidelines (Wiley et al., 2015). This includes follow-up medical and/or specialist appointments, procedures, screening and adjuvant treatments or medications that are recommended during the post-treatment phase of the cancer experience. Informal clinical management behaviours refer to healthy lifestyle behaviours as recommended in the post-treatment phase by the World Health Organization (2017) and incorporated into standard Cancer Survivorship Care Plan guidelines. The five key healthy lifestyle behaviour recommendations are maintaining a healthy weight & BMI, engaging in regular physical activity, healthy dietary intake (fruit & vegetable intake), limiting alcohol intake and being a non-smoker.

The aim of this study is to review potential factors associated with engagement in formal and informal clinical management regimes among regional cancer populations. As insufficient evidence was identified specifically within regional cancer populations, this study will aim to integrate evidence across other chronic conditions to highlight potential factors that may be influential within regional cancer populations.

METHODS

Review Design

This review employs the PRISMA-ScR methodological framework for the conduct of systematic scoping reviews.

Research Question

What factors have been identified to impact on adherence to medical regimes and healthy lifestyle behaviours in regional populations with chronic health conditions?

Search Strategy

Search Phrases

Boolean Search Phrase:

TITLE / KEYWORDS (engage* OR participat* OR adher* OR continu* OR commit* OR compli*)

AND

TITLE / ABSTRACT / KEYWORDS (health behav* OR “healthy lifestyle” OR weight OR “weight management” OR bmi OR “body mass index” OR overweight OR obes* OR smoking OR cigarette$ OR nicotine OR tobacco OR alcohol* OR drinking OR “fruit and vegetable” OR nutrition OR diet OR exercise OR “physical activity” OR “active lifestyle” OR medication OR “adjuvant treatment” OR “adjuvant therapy” OR surveillance OR monitor* OR followup OR “care plan”)

AND

TITLE / ABSTRACT / KEYWORDS (factor$ OR predict* OR influen* OR characteristic$ OR cultur*)

AND

TITLE / ABSTRACT / KEYWORDS (cancer* OR neoplasm$ OR “chronic health” OR “chronic condition” OR “chronic disease” OR condition OR “cardiovascular disease” OR “chronic obstructive pulmonary disease” OR “COPD” OR diabetes OR asthma OR “chronic respiratory disease")

AND

TITLE / ABSTRACT / KEYWORDS (rural* OR regional OR remote OR isolated OR small-town OR geograph* OR spatial)

Databases

Databases searched will include EBSCOhost platform – psycARTICLES, psycINFO, Psychology and Behavioural Sciences Collection; Academic Search Ultimate, Scopus; ScienceDirect, PubMed, MEDLINE, Embase, CINAHL, The Cochrane Library.

Grey literature searching will be conducted through ProQuest Dissertations and Theses, targeted web searches of state and federal government health websites, non-government cancer and/or health association websites, web search engines (Google, Google Scholar), and manual hand searching of reference lists of included articles.

Inclusion/Exclusion Criteria

1. The review will include primary studies that assess:
    - A Rural population, including regional, rural, remote - any population outside of metropolitan areas;
    - Participants with cancer, other chronic condition or diagnosis;
    - Health behaviours (physical activity, nutrition, weight management/BMI, alcohol intake, smoking) or medical management (follow-up treatment, medication,

screening, surveillance, monitoring) e.g. long-term care, management or follow-up;

2. There will be no restrictions on study design or publication type. This review will aim to include all relevant materials from published, unpublished and government/relevant organisations
3. No restrictions on country of origin
4. Restricted to adult populations 18+ years
5. Restricted to English language
6. Searches will be limited from 1990 - present

Screening Strategy and Study Selection

A three-step search strategy will be employed. An initial limited search was conducted to identify relevant key words and index terms. This search assisted in the development of the review protocol and was subject to feedback from the research team.

Following review and any necessary refinement, a comprehensive search will be conducted across relevant databases. Identified articles will be organised and screened in EndNote X8. The search will be extended to include grey literature (unpublished, theses, manuscripts, government and relevant organisation materials) in order to capture as much relevant material as possible.

A double screening approach will be adopted. Two reviewers (AR & FCW) will independently screen the title and abstract of articles, classifying each as “relevant”, “irrelevant” or “unclear” using predetermined inclusion/exclusion criteria. Any disagreement between reviewers with respect to inclusion will be resolved through discussion.

Full text will be obtained for remaining articles, which will undergo secondary screening and review by the same reviewers against inclusion/exclusion criteria. The reference list of all final identified literature will be screened for additional resources of relevance.

Data Extraction

Relevant data will be extracted from the final group of full text articles by the first author (AR); the second reviewer (FCW) will review this data for accuracy. Data to be extracted will include:

- Referencing/Citation data (Author/s, Year)
- Participant characteristics (Behaviour/s Examined, Setting, Sample Size, Cancer Type, Survivorship phase [diagnosis, treatment, recurrence, end of life])
- Country of origin
- How rurality was defined/measured
- How adherence was defined/measured
- Study design and method
- Key findings related to research question (predictive factors)
- Recommendations for future research made by authors

As the purpose of this review is to provide an overview of existing evidence regardless of quality, texts will not undergo any formal evaluation of methodological quality.

Data collation

Data will be collated into tables according to its relevance to medical management and health-promoting behaviours where possible. Should the results allow, medical management and health-promoting behaviours will be discussed separately in the results.

OUTCOME/SIGNIFICANCE

The review will build upon existing research by drawing from and synthesising research across multiple disciplines (and potentially health conditions if insufficient evidence is available) in order to identify factors that may contribute to poor adherence and engagement in follow-up clinical management and recommended health behaviours for regional cancer populations. This review is necessary to inform survivorship research generally, and to ground and inform further research on factors that might contribute to geographic variations in health behaviours and medical management following treatment for cancer.

Appendix B: Scoping Review Search Strategy

Database	Search Phrase	Number of Hits
EBSCOhost – psycARTICLES, psycINFO, Psychology and Behavioural Sciences Collection, Academic Search Ultimate, CINAHL	AB (rural* OR regional OR remote OR isolated OR small town OR geograph*) AND AB (cancer* OR neoplasm$ OR "chronic health" OR "chronic illness" OR “chronic condition” OR “chronic disease” OR condition OR “cardiovascular disease” OR “chronic obstructive pulmonary disease” OR “COPD” OR diabetes OR asthma OR “chronic respiratory disease”) AND AB (factor$ OR predict* OR influen* OR characteristic$ OR cultur*) AND TI (adher* OR engage* OR participat* OR continu* OR commit* OR complia*) AND AB (health behav* OR medical regime$ OR "healthy lifestyle" OR weight OR "weight management" OR BMI OR "body mass index" OR overweight OR obes* OR smoking OR cigarette$ OR nicotine OR tobacco OR alcohol* OR drinking OR "fruit and vegetable" OR nutrition OR diet OR exercise OR "physical activity" OR "active lifestyle" OR medication OR "adjuvant treatment" OR "adjuvant therapy" OR surveillance OR monitor* OR followup OR "care plan") Search restricted to publication range Jan 1990 to Nov 2018; English language	186
Scopus	TITLE-ABS-KEY (rural OR regional OR remote OR isolated OR small?town OR geograph*) AND TITLE-ABS-KEY (cancer* OR neoplasm$ OR “chronic health” OR “chronic illness” OR “chronic condition” OR “chronic disease” OR condition OR “cardiovascular disease” OR “chronic obstructive pulmonary disease” OR “COPD” OR diabetes OR asthma OR “chronic respiratory disease”) AND TITLE-ABS-KEY (factor$ OR predict* OR influen* OR characteristic$ OR cultur*) AND (TITLE (adher* OR engage* OR participat* OR continu* OR commit* OR complia*) OR KEY (adher* OR engage* OR participat* OR continu* OR commit* OR compli*)) AND TITLE-ABS-KEY (health AND behav* OR medical AND regime$ OR “healthy lifestyle” OR weight OR “weight management” OR bmi OR “body mass index” OR overweight OR obes* OR smoking or cigarette$ OR nicotine OR tobacco OR alcohol* OR drinking OR “fruit and vegetable” OR nutrition OR diet OR exercise OR “physical activity” OR “active lifestyle” OR medication OR “adjuvant treatment” OR “adjuvant therapy” OR surveillance OR monitor* OR follow?up OR “care plan”) Search restricted to publication range Jan 1990 to Nov 2018; English language	961
PubMed/MEDLINE	(((((rural[Title/Abstract] OR regional[Title/Abstract] OR remote[Title/Abstract] OR isolated[Title/Abstract] OR small town[Title/Abstract] OR geograph*[Title/Abstract])) AND (cancer*[Title/Abstract] OR neoplasm$[Title/Abstract] OR "chronic health"[Title/Abstract] OR "chronic condition"[Title/Abstract] OR "cardiovascular disease"[Title/Abstract] OR "chronic	102

	obstructive pulmonary disease"[Title/Abstract] OR "COPD"[Title/Abstract] OR diabetes[Title/Abstract] OR asthma[Title/Abstract] OR "chronic respiratory disease"[Title/Abstract])) AND (factor$[Title/Abstract] OR predict*[Title/Abstract] OR influen*[Title/Abstract] OR characteristic$[Title/Abstract] OR cultur*[Title/Abstract])) AND (adher*[Title] OR engage*[Title] OR participat*[Title] OR commit*[Title] OR complia*[Title])) AND (health behav*[Title/Abstract] OR medical regime$[Title/Abstract] OR "healthy lifestyle"[Title/Abstract] OR weight[Title/Abstract] OR "weight management"[Title/Abstract] OR bmi[Title/Abstract] OR "body mass index"[Title/Abstract] OR overweight[Title/Abstract] OR obes*[Title/Abstract] OR smoking[Title/Abstract] OR cigarette$[Title/Abstract] OR nicotine[Title/Abstract] OR tobacco[Title/Abstract] OR alcohol*[Title/Abstract] OR drinking[Title/Abstract] OR "fruit[Title/Abstract] AND vegetable"[Title/Abstract] OR nutrition[Title/Abstract] OR diet[Title/Abstract] OR exercise[Title/Abstract] OR "physical activity"[Title/Abstract] OR "active lifestyle"[Title/Abstract] OR medication[Title/Abstract] OR "adjuvant treatment"[Title/Abstract] OR "adjuvant therapy"[Title/Abstract] OR surveillance[Title/Abstract] OR monitor*[Title/Abstract] OR followup[Title/Abstract] OR "care plan"[Title/Abstract]) Search restricted to publication range Jan 1990 to Nov 2018; English language	
The Cochrane Library	rural OR regional OR remote OR isolated OR "small town" OR geograph*:ti,ab,kw AND cancer* OR neoplasm? OR "chronic health" OR “chronic condition” OR “chronic disease” OR condition OR “cardiovascular disease” OR “chronic obstructive pulmonary disease” OR “COPD” OR diabetes OR asthma OR “chronic respiratory disease” :ti,ab,kw AND factor? OR predict* OR influen* OR characteristic? OR cultur*:ti,ab,kw AND adher* OR engage* OR participat* OR continu* OR commit* OR complia*:ti AND "health behav*" OR "medical regime?" OR "healthy lifestyle" OR weight OR "weight management" OR BMI OR "body mass index" OR overweight OR obes* OR smoking OR cigarette? OR nicotine OR tobacco OR alcohol* OR drinking OR "fruit and vegetable" OR nutrition OR diet OR exercise OR "physical activity" OR "active lifestyle" OR medication OR "adjuvant treatment" OR "adjuvant therapy" OR surveillance OR monitor* OR "follow up" OR "care plan":ti,ab,kw Search restricted to publication range Jan 1990 to Nov 2018	148
ProQuest Dissertations & Theses	ab(rural OR regional OR remote OR isolated OR "small town" OR geograph*) AND ab(cancer* OR neoplasm? OR "chronic health" OR "chronic condition" OR "chronic disease" OR condition OR "cardiovascular disease" OR "chronic obstructive pulmonary disease" OR "COPD" OR diabetes OR asthma OR "chronic respiratory disease") AND ti(factor? OR predict* OR influen* OR characteristic? OR cultur*) AND ab(adher* OR engage* OR participat* OR continu* OR commit* OR compli*) AND ab("health behav*" OR "medical regime?" OR "healthy lifestyle" OR	508

	weight OR "weight management" OR BMI OR "body mass index" OR overweight OR obes* OR smoking OR cigarette? OR nicotine OR tobacco OR alcohol* OR drinking OR "fruit and vegetable" OR nutrition OR diet OR exercise OR "physical activity" OR "active lifestyle" OR medication OR "adjuvant treatment" OR "adjuvant therapy" OR surveillance OR monitor* OR "follow up" OR "care plan") Search restricted to publication range Jan 1990 to Nov 2018	
Total Hits		**1905**

Appendix C: Multilevel- model Mplus syntax example, using fruit intake

```
ANALYSIS:
 ESTIMATOR = MLR;
 COVERAGE = .05;

 OUTPUT:
 STDYX;

 MODEL:
 T1-T3 (totvar);
 T1-T3 WITH T1-T3 (totcov);
 [T1-T3](mean1-mean3);

 MODEL TEST:
 0=mean1-mean2-mean3;
```