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The Experiences of Young People Living with Cancer in Outer Regional and Remote Queensland: A Qualitative Phenomenological Study

Submitted by

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Dedication

This PhD Thesis is dedicated to the memory of Joseph Barry Kearsley

Statement of the Contribution of Others

Assistance	**Contribution**	**Names**
Intellectual Support	Advisors	**Primary Advisor:** Adjunct Associate Professor Nonie Harris (JCU) **Secondary Advisor:** Dr Desley Harvey (Allied Health Research Fellow, Cairns & Hinterland Hospital and Health Service until retirement June 2022; and JCU – Adjunct Lecturer) **Secondary Advisor:** Dr Ann Carrington (JCU) (June 2022 – March 2024)
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Abstract

Social work research has contributed to a broad understanding of the psychosocial needs of young people living with cancer in nonmetropolitan areas. However, there is little qualitative research on the experiences of young people living with cancer in nonmetropolitan Australia and on social work practice with young Australians living with cancer from outer regional and remote areas. This research seeks to address these gaps, offering an original contribution to social work literature. This study uses multiperspective interpretative phenomenological analysis (IPA) methods to explore young people's experiences living with cancer in outer regional and remote Queensland. In-depth interviews were conducted with 10 young people living with cancer from this region and six social workers from outer regional and metropolitan Queensland sites. Data analysis of young people and social work perspectives revealed that travelling away from home communities for specialist cancer care is filled with multiple hardships for young people, marked by cumulative loss and trauma. Young participants desired connection with and within six spheres: place, knowledge, people, support, peers and lifestyle. Travelling away for cancer care emerged as a liminal, life-changing experience for young people. Young people are often between two states whilst away from home communities having cancer care. They are no longer their former, pre-cancer diagnosis selves and are yet to become their new selves. The results suggest that returning home and establishing a new normal is the goal of the liminal experience psychosocially for young people, even when their cancer becomes incurable. Social work support for young people would benefit from understanding and application of the spheres of connection model that emerged in this study. The spheres of connection model can assist social workers in helping young people living with cancer from nonmetropolitan areas maintain and build connections important to them, whilst building connections between young people and social workers.

Table of Contents

List of Tables

List of Figures

Chapter One: Introduction

Social workers in regional Australia face unique practice experiences, including in cancer care. Geographical distance from major regional and metropolitan specialist cancer care services necessitates travel for a large proportion of outer regional and remote people in Queensland (McGrath, 2017). In my own regional oncology social work practice with all ages across the lifespan, I observed the disadvantages people living with cancer and their families experience when having to relocate for cancer care. I developed an interest in understanding what the experience was like for young people in my paediatric oncology role. At times, I felt my knowledge and training was an insufficient base for helping the young people I worked with. Frameworks for working with young people living with cancer were not specific to the context of regional and remote practice. My practice and knowledge gaps inspired me to learn more, leading to this research.

1.1 Positioning the Researcher

I have been a social worker in government health services in outer regional Queensland for 31 years, practising in cancer care for 20 years. Cancer care, in this thesis, refers to care provided to those diagnosed with cancer. Medical terminology used in this thesis divides cancer into two types: ‘oncology’ refers to the medical specialty of solid cancer tumours, whilst ‘haematology’ refers to the medical specialty of blood and blood-related cancers. When I refer to oncology in this thesis, unless citing specific research, ‘oncology’ and ‘cancer’ means both solid and blood or blood-related cancers. Over my 20 years of oncology social work practice, I worked with people diagnosed with cancer of all ages, including in a dedicated palliative care role for nine years, adult oncology for one year, and 10 years in a dual paediatric (generalist) and paediatric oncology role. A large part of my paediatric oncology work involved supporting children and young people, including their families, through their cancer experiences.

In my paediatric cancer care practice, young people – defined in this study as 15–25-year-olds – from the outer regional and remote areas my outer regional hospital serviced almost always had to travel away to specialist outer regional or metropolitan cancer care centres for their treatment. Travel away was required because the specialist cancer care young people needed was generally not available at my health service. The rare exceptions were some types of cancers that could be treated in the adult cancer care service. I was involved in helping young people relocate to the cities where specialist cancer care services were available. The cancer diagnosis and relocating for treatment were huge upheavals for young patients and their families.

I typically provided crisis interventions at those times of diagnosis and relocation, assisting with initial shock reactions to the diagnosis or suspected diagnosis of cancer. I also assisted with practical tasks related to patient travel through Queensland Health's Patient Travel Subsidy Scheme (PTSS). Assisting with travel typically involved advocacy for extra escorts for young people, as only one escort was financially subsidised through PTSS. I prepared the young person and family as best I could with what to expect in the transfer and relocation process. I made referrals to social work and welfare services at the hospital they were transferring to. I provided advocacy for relatives, such as letters of support to schools or universities to pause or make allowance in exams for family members. I provided counselling or referrals for counselling and welfare support for family members left behind. For the transfer process, a colleague and I developed a booklet for young people and their families, outlining the transfer process and staff, including contact details for key services that I had referred them to in the city they were relocating to.

The busy, acute paediatric hospital ward I covered often meant I was responding to the next crisis or issue patients and their families were going through. My work as a paediatric oncology social worker was often the 'poor cousin' to the demands of crisis inpatient work. I did not feel, despite the positive feedback I received at times from young people or their families, that what I was offering was enough. Young people would return from their relocation and cancer treatment experience, and I had little time to spend with them. Some were returning home with incurable cancer, and I was, therefore, providing end-of-life care. At times, I felt hopelessly inadequate.

1.1.1 Theoretical and Practice Frameworks Guiding My Practice

Theory-guided social work practice, including research, underpins the social work profession's values, ethics and practice standards set out by the Australian Association of Social Work (AASW) (AASW, 2020, 2023). Theory contributes to and guides social work practice (Healy, 2022).

Theory helps social workers understand and contest ideas, explain and understand human behaviour, form practice frameworks to guide often complex and complicated situations clients experience and promote accountable, self-disciplined, professional social work conduct (Payne, 2020). Social work research needs to be grounded in theory for credibility (Connolly et al., 2018). Articulating my social work theoretical and practice frameworks is, therefore, an important part of positioning myself as a researcher in this study.

At the commencement of my research, my social work practice with young people was underpinned by empowerment, systems, strengths-based, solution-focused and child developmental theories. My goals in practice were to empower the young people I was working with, ensuring they had the necessary resources required to understand themselves, their relationships and their lives, which helped with their own decision-making (Healy, 2022). Systems (see Payne, 2020) and child development psychological (for example, Piaget, 2008) theories guided my approach to how children and young people interacted with their families and other systems in their lives. I contextualised my understanding, informing my practice with developmental milestones and markers known to be important at children and young people's ages and stages of life (Peterson, 2014). Of particular assistance in understanding the transition from childhood through adolescence into adulthood were Jean Piaget (2008; Bringuier & Piaget, 1980) and Erik Erikson (Tyson & Tyson, 1990). Developmental theories informed my understanding that young people were able to receive counselling, problem-solve, engage in conversations and choose strategies to help them through their cancer diagnosis and treatment, including how having cancer impacted their relationships, lives and hopes or fears for their future.

Strengths-based and solution-focused theories (see Payne, 2020) complemented my empowerment-based theoretical practice framework. These approaches draw on a person's existing strengths to manage various problems they may be experiencing, including identifying goals and solutions (Payne, 2020). It was an empowering way of practice where, through the helping relationship, I could assist young people in finding and creating ways to navigate life's challenges.

I was simultaneously guided by crisis and task-centred practice (see Healy, 2022; Payne, 2020) and Abraham Maslow's (1987) hierarchy of human needs in the acute hospital setting I worked in. Crisis theory informed me that working with people in crisis, such as young people with a new cancer diagnosis and their families, necessitated focusing on the immediate and highest-priority needs of people (Connolly et al., 2019). Task-centred practice guided me to meet the highest-priority needs, ensuring specific tasks (such as organising travel and referrals to social work support at the site they were transferring to) were undertaken (Healy, 2022). Maslow's (1987) model informed me, throughout my crisis and task-centred practice, that attending to higher levels of human needs in Maslow's hierarchy, such as self-actualisation goals, is generally not a priority when people have basic welfare or survival needs (like surviving their cancer, transport and accommodation).

Grief and loss theories informed my practice in palliative care work for all ages, including children and young people whose cancer was no longer curable. The 'stages of grief' espoused by Kübler-Ross (Kübler-Ross & Kessler, 2005) were no longer considered the most helpful way to look at grief for the death of a loved one. Critics of discreet stages of grief in bereavement included Mal McKissock (McKissock & McKissock, 1995), whose grief workshops I had attended. I subsequently coordinated a full-day grief and loss event with McKissock as the speaker. The theory guiding my bereavement practice included Worden and especially Worden's four tasks of mourning (Worden, 2009; Worden, 2015) and Neimeyer's continuing bonds and meaning making (Neimeyer et al., 2006; Neimeyer & Thompson, 2014). These theoretical frameworks informed my work with children, young people and their families, who needed assistance preparing for end-of-life through advance care planning practices. For example, meaning-making activities included the narrative practice of writing stories of their lives and collecting hand and footprints. I introduced the use of 'Voicing my CHOiCES™: A Planning Guide for Adolescents and Young Adults' (Zadeh et al., 2015), purchasable through cancer support organisations, with young people who had incurable cancer when it became available in 2013. I provided resources and books to foster continuing bonds for children and young people facing end-of-life experiences and to help in bereavement, such as 'The Invisible String' (Karst, 2014) and 'Something I've Never Felt Before: How Teenagers Cope with Grief' (Zagdanski, 1990).

I commenced my research journey with a separate study exploring regional social work theory and practice with young people living with cancer (Sariman, 2017). That study identified one of the gaps in the literature was a lack of qualitative research informing social work practice with young people living with cancer, in particular, those from nonmetropolitan areas (Sariman, 2017). The voices of young people from regional and remote areas were missing from the literature. My next goal was to discover what young people from nonmetropolitan areas were saying about their needs.

I led an integrative literature review, which showed there was limited evidence on the experiences of young people living with cancer in nonmetropolitan areas (Sariman et al., 2020). Most research focused on nonmetropolitan cancer care issues in adults aged 18 and over and was not specific to the age range for young people (15–25). Only three studies comprised young people aged 15–39, specifically in the participant pool (see Dyson et al., 2012; Marris et al., 2011; Miedema et al., 2013). This review found that the published literature and practice frameworks (Commonwealth of Australia, 2008; D'Agostino & Edelstein, 2013; DeRouen et al., 2015; Marris et al., 2011; Palmer et al., 2014; Zebrack et al., 2013) available to guide psychosocial interventions with young people living with cancer were informed by metropolitan-based research (Sariman et al., 2020). Nonmetropolitan research was, therefore, not informing psychosocial literature and practice frameworks. In addition, few studies highlighted a gap in the literature on young people living with cancer from nonmetropolitan areas. There was also a gap in social work-led research into the experiences of young people living with cancer from nonmetropolitan areas. My goal, therefore, in this PhD research was to explore this phenomenon, ultimately hoping to find ways to improve social work practice.

1.2 Social Work in Health and Cancer Care

Social work is concerned with the wellbeing of all individuals in society, and health is central to wellbeing. Beddoe and Pockett (2018) highlight that health and wellbeing are intrinsic to quality of life. Bywaters and Napier (2009) assert that social work is health work. The World Health Organization's (WHO) constitutional definition of health states: "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (WHO, 2023). Social work has a central responsibility for the health of human populations as a profession concerned with the human rights and wellbeing of all (AASW, 2020). The International Federation of Social Workers (IFSW) asserts that health is a fundamental human right and a key feature across all fields and settings of social work practice, including health, education, research and policy-making (IFSW, 2023). The IFSW (2023) claims social work has a global responsibility to the equitable and fair provision of services through government policies that maximise health for all, seeking to ensure social workers identify and challenge adverse health effects of social policies, services or practices and advocate for health-promoting, protecting and sustaining policies, service and practices. Social work has a central role in ensuring fair, equitable health services responsive to the needs of those most vulnerable in society.

In my experience, the social work role in children's, adolescent and young adult oncology is to design evidence-based, patient-focused interventions and psychosocial care throughout the cancer care trajectory at diagnosis, during treatment and after treatment. Social work interventions include psychosocial assessments, crisis interventions (for example, crisis counselling in response to a cancer diagnosis, emergency relief, transport, accommodation and other urgent welfare assistance), counselling for patients and their families and referrals to community services for tailored psychosocial support. Typically, in a hospital environment, oncology social work practice is crisis-driven and reactive, relying on individual practitioners' own frameworks, which are problematically informed by a metropolitan evidence base.

In outer regional and remote areas, many young people are required to transfer to a specialist cancer care facility in major regional or metropolitan areas for diagnosis, staging and treatment. Greater detail is provided about the medical need for and processes involved in these transfers in Chapter Three under the heading "Research Setting/Locations". These times of transfer are often a crisis point for the young person and their loved ones. Social workers are, therefore, involved due to the impact of diagnosis (including shock and fear) and provide psychosocial crisis assessments and interventions, including crisis counselling, family meetings, practical assistance with travel, accommodation, and welfare-related needs like financial, housing, work and school-related matters. Liaison with and referral to other members of the multidisciplinary team at both sending and receiving sites and advocacy within and outside Queensland Health to meet psychosocial needs are common social work interventions at these times of transfer.

The contexts for social work health practice include health conditions or experiences (for example, oncology social work) and agencies delivering the services (for example, hospital or community health social work practice) (Beddoe & Pockett, 2018). Social work practice is required to be evidence-based (AASW, 2023). A primary difficulty occurs when there is no evidence for the required area of practice (Plath, 2006; Whiteside et al., 2016). There are few studies on young people living with cancer in nonmetropolitan areas (Sariman et al., 2020). However, social workers have both led and been involved with some relevant studies informing the field of practice with young people living with cancer. For instance, social work researchers Bradley Zebrack (Zebrack & Walsh-Burke, 2004; Zebrack, 2006) and Kate Thompson (as co-author in Palmer et al., 2007) have led or been involved in studies informing three Australian National documents informing cancer care practice with young people. The first National document, “A practice framework for working with 15–25-year-old cancer patients treated within the adult health sector” (Palmer & Thomas, 2008) was a key evidence paper driving the second National document, “National service delivery framework for adolescents and young adults with cancer” (Commonwealth of Australia, 2008). Commonwealth of Australia (2008) then informed the third National document, “Australian youth cancer framework” (Canteen, 2017).

Whilst social work researchers have made significant contributions to the literature, none have focused exclusively on the experiences of young people living with cancer in nonmetropolitan areas. Young people living with cancer in nonmetropolitan areas cannot expect improvements in their psychosocial care if there is limited evidence to guide the social workers who work with them. Nonmetropolitan social work practitioners in regional northern Queensland, Australia, have been found to be willing to conduct research; however, barriers included low confidence, research knowledge and skills deficits and practical constraints (Harvey et al., 2013). This research has the potential to address gaps in the evidence base. It is the first qualitative study to explore young people’s experiences living with cancer in nonmetropolitan areas led by a social work researcher.

1.3 Aims and Objectives of the Study

The overall aim of the research is to conduct an in-depth study of the experiences of young people living with cancer in nonmetropolitan Australia at key transition points of diagnosis, during treatment and after treatment. The study's exploration of what is important to young nonmetropolitan Australians throughout their cancer experiences is intended to inform social work practice.

The main objective is to explore the experiences of young people living with cancer in outer regional and remote Queensland through a multiperspective interpretative phenomenological analysis (IPA) (Larkin et al., 2019; Smith et al., 2009) study, with two groups of participants. The first group are young people from outer regional and remote Queensland. The second group are social workers from nonmetropolitan and metropolitan Queensland sites. Synthesising the data analysis from both groups will comprehensively address the dearth of literature informing social work practice with young people living with cancer in nonmetropolitan areas, thereby harnessing multiperspective IPA's ability of developing a more detailed, multifaceted account (Smith et al., 2009) of young people's experiences.

1.3.1 Research Questions

The following research questions guided this study:

1. How do young people diagnosed with cancer from outer regional and remote Queensland describe their experience of living with cancer?
2. What is important to young people living with cancer in outer regional and remote Queensland when they are diagnosed with cancer, during cancer treatment and after treatment or when they return home?
3. What are social workers' perspectives on the experiences of young people living with cancer from outer regional and remote Queensland and their encounters with the health system at diagnosis, during cancer treatment and after treatment or when they return home?

4. What do the perspectives of young people and social workers tell us about the experience of being a young person living with cancer in outer regional and remote Queensland, and how might this inform social work practice?

1.4 Theoretical Framework

The theory of knowledge, or epistemology, guiding the research approach for this study is social constructionism. Social constructionism holds that meaning is constructed through people's social interactions within and because of their culture (Crotty, 2020). Social interactions and culture are central to social work (Connolly et al., 2019). Social workers assist people in their interactions within their social environments (IFSW, 2023). My theoretical and practice frameworks, outlined earlier, are largely concerned with how people interact and gain mastery within their environments and over their problems, using empowerment, systems, strengths-based, solution-focused, developmental, crisis and task-centred approaches within a hierarchy of needs. End-of-life care is informed by prominent, contemporary grief theorists who recognise the deep connection and bonds between people. Social constructionism is consistent with these theoretical and practice frameworks.

Within social constructionism, this research draws from phenomenology, specifically interpretive phenomenology (Creswell & Poth, 2018; Crotty, 2020). Interpretive phenomenology involves the researcher interpreting the meaning of participants' lived experiences of a shared phenomenon (Creswell & Poth, 2018; van Manen, 1990). Philosopher Martin Heidegger's (Heidegger, 2010) work is of particular interest given the central tenet of time being the horizon through which human experience can be understood. With a sparse evidence base to guide practice with young people living with cancer from nonmetropolitan areas, Heidegger's philosophy guided the decision for this research to cover the whole duration of cancer experiences – at diagnosis, during treatment and after treatment. This provides a more comprehensive coverage of what the experience is like.

Within interpretive phenomenology, this study uses interpretative phenomenological analysis (IPA). IPA explores how people make sense of major life experiences and has become a popular methodology to use for research on major health diagnoses like cancer (Smith et al., 2009). Some IPA research, such as this study, is underpinned conceptually by the understanding that the researched phenomenon can be explored through additional perspectives (Larkin et al., 2019). To meet this study's overarching research aim to inform social work practice, choosing a multiperspective IPA design recognises the value of the perspectives of young people and the social workers engaging directly with them in practice. Multiperspective IPA increases the capacity for greater impact, whereby "…convergence and triangulation of viewpoints can be more persuasive than an analysis drawn from a single sample" (Larkin et al., 2019, pp. 194-195). This study's guiding theoretical and philosophical framework will be explored in depth in Chapter Three.

1.5 Definition of Terms

Young Person: In this study, 'young person' refers to an adolescent or young adult aged between 15–25. This reflects local Australian terminology in cancer care (Canteen, 2017). However, the literature review in Chapter Two includes studies with young people in the age ranges of 15–39 years to capture international variations in terminology defining adolescents and young adults (McInally et al., 2021). The term 'young people' is used interchangeably in the literature with 'adolescents and young adults', which, in turn, is often written as 'AYAs'. It could be argued that social workers should reflect on terminology and how the literature refers to young people. McLaughlin (2009) suggests that, in line with social work values of empowerment, liberation and promoting social justice, we should ideally ask how service users themselves would like to be defined in language. In the literature searched, no studies have asked young people with cancer how they would like to be described. As a social worker strongly aligned with the values underpinning my profession, I refer to adolescents and young adults as 'young people'.

Living with Cancer: 'Living with cancer' means someone who has been diagnosed with cancer and is undergoing cancer treatment or recovering from cancer treatment (Cancer Council Victoria, 2016). Such a person is also commonly referred to in the literature as a 'cancer survivor' (National Coalition for Cancer Survivorship, 2014).

Nonmetropolitan: In this study, the Australian Standard Geographical Classification (ASGC) Remoteness Areas for Australia are used to denote the difference between metropolitan (major city) and nonmetropolitan (inner regional, outer regional, remote or very remote) (AIHW, 2023b). In Australia, all the capital cities, nearby cities and their surrounding suburbs are classed as major cities (AIHW, 2023b) and thus are referred to as ‘metropolitan’ in this study. All other areas are ‘nonmetropolitan’ and may be referred to alternately in this study as ‘regional’ (encompassing both ‘inner regional’, e.g., Gold Coast, and ‘outer regional’, e.g. Cairns) or ‘remote’ (both ‘remote’, e.g. Cooktown, or ‘very remote’, e.g. Aurukun, Torres Strait Islands) according to ASGC Remoteness Areas classifications (AIHW, 2023b).

Transitions: Transitions are points in time during a cancer care journey where the young person’s circumstances change. Transitions can occur at diagnosis, changes in treatment goals (such as from curative to palliative), or changes in types of treatment (such as from surgery to radiotherapy). Other transitions include when treatment finishes and when the young person relocates for reasons like treatment commencing or to return home.

Aboriginal and Torres Strait Islander: First Peoples, First Nations and Indigenous are all terms describing the original inhabitants of countries, such as Australian Aboriginal and Torres Strait Islanders. In this thesis, the term ‘Aboriginal and Torres Strait Islander’ is used, following Queensland Health terminology guidelines (Queensland Health, 2023), except in literary or research citations that use different terms.

1.6 Outline of Thesis

This thesis has eight chapters: the introduction, review of related literature and research, methodology, findings of phases one and two, synthesis of the analysis of phases one and two, discussion and conclusion. This first chapter has provided an introduction and rationale for the study topic, the relevance of the research for social work, research aims and objectives, guiding theoretical framework, methodology and a definition of terms used in the thesis. Chapter Two expands on this, critically reviewing related literature and research and identifying gaps that have led to the current study. The literature review highlights a paucity of social work research into the experiences of young people living with cancer in nonmetropolitan areas. Chapter Three then details the research methodology, including the theoretical and philosophical framework underpinning the study, an outline of the approach, data collection methods, analysis methods and ethical considerations.

Chapters Four and Five detail the study's main findings. Chapter Four describes the young people's perspectives, phase one of the research. Using IPA inductive thematic processes, key themes emerged from young people's perspectives, represented in a spheres of connection model. Young people desired connection with and within six spheres of place, knowledge, people, support, peers and lifestyle. Chapter Five details the study's main findings from the social workers' perspectives, phase two of the research. IPA inductive thematic processes were again used to find key themes. These are 'cumulative loss' and 'cumulative trauma'. Chapter Six synthesises the analysis of data from both young people's and social workers' perspectives. The findings are that travelling away for cancer care is a liminal, life-changing experience for young people from outer regional and remote Queensland. The liminal experience is an interpretative concept that is linked with relevant anthropological and Greek philosophical literature.

Chapter Seven discusses the major themes emerging from the study and how these build upon and add to existing literature in the field, exploring some study limitations. Chapter Eight then identifies the studies' conclusions, providing a thesis summary and highlighting the study's original contribution to the literature. I present implications for social work practice and outline a quality improvement activity being conducted in my health service using phase one findings. Suggestions are made for future research that may further improve the experiences of young people living with cancer in nonmetropolitan areas.

Chapter Two: Review of Related Literature and Research – A Social Work Perspective on Young People Living with Cancer in Nonmetropolitan Areas

This literature review describes the context for social work practice with young people in nonmetropolitan areas who are living with a cancer diagnosis, critically reviewing the evidence relating to the experiences of these young people and establishing the need for the present study. Chapter two begins with a social work rationale for researching young people living with cancer in nonmetropolitan areas. It then describes the literature search strategy. This literature review then identifies and explores the following:

1. The experiences of young people living with cancer in nonmetropolitan areas
2. Social work practice with young people living with cancer from nonmetropolitan areas

Gaps in the literature leading to the present study are presented before the chapter's conclusion.

2.1 Rationale for Social Work Investigation into Young People Living with Cancer in Nonmetropolitan Areas

Regional and remote Australian social work practice has distinctive features. Chief among these is the distance from major metropolitan health and other services. Poorer health outcomes are known to be issues for residents of rural and remote Australian localities (Cosgrave et al., 2019). Poorer health outcomes are linked with barriers to accessing specialist health services due to distance (AIHW, 2020a), including cancer services (AIHW, 2020b). Health is a fundamental human right for all people (WHO, 2023). Human rights are central to the values underpinning social work (AASW, 2020; Connolly et al., 2018; IFSW, 2023). Equitable health care access is, therefore, of central concern to social work (AASW, 2020, 2023; Connolly et al., 2018). The social work profession works with those in society who are disadvantaged because of the inequitable distribution of resources or services. It addresses the factors contributing to that disadvantage, engaging in interventions that contribute to potential solutions, including direct clinical practice, appropriate research and advocacy to relevant human service organisations and government bodies (AASW, 2020, 2023; Beddoe & Pockett, 2018; Connolly et al., 2018; Petrakis, 2018). Given the barriers in accessing health care, and poorer health outcomes for regional and remote Australians, regional social workers are ideally and ideologically placed to help where barriers exist. Health access barriers for more vulnerable groups are typical points of intervention for regional social workers – these include those diagnosed with life-threatening illnesses like cancer, including the most vulnerable of these. Access to health care is therefore a central concern in regional and remote social work practice.

Young people are a vulnerable group of health consumers due to adolescence and young adulthood being a time of significant growth and change encompassed by psychosocial and developmental needs (Canteen, 2011/2021). Young Queenslanders are at greater risk of getting cancer than in other Australian states, in part due to their higher incidence of melanoma (AIHW, 2023a). Young people from Australian regional and remote areas also experience worse health and poorer cancer outcomes, including death, than those from metropolitan areas (AIHW, 2023a). Young Aboriginal and Torres Strait Islander people also experience worse health and cancer outcomes than non-Indigenous Australians, with these outcomes worsening the more remote they live (AIHW, 2023a). A cancer diagnosis for young people interrupts many important developmental processes and milestones (Zebrack et al., 2016). This important developmental period is further disrupted for young Australians diagnosed with cancer from regional and remote areas, who must usually travel or relocate to specialist outer regional or metropolitan cancer care services (Afshar et al., 2020; Sariman et al., 2020). Young people living with cancer from outer regional and remote areas are, therefore, a target population for social work interventions.

Pockett, Dzidowska and Hobbs (2015) note there are few studies by social work researchers in Australia specific to people living with cancer. Social workers have tended to be contributors rather than leads in the existing research (Pockett et al., 2015). Social work-led research can shed light on the vulnerable population of young people living with cancer, helping to better address the barriers and vulnerabilities they face due to their age, developmental stage and geographical location (if from nonmetropolitan areas).

2.2 Empirical Literature Search Strategy

The methodological framework underpinning this research is interpretative phenomenological analysis (IPA) (Smith et al., 2009). There is no guidance in IPA literature for the type of literature reviews IPA should adopt (see Larkin et al., 2019; McInally & Gray-Brunton, 2021; Smith et al., 2009; Smith & Nizza, 2022). To achieve the aims of this literature review, empirical research related to the experiences of young people living with cancer in nonmetropolitan areas and social work practice in this area was searched over the study duration between 2017 and May 2024. Literature search methods common in systematic, integrative and narrative reviews (see Alston & Bowles, 2018; Ferrari, 2015; Neuman, 2014) were used.

To investigate the literature related to the experience of young people with cancer in nonmetropolitan areas, I conducted a search for the period 1999–2024, to capture what I discovered to be a limited pool of research specifically on young people from nonmetropolitan areas internationally, or in Queensland, Australia. I focused on research articles and studies selected from the following databases: CINAHL, Medline, Psychinfo, Social Sciences Citation Index (SSCI), PsycARTICLES, Socindex. I also used open database searches, including Google Scholar, JCU One Search and Google. Keywords used were cancer, patient*, neoplasm*, adolescent*, young adult*, teenager*, youth, young people, social work, regional, rural, remote, nonmetropolitan, urban, metropolitan, psychosocial, information, support, experience*, need*, living with, diagnosed with, comparing, Aboriginal, Torres Strait Islander and Indigenous. Library catalogues (James Cook University, Queensland Health) were also searched for relevant books, book sections and reports relevant to the topic. Cited studies and reference lists in relevant articles were also used to extend the scope of the search. I also employed a librarian-assisted search in October and November 2023, updated in May 2024.

To investigate the literature on social work practice with young people living with cancer from nonmetropolitan areas, I also conducted JCU Library, Queensland Health Library and Google Scholar searches for literature relating to social work theory and practice in health, regional, rural, remote and nonmetropolitan areas, with young people (adolescents and young adults), with young people living with cancer and with children and young people living with cancer in regional, rural, remote and nonmetropolitan areas. My search included the terms: “social work oncology practice”, “rural social work”, “social work with young people living with cancer”, “social work with adolescents and young adults living with cancer” and “social work with adolescents and young adults living with cancer from nonmetropolitan areas”. My librarian-assisted search from October to December 2023, updated in May 2024, used the following string search: (“Social work” OR Counsellor OR “psychosocial practice”) AND (Adolescence OR Youth OR “Young Adult” OR Adolescent OR teen* OR AYA*) AND (Neoplasms OR Cancer OR Leukaemia OR Leukemia) AND (Regional OR Rural OR Remote OR “Inner Regional” OR “Outer Regional” OR “Very Remote” OR “nonmetropolitan” OR nonmetropolitan OR urban OR metropolitan) AND Australia.

The key empirical studies identified through the above searches were then searched within Google Scholar to capture any new empirical studies or literature not included in those searches. The authors of each empirical article were also searched in Google Scholar, and those with accounts on ResearchGate were searched to ensure I captured all relevant research papers. I ran a Google Scholar search in May 2024, with a line of words encompassing the most common key words from articles selected for my literature review: “Young people AYAs living with cancer in nonmetropolitan urban regional rural and remote areas”, which captured two more articles meeting inclusion criteria.

Inclusion criteria for the selected empirical research articles were that they were peer-reviewed, published studies comprising original research or literature reviews, including young people (aged 15–39 years) living with cancer from nonmetropolitan areas in the participant pool. I used the age range of 15–39 years to capture international variations in terminology defining adolescents and young adults. Exclusion criteria were oral presentations (see Muffly et al., 2022). Other than a separate, unpublished study (Sariman, 2017) I conducted prior to the current research, there were no empirical studies on social work practice, including theory underpinning social work practice with young people living with cancer from nonmetropolitan areas or people of any age living with cancer from nonmetropolitan areas. Twenty-one studies, reported in 29 articles, met the inclusion criteria for empirical research selection.

Articles, reports and data not meeting empirical literature selection criteria have been used to provide context to regional, rural and remote people's cancer experiences, or young people's cancer experiences not specific to regional, rural or remote areas, where articles in the last 10 years focused on young people living with cancer from nonmetropolitan areas were limited.

2.3 Young People Living with Cancer from Nonmetropolitan Areas

This section reviews the empirical literature that informs an understanding of the experiences of young people living with cancer from nonmetropolitan areas. Seven key findings emerged from the reviewed literature, explored below.

2.3.1 Vulnerabilities of Being Diagnosed with Cancer Young

The literature highlights that survival rates for young people living with cancer are less than, and not improving at the same rates as children under 15 years or adults aged 29 years or older (Mobley et al., 2019; Patterson et al., 2021a). Adolescence and young adulthood is a time of significant growth and change, with unique psychosocial needs and can be significantly affected by a cancer diagnosis (Block, 2015; Canteen, 2011/2021; Lin et al., 2017; Patterson et al., 2021b; Zebrack et al., 2016). A young person diagnosed with cancer during this developmental life stage typically endures physical, financial and emotional upheaval through disruptions to education and work, social isolation and difficulties comprehending medical information (Morgan et al., 2010; Palmer & Thomas, 2008; Zebrack et al., 2007; Zebrack et al., 2014). Disruptions to emerging social and spiritual selves also occur (Gualthérie van Weezel et al., 2022). Young people require adjustment and disease management strategies that can impact these important areas of change (Block, 2015; D'Agostino et al., 2011; Morgan et al., 2010; Sansom-Daly et al., 2021; Zebrack et al., 2007; Zebrack et al., 2014; Zebrack & Isaacson, 2012).

Whilst there is empirical evidence on the kinds of psychosocial support that benefits young people with cancer (Commonwealth of Australia, 2008; D'Agostino & Edelstein, 2013; DeRouen et al., 2015; Marris et al., 2011; Palmer et al., 2014; Zebrack et al., 2013), there is limited empirical research into the needs or experiences of young people with cancer from nonmetropolitan areas.

However, the following themed sections summarise research that included young people from nonmetropolitan areas, along with Australian statistical data.

2.3.2 Health Disadvantages of Living in Outer Regional and Remote Areas in Australia

Every day in Australia, an average of three young people are diagnosed with cancer (AIHW, 2023a). This is more than 1000 young people annually (Schilstra et al., 2024). The overall survival rates for young people aged 15 to 24 years living with cancer are less than those of children (those under the age of 15) or older adults (25 years and older) (Holland, Bradford, et al., 2021). Young people from regional and remote areas have comparatively worse health in general than those from major cities (AIHW, 2023a). Some sub-populations of young people aged 15–24 have poorer cancer outcomes (adjusted 5-year relative cancer survival), including those in outer regional, remote and very remote areas (AIHW, 2023a). Survival rates of cancer decrease the more remotely young Australians live (AIHW, 2023a). In the period 2011–2020, death rates for young people aged 15–24 due to all cancers combined were higher in inner regional and outer regional Australian areas (36 and 38 deaths per 1,000,000 population, respectively) than in major cities (28 deaths) (AIHW, 2023a). Young people also had higher rates of cancer incidence in the Australian state of Queensland in the nine years between 2010 and 2018 (at 324 per 1,000,000 population) than the Australian average (292) (AIHW, 2023a). Combined, these statistics highlight that young people are at greater risk than those living in cities of not surviving their cancer, with this risk increasing the more remote they live. Young people are also at increased risk of getting cancer in Australia if they live in Queensland. The Australian Cancer Plan recognises these disparities and prioritises those at risk of poorer cancer outcomes, including adolescents and young adults and people living in rural and remote areas (Cancer Australia, 2023).

Risk factors for poorer health outcomes for young people living with cancer in nonmetropolitan areas include lack of access to services and increased barriers and social determinants of health leading to higher rates of cancer for young Australian Aboriginal and Torres Strait Islander people than non-Indigenous young Australians. Many authors have postulated that lack of access to health care services contributes to disparities in survival and disease-related outcomes between metropolitan and nonmetropolitan patients (Chan et al., 2015; Harriss et al., 2016; Sabesan et al., 2012). Other contributors are that nonmetropolitan populations have higher levels of socioeconomic disadvantage compared to those living in metropolitan areas (Harriss et al., 2016; Meiklejohn et al., 2017). There is also a higher number of Aboriginal and Torres Strait Islander people living in nonmetropolitan Australia (AIHW, 2023a; Cancer Australia, 2024). Overall, Aboriginal and Torres Strait Islander Australians have worse disease and death rates than non-Indigenous Australians (Bailie et al., 2017; Caffery et al., 2017; Cancer Australia, 2023, 2024; Meiklejohn et al., 2017; Sabesan et al., 2012). This includes young people living with cancer (Cancer Australia, 2023, 2024; Canteen, 2015). In comparison to non-Indigenous patients diagnosed with the same cancer, Aboriginal and Torres Strait Islander young people aged 15–24 are less likely to survive their cancer than non-Indigenous young people (AIHW, 2023a). The further Aboriginal and Torres Strait Islander people live from metropolitan centres, the greater the likelihood they will not survive their cancer (AIHW, 2023a, 2023b; Cancer Australia, 2023, 2024; Diaz et al., 2015).

Quantitative studies in Canada (Tulk et al., 2023), the United States of America (Johnson et al., 2021) and Australia (Afshar et al., 2020) reflect the increased health disadvantages nonmetropolitan young people living with cancer experience. Tulk et al.'s (2023) study found worse health was reported by nonmetropolitan young adults, who also reported lower physical health-related quality of life scores than those from urban areas. Rural cancer patients had lower mental and physical health outcomes following cancer treatment, linked with a lack of access to services and harsher treatment regimens (Tulk et al., 2023). Worse health was also reported by young people aged 15–39 in Johnson et al.'s (2021) study. Rural residence and living long distances from the reporting hospital were associated with later-stage diagnoses and lower survival in young people living with cancer than those from urban areas (Johnson et al., 2021). Rural residence was also an indicator of lower levels of community support than urban young people (Johnson et al., 2021). Lower survival rates for those from nonmetropolitan areas compared with metropolitan areas were found for 11 types of cancer, including those specific to young people, such as cancer of the connective soft tissue in Afshar et al.'s (2020) study. Lower survival rates for some cancers were partly due to the increased socioeconomic disadvantage experienced by rural residents (Afshar et al., 2020). These results highlight the poorer health outcomes for those living with cancer in nonmetropolitan areas, including young people.

While the aforementioned studies reported poorer health outcomes, one study from the United States of America (USA) found a positive relationship between nonmetropolitan residence and cancer clinical trial enrolment (Mobley et al., 2019). Given the lack of advancement in young people's cancer survival compared with other age groups, involvement in clinical trials is an important way to enhance knowledge (Mobley et al., 2019). Similar to Australia, people from rural areas in the USA travel longer distances for specialist cancer care because specialist oncology services are mostly located in metropolitan areas (Mobley et al., 2019). Clinical trials are conducted through specialist cancer care services. The higher rate of clinical trial enrolment for young nonmetropolitan people was associated with their treatment being at specialist cancer care services within large hospitals, which were mostly in metropolitan areas (Mobley et al., 2019). The quantitative study did not seek reasons for young people's choices to participate in clinical trials. The authors speculated why enrolment rates were higher for nonmetropolitan young people – that young people from nonmetropolitan areas were more likely to travel to metropolitan sites for their treatment and these are the sites where clinical trials were conducted; however, they acknowledged the data itself did not provide reasons for young people's participation.

2.3.3 Tyranny of Distance from Specialist Cancer Care Services

There are barriers and issues accessing care for young people living with cancer in nonmetropolitan areas. Living great distances away from major cancer treatment centres had negative consequences for young people from nonmetropolitan areas in the literature reviewed. These negative consequences are explored under the headings travel/relocation, delayed diagnosis, financial stress and psychosocial issues.

2.3.3.1 Travel/Relocation. The level of specialist care required to diagnose and treat the various forms of cancer young people are diagnosed with is generally not available in many regional and almost all rural and remote areas (Cancer Australia, 2024; Cancer Council Queensland, 2024; Canteen, 2017; Marris et al., 2011; Palmer & Thomas, 2008). Therefore, travel or relocation is usually required for young people diagnosed with cancer in nonmetropolitan areas (Cancer Australia, 2024; Marris et al., 2011; McGrath, 2015c; Miedema et al., 2013; Paul et al., 2013). Travel is a significant barrier to accessing cancer care for those from rural and remote areas in Australia, with stress associated with the demands of travel (Cancer Australia, 2024; Goodwin et al., 2023; McGrath, 2015a, 2015b, 2015c). Australian research found nonmetropolitan adult cancer patients were 17 times more likely to list distance as a barrier to accessing treatment than those from metropolitan areas with more than half needing to relocate to a metropolitan specialist centre for the cancer care they required (Paul et al., 2013).

Regional social workers from Queensland stated it was "'a given' that young people diagnosed with cancer have to travel to Brisbane [Queensland's capital city] for their treatment" (Sariman, 2017, p. 47). Holland, Walker et al. (2021) researched the barriers to accessing psychosocial support for young people living with cancer in Queensland. Holland's qualitative research found two young people, aged 22 and 18, lacked access to services due to their regional locations, with the following quote indicative of both experiences relating to regional barriers in accessing care: "Even just something a bit more local would be good so I don't have to go down to Brisbane (Male, 18 years)" (Holland, Walker, et al., 2021, p. 51). The distance involved in travelling away to specialist cancer care centres for treatment interrupts important connections with home, loved ones and lifestyles, published phase one results of the present research highlight (Sariman et al., 2022). Published phase one findings are reported in depth in Chapter Four.

Research in the United Kingdom (UK) has been mixed, with one study finding that young participants ranked treatment close to home as a low priority, with two-thirds prepared to travel to receive the specialist cancer care they required for up to half a day or any distance required (Marris et al., 2011). Another, more recent UK study compared satisfaction with treatment and supportive care received by all young people in one central specialist cancer treatment centre from metropolitan and nonmetropolitan residential locations (Murphy et al., 2021). Murphy et al. (2021) found those from nonmetropolitan locations were less satisfied with treatments, and those living more than 20 miles away from the cancer treatment centre said their distant location was a barrier to receiving supportive care (Murphy et al., 2021). In Marris et al.’s (2011) study, preparedness to travel for life-saving cancer care does not preclude the associated negative consequences that travel and relocation bring.

Anxiety and distress are reported issues for young people at major transition points throughout their cancer experience. Major transition points occur at diagnosis, treatment changes and adjustment to life post-treatment (Dyson et al., 2012; Patterson et al., 2021b). Dyson et al.'s (2012) Australian study found there is increased anxiety and distress at these key times of transition. These transitions occur when care needs change (Dyson et al., 2012). Whilst this research is older, it highlights current realities that important decisions are often required at these times around treatment, school or work, personal relationships and other psychosocial issues (Dyson et al., 2012). The noted transition points could greatly impact those from nonmetropolitan areas, given the need to travel away from, or back home, at such times. Other studies (Goodwin et al., 2021; Mathews et al., 2009; McGrath, 2017; Paul et al., 2013) have highlighted the significant psychosocial and financial impacts associated with travelling away for treatment. If decisions need to be made by those on cancer treatment while at a metropolitan centre, being away from their usual extended support networks in their community during this time of heightened anxiety and distress could adversely affect their decision-making processes, particularly if support is not available (Goodwin, 2023; McGrath, 2015d). Added financial costs of relocation often mean family and community are unable to visit. Despite a longing for those from nonmetropolitan areas to return home, the stoicism of rural living might mean they do not share these feelings with treating staff or, even if they do, may not be understood (Goodwin et al., 2021; McGrath, 2015d).

2.3.3.2 Delayed Diagnosis. One negative consequence highlighted in the reviewed research on distance from specialist cancer care centres was delayed cancer diagnoses. (Shahid et al., 2016) found in their Western Australian study into reasons for delayed cancer diagnosis of adult Aboriginal participants (ages not specified), 68% of whom were from rural and remote communities, that multiple factors contributed to timely diagnoses. These factors were themed into contextual (socioeconomic deprivation), historical/political (impact of colonisation, racism), health system (reduced access to health services, especially for rural patients) and patient factors (shame, embarrassment, fear, psychological trauma, male stoicism) (Shahid et al., 2016). Delays in lung cancer diagnosis of between 14-242 days were found in a North Queensland study of adults (ages not specified) from outer regional, remote and very remote locations (Verma et al., 2018).

Narrowing the focus to young people, studies from Canada (Miedema et al., 2013) and the USA (Johnson et al., 2021) reported delayed diagnoses as an issue for young people living in nonmetropolitan areas. Miedema et al.'s (2013) qualitative geographical comparative study found those living in rural communities experienced greater levels of delayed diagnosis than urban participants. Young rurally located adults noted not being taken seriously by health services or physicians, in some cases for years at a time (Miedema et al., 2013). Nicoll et al.'s (2023) large rural Canadian study had 69 young people aged 18-19 years in their participant pool, finding

Johnson et al.'s (2021) quantitative study compared metropolitan, urban and rural young people's experiences and found that delayed cancer diagnoses were more frequent in young people from rural areas.

2.3.3.3 Financial Stress. Financial problems, challenges and distress are commonly referred to in current literature on young people living with cancer as 'financial toxicity' (Kaddas et al., 2020; Skrabal Ross et al., 2021). Stress associated with increased financial costs due to having to travel or relocate is a common theme in the literature for people, including young people, and their families living in nonmetropolitan areas (Dyson et al., 2012; Goodwin et al., 2023; AIHW, 2023b; Mathews et al., 2009; McGrath, 2016a, 2016b, 2017; Meiklejohn et al., 2017; Miedema et al., 2013; Paul et al., 2013; White et al., 2011). Increased financial costs have been found for people from nonmetropolitan areas (Cancer Australia, 2023, 2024; AIHW, 2023b; McGrath, 2016a, 2016b).

Out-of-pocket costs were highlighted as stressors associated with relocating (Cancer Australia, 2024; McGrath, 2016b). Finances have to stretch to cover extended periods of treatment, travel and accommodation needs (AIHW, 2023b). Out-of-pocket costs occurred at diagnosis, during treatment, with travel and accommodation, care of family and friends during relocation, and parking if they were driving a vehicle (McGrath, 2016b). At the metropolitan specialist cancer care site, one Queensland study, although older, detailed financial costs as being higher shopping prices, more telephone calls, loss of local support (family/friends), medical expenses, accommodation, maintaining two households (one's regional or remote home and also the metropolitan-based accommodation in the city of Brisbane) and incidental costs of relocating (McGrath, 2000). The Queensland context is relevant to the present research, conducted in Queensland, given young people from outer regional and remote areas are still required to travel to specialist cancer care centres in metropolitan areas (Children’s Health Queensland, 2024b). Loss of income from work exacerbated financial costs in McGrath’s 2000 study, with buffers like supportive employers, accessing financial help from cancer organisations and personal savings. Financial crisis resulted for those on Centrelink payments with no savings or who could not repay mortgages or other debts (McGrath, 2000).

McGrath’s (2016a, 2016b, 2017) research found financial distress is more likely for those who lose or reduce employment, have limited or no work cover or other leave, have limited savings or have major financial debts. A combination of these factors exacerbated acute and long-term financial distress (McGrath, 2016a). One participant explained that Centrelink would not provide income maintenance until their own financial resources were depleted. This, the participant noted, meant there were no finances in reserve for when bills came, which exacerbated their financial distress (McGrath, 2016a).

A further significant finding in the studies reviewed was how the financial costs associated with having cancer and living in nonmetropolitan areas can affect decision-making around the choices people make in their cancer treatment. Mathews et al.'s (2009) Canadian study found that rural residents were more likely to list travel, medical and childcare costs as important factors in their decisions about the kind of cancer care they undertook. The authors stated that these findings could mean cancer patients forgo or alter their care due to these costs (Mathews et al., 2009). This issue was also raised in McGrath's (2015b) study, with one respondent stating, “I am saying financially if I had to choose I would choose my home and stop treatment” (McGrath, 2015b, p. 289). The impacts of travel and relocation for treatment can be seen in both these studies as having negative effects on rural residents, with McGrath's (2015b) study highlighting the gravity of those impacts.

Miedema et al.’s (2013) study, however, found rural participants did not raise this issue of out-of-pocket expenses as often as urban participants. The authors discussed their surprise at the finding, surmising that travel costs may be considered ‘normal’ for those from rural areas and thus not considered as ‘out-of-pocket’ (Miedema et al., 2013). Whilst Miedema et al.’s (2013) study found this, the other studies explored above clearly report concerns about significant out-of-pocket costs associated with travelling away for their cancer care.

A recent scoping review (Lim et al., 2024) of financial aid in children, adolescents and young adult's cancer care, searched articles published between January 2000 and December 2022. The date range of articles reviewed by Lim et al. (2024) is perhaps reflective of the lack of research in the last decade on young people living with cancer in general, let alone those living in outer regional or remote areas. Their review, not specific to the regional or remote context, found access to and delivery of support, administrative and psychosocial factors were barriers to accessing financial aid. Enablers to accessing financial aid were support navigators, establishing a direct connection between aid suppliers and beneficiaries, digital solutions to improve outreach and cultural and community values being used to encourage financial aid supply (Lim et al., 2024). Another systematic literature review (Di Giuseppe et al., 2023) on financial stress for young cancer survivors, not specific to the regional, rural or remote context, located 12 articles between 2010 and 2022. The authors cite amongst what they termed as "limited evidence" (p. 103914), survivors were more often unemployed, had lower incomes and required social security for financial support (Di Giuseppe et al., 2023). Risk factors for greater financial stress were being female, diagnosed with brain cancer and presence of late-effects from cancer treatment (Di Giuseppe et al., 2023).

2.3.3.4 Psychosocial Issues. A systematic literature review (Tanner et al., 2023) of young people living with cancer and not specific to the regional, rural or remote contexts, found 58% of studies reported poorer mental health among young participants with cancer than non-cancer participants. Narrowing the focus to nonmetropolitan research, this finding is consistent with reported distress experienced by young people living in regional, rural or remote areas. Numerous Australian and Canadian studies, either focused on young people or with young people in the participant pool, found negative psychosocial impacts were experienced by people and their families living in nonmetropolitan areas, including the need to travel away for cancer treatment (Dyson et al., 2012; Mathews et al., 2009; McGrath, 2015a, 2015b, 2015c, 2015d, 2016a, 2016b, 2017; Meiklejohn et al., 2017; Miedema et al., 2013; Paul et al., 2013; Sariman, 2017; Sariman et al., 2022; Tulk et al., 2023; White et al., 2011). Negative psychosocial impacts included dislocation from loved ones, education, employment and home communities, lower levels of support and higher levels of distress. Higher levels of help-seeking behaviour by young people in nonmetropolitan areas were found in one study (Goodwin et al., 2021). Navigating additional psychosocial challenges for those from nonmetropolitan areas is exacerbated by adjusting to a life-threatening diagnosis and aggressive, invasive cancer treatments (McGrath, 1999). Dislocation from family, friends, work, school and community was a negative experience for those having to travel away for cancer treatment (McGrath, 2015a).

Lower levels of community support, higher levels of distress and higher levels of help-seeking behaviour were reported by nonmetropolitan participants in research comparing nonmetropolitan and metropolitan experiences of living with cancer. Qualitative Australian research by Miedema et al. (2013) found that young adults from rural areas reported lower levels of community support (meals, financial, emotional, faith and cancer support organisations) than urban participants. Urban participants received almost three times the level of community support of rural participants (Miedema et al., 2013). Canadian quantitative research found higher levels of distress for young adults from rural compared to urban areas (Tulk et al., 2023). Rural young adults lacking social support were also more likely to report higher distress than those lacking social support in urban areas (Tulk et al., 2023). Tulk et al. (2023) pondered whether fewer sources of social support in rural locations may account for their higher reported distress levels (Tulk et al., 2023). Higher levels of help-seeking behaviour by young people from nonmetropolitan areas was a finding in one Australian study (Goodwin et al., 2021). Participants were marginally more likely to seek at least one source of support, with online support favoured more often by younger people (Goodwin et al., 2021). Younger and female participants were also marginally more likely to seek support through cancer support groups (Goodwin et al., 2021).

Lower levels of access to psychosocial support were found for nonmetropolitan young residents in Western Australia living with cancer than their metropolitan counterparts (Shirazee et al., 2016). Seeing a mental health professional, social worker or occupational therapist only occurred for those attending metropolitan hospitals (Shirazee et al., 2016). Those who attended nonmetropolitan centres received less psychosocial support (Shirazee et al., 2016).

Research findings in psychosocial domains have been mixed, with not all noting more negative results for those in nonmetropolitan areas. One study found that Aboriginal people living remotely had higher quality of life scores than those from an outer regional city (Elder-Robinson et al., 2021). The authors pondered whether a higher percentage of Aboriginal people in remote areas might mean unknown elements accounted for higher quality of life scores like connections with land, language and culture (Elder-Robinson et al., 2021). Four other quantitative studies did not find a significant statistical difference between nonmetropolitan and metropolitan participants' self-reports of unmet needs or financial/social impacts of having cancer (Cox et al., 2016; Dyson et al., 2012; Paul et al., 2013; White et al., 2011).

A systematic review of the literature (Fox et al., 2023) not specific to young people from regional, rural or remote areas, found social isolation was prevalent among young adults aged 18-44 years living with cancer to a similar level as those from older cancer and noncancer populations. Social isolation was connected with poorer psychological well-being, but social connectedness improved psychological well-being in many, but not all cases (Fox et al., 2023).

2.3.4 Unique Considerations for Aboriginal and Torres Strait Islander Young Australians

Issues unique to Aboriginal and Torres Strait Islander adults aged 18 and over from nonmetropolitan areas emerged from three Australian studies (Elder-Robinson et al., 2021; Meiklejohn et al., 2017; Sanjida et al., 2022). These are broadly grouped into four main themes: lower mental health scores, service access issues, metropolitan hospital environment issues and an aversion to travelling away again once home. Lower mental health quality of life scores for Aboriginal compared to non-Aboriginal participants from regional and remote areas were found in Elder-Robinson et al.'s (2021) study. The authors did not determine set reasons for lower mental health quality of life scores from the quantitative data. They indicated that further methodological approaches that culturally privilege Aboriginal ideas of wellbeing are needed (Elder-Robinson et al., 2021).

Under service access issues, long waiting times (Sanjida et al., 2022), availability (Sanjida et al., 2022) and coordination of follow-up cancer care (Meiklejohn et al., 2017; Sanjida et al., 2022) were found to be problematic. Access to medication was prohibitive cost-wise for those not accessing the Closing the Gap PBS Co-payment Program (Meiklejohn et al., 2017). The benefits of accessing local primary health centres included feelings of belonging, receiving comprehensive, holistic care, experiencing wider social connections and local transport availability for accessing primary health centres (Meiklejohn et al., 2017).

Metropolitan hospital environment issues included communication barriers and feeling alienated, isolated and culturally unsafe (Sanjida et al., 2022). Communication barriers were language, health staff not attempting to help people with literacy problems, lack of understanding of hospital environments, care pathways and information (including where or how to get information) (Sanjida et al., 2022). The hospital environment was seen as "'alienating' and 'isolated' compared to their country (residence)" (Sanjida et al., 2022, p. 5). Fear of lifts, surgical procedures, recovery time, visiting specialists, medical tools and sterile rooms were common issues (Sanjida et al., 2022). Barriers to cultural safety included a lack of trust in the system, lack of privacy, racism, poor patient-health care provider relationships and removal of hair or body parts due to surgery, which is considered "a violation of culture because body parts should return safely to their country (Sanjida et al., 2022, p. 8).

Meikeljohn et al. (2017) found that, after returning home from treatment, participants had an aversion to travelling away again. Participants expressed a fear of relapse, or their cancer returning. They experienced adverse psychosocial impacts when returning to specialist cancer centres for follow-up due to reminders of their cancer and fear and dread regarding "not receiving 'the all clear'" (Meiklejohn et al., 2017, p. 1599). Some participants considered not reporting symptoms to their GP or refusing allied health referrals if they thought it would involve travelling away, given the physical discomfort, financial costs and time that travel required.

2.3.5 Young People's Needs Upon Returning Home Following Cancer Care Completion

Several studies explored participant's needs upon returning home after their cancer care completion (Goodwin et al., 2023; Holland, Walker, et al., 2021; McGrath, 2001). Emotional, medical and practical support were the highest needs reported by McGrath (2001). Informal relationships are a highly significant way support needs are met in nonmetropolitan areas, and participants wanted emotional support from non-professional sources like family, friends and others going through a cancer experience (McGrath, 2001).

Psychosocial support was the highest post-treatment need for young people living with cancer in Holland et al.'s (2021) study. The biggest barriers for young people accessing psychosocial support came after treatment was finished. The authors noted that in Queensland, post-treatment or survivorship care was inequitable due to geographical location of residence, with nonmetropolitan residents having less access to that care than those in metropolitan areas (Holland, Walker, et al., 2021). Holland et al. (2021) concluded, in alignment with another Queensland study by Bradford et al. (2018), that further work was needed to build equity in access to survivorship care for young people living with cancer from regional and remote areas.

Information needs post-treatment were explored in Goodwin et al.'s (2023) systematic literature review of rural Australian adult cancer survivors. The authors divided the study into two types of needs: content-related information needs and delivery-related information needs (Goodwin et al., 2023). Content-related information included managing side effects and self-management, healthy lifestyle and long-term recovery, follow-up and psychosocial support (Goodwin et al., 2023). Delivery-related information included source-recipient of information (delivered by a care coordinator, counsellor, nurse or support worker), mode of delivery (written care plans, face-to-face conversations and digital exercise tracking tools), timing (delivered at multiple points) and accessibility (not always delivered sensitive to person's current health status or emotional state, user-friendly and delivered in person's native language) (Goodwin et al., 2023).

2.3.6 Potential Solutions

The literature review thus far highlights the potential issues young people living with cancer from nonmetropolitan areas face. After reviewing McGrath (2017), Meiklejohn et al., (2017) and Paul et al. (2013), the integrative literature review I led (Sariman et al., 2020) identified potential solutions to some of these problems. These solutions included (a) coordinating multiple appointments at specialist cancer care sites to reduce the need to travel away as often, (b) establishing long-term trusting relationships, especially for First Nations patients, with staff, including between metropolitan and nonmetropolitan sites, (c) flexible appointment times so employed patients can attend after-hours, (d) preparing young people at diagnosis for potential financial distress and how to get help, (e) use of telehealth or phone calls for young people to maintain contact with loved ones back home, (f) help, where available, to bring a loved one to the treatment sites for visits and (g) using technologies and resources to provide clinical services in people's home towns, including fly-in, fly-out specialist cancer services (Sariman et al., 2020). Goodwin et al. (2021) also pose strategies to improve the appropriateness of support available for regional and remote adults living with cancer. The authors concluded that access to virtual forms of cancer support and information is important for adults from nonmetropolitan areas with less access to the range of face-to-face support services in major regional or metropolitan cities (Goodwin et al., 2021).

2.3.7 Points of Difference Between Contributions of Quantitative and Qualitative Studies

Reviewing the methodological approaches of the literature revealed some important differences in findings according to whether the research undertaken was quantitative or qualitative. Thirteen quantitative studies used measures such as a Childhood Cancer Survivor Study Needs Assessment Questionnaire (Cox et al., 2016), 10-item Kessler Psychological Distress Scale (Tulk et al., 2023) or an accommodation data sheet at a metropolitan Leukaemia Foundation accommodation service (McGrath, 1999). These 13 studies generally reported on measurable items like demographic, health service or statistical data, or ratings on scales. As noted previously, one study found a positive relationship between young people's nonmetropolitan residency and clinical trial enrolment but could not provide reasons other than an association with being treated at large hospitals (Mobley et al., 2019). Other quantitative studies found no difference between metropolitan and nonmetropolitan responses on psychosocial domains of quality of life (Elder-Robinson et al., 2021), unmet needs (Cox et al., 2016; Dyson et al., 2012; White et al., 2011) or the 'financial and social' impacts of having cancer (Paul et al., 2013). Authors of these studies speculated about reasons for their results, but in the absence of qualitative enquiry could provide little context for participant answers; reasons were not available in the data.

By contrast, across the six qualitative studies exploring people's lived experiences of cancer, other findings emerged which spoke to a more complex and nuanced experience in regional, rural and remote areas. For instance, in Meikeljohn et al.'s (2017) qualitative study, one direct participant quote noted that appointments should be coordinated at the metropolitan cancer centre so they did not have to make multiple trips from their nonmetropolitan home to attend them (Meiklejohn et al., 2017). Taken together, the differences in findings in the qualitative literature and the capacity for young people's lived experiences to be better and more directly captured through qualitative methods highlight the need for further qualitative explorations of this topic.

2.4 Social Work Practice with Young People Living with Cancer from Nonmetropolitan Areas

This section outlines current social work practice with young people living with cancer from nonmetropolitan areas, including the literature available to inform practice and the body of theoretical knowledge social workers may draw from. To understand what is currently known about this topic, literature was sourced that relates to social work practice in health, social work practice in regional, rural or remote areas, social work practice with adolescents and young adults and the various theories available for social work professionals to draw from in their practice.

2.4.1 Social Work Practice in Health, Outer Regional and Remote Areas

Evidence-based practice (EBP), the systematic search, appraisal and integration into practice of relevant research evidence in conjunction with client preferences and the practitioner's knowledge, is deemed an aspirational goal for health social workers (Petrakis, 2018). Social workers are always required, no matter where they are situated, to practice with a sound behavioural and psychosocial theoretical and practice knowledge base relevant to the people they are working with (AASW, 2023; Connolly et al., 2019; Petrakis, 2018).

Maidment and Bay (2012) argue for social workers to develop a 'place-based' social work practice model for working in regional, rural or remote areas (Maidment & Bay, 2012). This involves a recognition of the centrality of geography in people's lives where "place, space, sustainability and identity are considered central to personal, community and global well-being" (Maidment & Bay, 2012, p. 222). Belonging to a place or locality occurs through kinship, neighbourhood, friendships, occupations and beliefs (Pugh & Cheers, 2010). For smaller communities, in particular, identity and social position are linked to people's ideas about the place they live in (Pugh & Cheers, 2010). This understanding of the importance of place for people from regional, rural and remote areas can inform social workers’ knowledge of how leaving one’s place, one’s community, can be a significant issue for young people newly diagnosed with cancer who must travel away for treatment. Young people experience emerging independence, identity formation and relationships with family and friends, including educational goals, whilst traversing a time of significant developmental change in adolescence and young adulthood (Gualthérie van Weezel et al., 2022). Not only is a cancer diagnosis a major disruption to these normal developmental processes (Zebrack et al., 2016), but having to move away for diagnosis or treatment brings many hardships for young people (Sariman, 2017; Sariman et al., 2020, 2022).

2.4.2 Social Work Practice with Young People

Petrakis (2018) has written extensively on health social work practice with children and young people, noting that social workers typically intervene at times of transition or crisis, such as when accidents, disabilities and illness occur. Health and hospital social workers will encounter young people and their families at these transition points, including when the young person is diagnosed or receiving treatment for cancer. Encounters occur in emergency departments, general paediatric wards, specialist clinics and oncology and palliative care (Petrakis, 2018). Petrakis believes social workers can most effectively help young people by understanding how they process illnesses, such as cancer, and diagnoses during the developmental life stage they are in. Theories of child and adolescent development are particularly useful, with human development theorists such as Piaget, Kohlberg and Erikson as good examples of where to source these theories (Petrakis, 2018).

A social work study into the supportive care need of young people living with cancer in the Netherlands concluded that social workers need to be involved in hospital and health service care provision to young people through the entire disease process from diagnosis, during treatment and after treatment, including end-of-life care (Gualthérie van Weezel et al., 2022). Age-specific care was recommended to assist young people in accessing age-specific resources and support, enabling young people living with cancer to maintain independent roles within their families and communities. Gualtherie van Weezel et al. (2022) recommended using a biopsychosocial model as a theoretical and practice framework to systematically assess young people's needs when living with cancer.

An Australian study into social work practice in oncology found that social work practice in cancer care typically involves a comprehensive psychosocial assessment that considers physical, psychological and social domains of a person's life in adjusting to their cancer diagnosis (Pockett et al., 2022). Capabilities required in oncology social work require an understanding of the contextual needs of people diagnosed with cancer, the hospital and health setting and the ability to perform complex tasks of liaison and interprofessional collaboration (Pockett et al., 2022). However, not all hospitals or health services have oncology teams or social workers employed to assist people with cancer (Pockett et al., 2022). Pockett et al.'s (2022) comprehensive literature review informing their study found no Australian research on social work interventions in cancer care.

2.4.3 Social Work Practice with Young People Living with Cancer

Social workers need to continuously screen and assess psychosocial needs over time for young people living with cancer, according to social work specialists and researchers in the area, Levin, Zebrack and their medical counterpart, Cole (2019). Levin et al. (2019) have introduced the idea of 'precision psychosocial medicine', arguing there is no universal, prescriptive method for providing psychosocial support to young people living with cancer. The authors state precision medicine's goal is to get the "right" treatment to the "right" patient at the "right" time in the "right" dose (Levin et al., 2019, p. 5). They suggest a "precision psychosocial medicine model" tailored to young people's individual behaviour and outcomes, taking biopsychosocial and environmental contexts into account at multiple points (Levin et al., 2019). The authors argue that social workers should assess and re-assess young people's needs at multiple points, as needs can change over time.

Pockett et al. (2016), in an Australian social work oncology workforce mapping study, found social work participants were well-qualified and highly experienced practitioners providing psychosocial cancer care throughout the geographically dispersed Australian country. They found that

68% of respondents reported professional development needs, concluding that a lack of resources or integrated psychosocial care impeded comprehensive social work cancer care (Pockett et al., 2016). In another Australian study, Pockett et al. (2022) explored the most common social work interventions in adult cancer care. These were psychosocial assessment, financial management counselling or education, service coordination and advocacy. Pockett et al. (2022) concluded from their study that social work comprehensive psychosocial cancer care was well-demonstrated by social work participants throughout Australia, especially in complex situations affected by social and health inequalities. Further, more social work services were needed where social risk factors contributed to worse cancer outcomes (Pockett et al., 2022).

Another Australian study by Joubert et al. (2022) comparing general medical and oncology social work practice found that oncology social workers typically provided care for issues of adjustment to cancer, anxiety and finances. Oncology social workers provided more interventions using advocacy, brief or single sessions and counselling than general medical social workers, and they reported greater use of narrative or supportive care models (Joubert et al., 2022). Joubert et al. (2022) concluded that oncology social work differed greatly from general medicine social work, highlighting the unique needs encountered in oncology social work practice.

Prior to the present research, the study I conducted with three regional Queensland social workers explored the theoretical and practice frameworks guiding social work practice with young people living with cancer in regional, rural and remote areas (Sariman, 2017). This study found that the social workers had well-developed practice theories and frameworks. The participants used client-centred, reflective and reflexive (understanding and improving sense of self in the helping relationship) practice. They foregrounded building the helping relationship from their first contact with young people, knowing this foundation would serve the longer-term helping work they would do with their young clients (Sariman, 2017).

Guidelines has been developed for caring for the social well-being of young people living with cancer in Australia (Schilstra et al., 2024). Whilst not specific to social work practice, the guidelines recommend which young people living with cancer should have their social well-being assessed, who might lead the assessment, when it should occur and with which tools, and how staff can optimally care for young people's concerns around their social well-being (Schilstra et al., 2024). The guidelines would be useful to adopt in clinical social work practice.

2.4.4 Theories for Social Work Practice with Young People During Transition/Crisis and Living with Cancer

Having established that health social workers typically meet young people at times of transition or crisis, such as a cancer diagnosis, theories can guide social work practice frameworks in the health settings where these meetings and interventions occur. First, I explore theories for social work practice with young people at times of transition or crisis. Next, I examine theories of social work practice with young people living with cancer.

A social worker's own theoretical practice framework is a foundational body of knowledge underpinning practice (Harms & Maidment, 2018). Systemic theories are useful in social work involving young people with cancer, given that, regardless of their age at diagnosis, they require a carer (usually a parent) throughout their treatment (including travel away); whole families are impacted (Petrakis, 2018). Attachment theories are also useful in understanding the young person's relationship with parents and caregivers through their cancer experience (Holmes, 2014). Cancer diagnosis is a crisis and, therefore, crisis theory is useful to guide in helping young people and their families manage a young person's cancer experience (see Healy, 2022; Payne, 2020).

Cancer is a life-threatening illness. A threat to a young person's life may be traumatic and elicit feelings of grief and loss, including in conjunction with other losses, such as having to leave one's home and community and disruptions to relationships and education to travel for treatment. Trauma theory and grief and loss theory may therefore be useful perspectives through which to understand young people's cancer experiences.

Adolescent and young adult research has explored the trauma and distress young people experience throughout a cancer diagnosis and treatment (see Fisher et al., 2018; Osmani et al., 2023; Sansom-Daly & Wakefield, 2013). Bloom (2018, 2020) is an often-cited trauma theorist. Bloom's work highlights how trauma effects people (Bloom, 2018), and provides indicators for when young people are experiencing trauma (Bloom, 2020). These approaches are useful in understanding how young people process trauma, signs they may be experiencing trauma and ways to support young people who are traumatised.

There are many grief and loss theorists, with those most often referred to being Elizabeth Kübler-Ross (see Kübler-Ross & Kessler, 2005), Colin Murray Parks (see Murray-Parkes, 1996) and J. William Worden (see Worden, 2009). Grief not recognised by society is known as disenfranchised grief, which is relevant if young people's family, friends, loved ones and communities do not appreciate the grief young people may be experiencing (Doka, 2002).

My previous, unpublished study (Sariman, 2017) is the only research I found on the theoretical and practice frameworks of social workers who work with young people living with cancer from nonmetropolitan areas. The three regional social work participants demonstrated an ability to provide theoretically sound information and support for young people living with cancer in nonmetropolitan areas. The social workers identified systems, empowerment, grief and loss, child development, crisis, attachment, narrative, strengths-based and solution-focused theories underpinning their practice. They adopted client-centred, person-in-environment approaches, including building rapport from first contact, being part of the young person's team, imagining what it was like for the young person to go through their cancer experience, treating young people like people and not their diagnosis and recognising all young people are different.

The practice frameworks in that study (Sariman, 2017) included interventions such as psycho-education, family therapy, compassion, narrative therapy, and culturally sensitive practice. Further interventions flowing from the regional social workers' theoretical and practice frameworks included psychosocial assessments, using their own practice wisdom to guide helping young people, seeking permission from young people to include their diagnosis or needs with loved ones and referrals to other help services. The study's social work participants could identify gaps in their theoretical and practice knowledge, which included child development, behavioural science, strengths-based, grief and loss theories, family therapy, mental health, interpersonal psychotherapy approaches and cognitive behavioural therapy. The social workers also identified ways they were currently or intending to bridge those theoretical and knowledge gaps. These findings were also characteristic of Pockett et al.'s (2016) study, where 68% of social work participants recognised professional development needs. Of those 68% of participants, the highest-rated areas of professional development needs were psychosexual concerns, use of a range of counselling skills, survivorship issues and use of complementary therapies (Pockett et al., 2016).

Social work research in cancer care was found to be limited in Pockett et al.'s 2015 literature review. The literature review showed social work researchers were more likely to be contributors to research than lead authors of adult oncology research. The reviewed studies indicated social work interventions most often used included cognitive/behavioural, information/education, non-behavioural, supportive counselling, family counselling, social support and social functioning. Patient advocacy, patient and systems navigation, resource location and community referrals were also common social work interventions. Other social work interventions included psychosocial assessments, risk assessments including screening for psychosocial distress, financial assistance, coordinating communication amongst cancer care teams social workers belong to, couples counselling, psychotherapy, maintenance/relapse prevention, referral to specialists and services, communication skills training, multidisciplinary team interventions, substance misuse interventions and peer to peer programs. The authors also found social work practice in the studies went beyond evidence-based interventions (Pockett et al., 2015).

Narrowing the focus to adults from nonmetropolitan areas, a more recent Australian study by Pockett et al. (2022) investigated the reasons for social work referrals in adult cancer care and the types of interventions oncology social workers undertake. Sixty per cent of cases referred to social workers in the study were from regional, rural or remote communities. Social workers in metropolitan areas also saw high numbers of adults from these nonmetropolitan areas. Over 50% of all referrals to social workers were for initial diagnosis of cancer, and once again, adults from regional, rural or remote locations represented the highest number of these referrals. The most frequent social work interventions provided by oncology social workers in the study, starting from the most frequently chosen, were psychosocial assessment, financial management counselling and education, service coordination and then advocacy. Counselling interventions accounted for 42% of all adult social work interventions in the study.

2.5 Gaps in the Literature and Further Social Work Research Required

As stated, adolescence and young adulthood are times of major developmental change with unique challenges. Young people in nonmetropolitan areas who receive a cancer diagnosis are vulnerable by age and geographical distance from major specialist cancer care services. These are issues directly relevant to social work practice with young people, given social work's focus on promoting health and wellbeing and addressing inequitable access to services. However, there is limited qualitative research on young people living with cancer from nonmetropolitan areas. Most research focusing on nonmetropolitan cancer care issues is of adults 18 and over and is not specific to young people. Young people’s own voices are missing in the literature. There is no social work-led research on young people living with cancer from nonmetropolitan areas. There is also no research targeting social work practice with young people living with cancer from nonmetropolitan areas. Three implications of this limited evidence base are, firstly, that social workers struggle to enhance service delivery to young people living with cancer from nonmetropolitan areas; secondly, practice frameworks guiding psychosocial care of young people living with cancer are not informed by research representing the nonmetropolitan context; and thirdly, young people with cancer from nonmetropolitan areas cannot expect improvements in care they may require given the limited understanding of their needs. Further research is required into the experiences of young people living with cancer, and the social workers who work with them, from nonmetropolitan areas.

2.6 Conclusion

This literature review found that young people living with cancer in nonmetropolitan areas are often reported as being disadvantaged due to poorer health outcomes, lower survival rates and higher incidences of cancer. A combination of limited qualitative research into the experiences of young people living with cancer from nonmetropolitan areas and no empirical studies into social work practice in this area is a gap in the literature. This gap informed this study’s objective to explore the perspectives of both young people living with cancer from nonmetropolitan areas and the social workers who work with them (as outlined in Chapter One). Exploring these two perspectives will answer the study’s fourth, overarching question: What do the perspectives of young people and social workers tell us about the experience of being a young person living with cancer in outer-regional and remote Queensland, and how might this inform social work practice?

Chapter Three: Methodology

Chapter Three outlines this study's methodology, including discussion of the research settings and location, research design, research methods and procedures, ethical considerations and how results will be disseminated.

3.1 Research Setting/Location(s)

To achieve the research aims and answer the research questions, I chose a single site for phase one and two sites for phase two of the research. The outer regional phase one site was the Cairns and Hinterland Hospital and Health Service (CHHHS). The CHHHS is a specialist outer regional cancer care site capturing young people from immediate geographical areas and more outer regional and remote Far North Queensland areas. CHHHS provides a range of specialised services to people of all ages diagnosed with cancer from regional, rural and remote areas south to Mission Beach, west through to Croydon and north through to Cape York Peninsula and the Torres Strait Islands (CHHHS, 2024). Those aged up to the age of 18 diagnosed with cancer through the CHHHS paediatric medical stream travel to the Queensland Children's Hospital (QCH) in Brisbane. Children's Health Queensland, which includes QCH, is a statewide network of health services and staff providing specialised paediatric care for children and young people up to the age of 18 (Children's Health Queensland, 2024a). A share-care model exists in the statewide Children's Health Queensland network, where low-risk cancer treatment and supportive care are provided at 10 Queensland hospitals (Children's Health Queensland, 2024b). The CHHHS paediatric oncology service at Cairns Hospital is one of the statewide share-care hospitals (Children's Health Queensland, 2024b).

Young people aged 18 and older who require specialist cancer services unavailable in Cairns (such as stem cell transplants, some specialist surgeries or clinical trials) may also travel to Townsville or Brisbane health sites. There are exceptions where young people older than 18 still travel to the QCH owing to their cancer type and the availability of paediatric oncology specialists who treat those types of cancers. Young people typically remain in Townsville between one and 14 weeks or in Brisbane between two weeks and 12 months for the specialist cancer treatment required, which is unavailable in Cairns.

Once they have completed their treatment regime in Townsville or Brisbane, young people return to Cairns/Far North Queensland and receive ongoing treatment and care through either the CHHHS paediatric oncology or adult cancer care services at Cairns Hospital. Share-care arrangements between sites often require trips back to Brisbane or Townsville, dependent on diagnosis and treatment protocol. Young people who have commenced treatment under Children’s Health Queensland remain under the share-care arrangement until their longer-term monitoring ceases. Longer-term monitoring commences once treatment is finished. Longer-term monitoring continues up to the age of 25 or older, dependent on cancer type and corresponding long-term monitoring protocol.

My employment in outer regional Far North Queensland involved providing care to young people meeting the eligibility criteria of my study. Far North Queensland was a site where I had working knowledge of services and staff, providing access to gatekeepers who could assist with accessing my research population (Krysik & Finn, 2013; Singh & Wassenaar, 2016). This direct access to service systems and processes supporting young people assisted me in gaining entry to the young people, forming the sampling pool for my study. Accessing a vulnerable population of young people living with cancer in health care requires a complex series of procedures and permissions with health human research ethics and staff responsible for maintaining the safety of patients (Singh & Wassenaar, 2016). Staff were aware and supportive of my reasons for conducting the research.

The phase two sites were the CHHHS and the Queensland Children’s Hospital (QCH) in Brisbane. The relatively small pool of social workers in the CHHHS (under 10) necessitated adding another site. As noted in Chapter Two, recent Australian research found that 60% of cases referred to oncology social workers in metropolitan hospitals were from regional, rural or remote communities, with higher numbers of oncology patients seen by social workers from nonmetropolitan than metropolitan locations (Pockett et al., 2022). These findings, although for a study of adult oncology social workers, strengthened my rationale of including a metropolitan site for this study. QCH is a major tertiary receiving site for young people up to 18 years of age diagnosed with cancer from all over Queensland, including outer regional and remote Queensland areas (Children's Health Queensland, 2024b). QCH employs oncology paediatric social workers who work with children and young people from all over Queensland. Social workers from CHHHS and QCH are ideally placed to offer a broad range of contextual perspectives through their direct psychosocial work with young people living with cancer from regional and remote Queensland areas.

3.2 Research Design

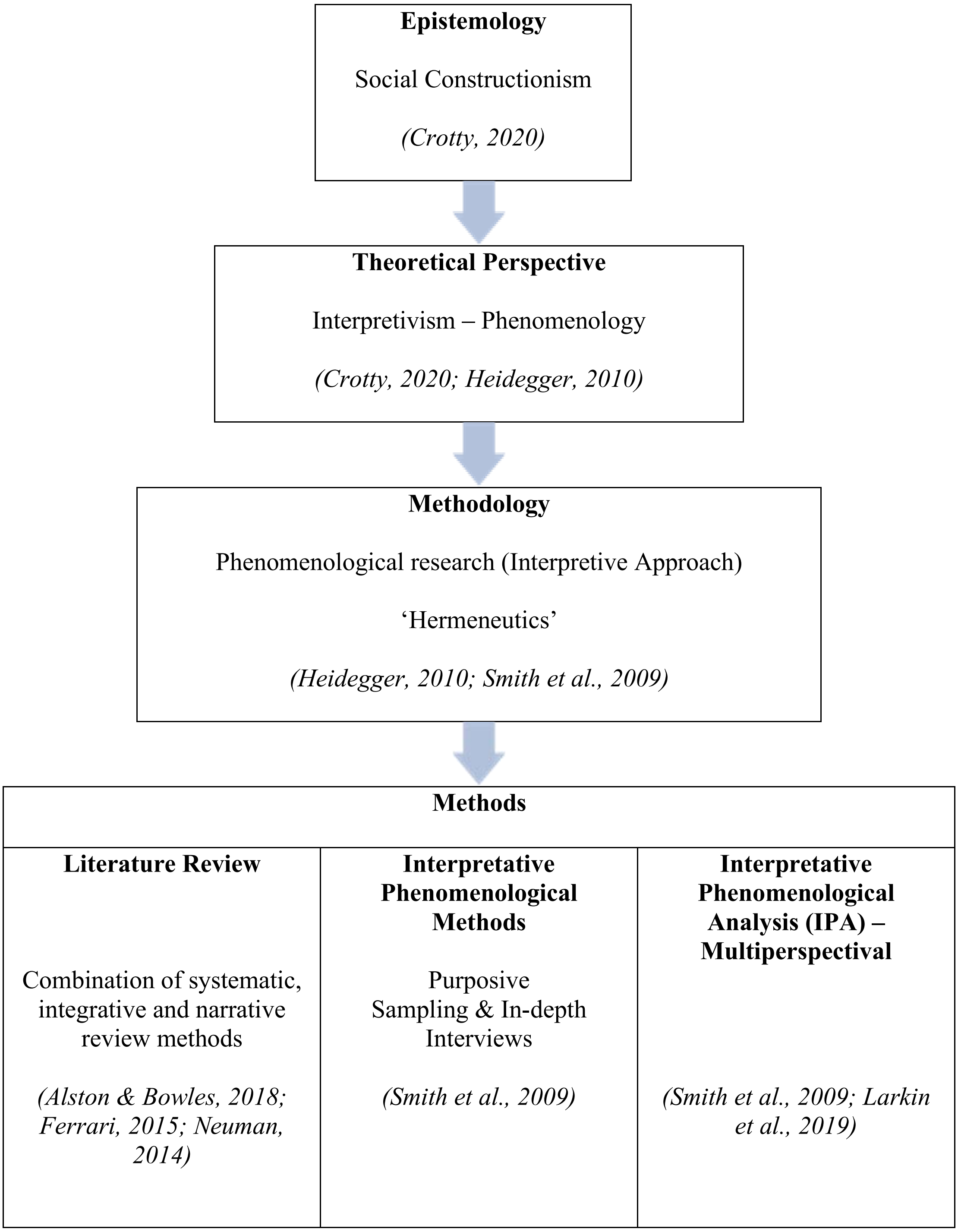
As introduced in Chapter One, this qualitative study is underpinned by social constructionism, using an interpretive phenomenological approach and multiperspective design. Qualitative research is ideally suited to studies seeking to understand human behaviour from the person’s perspective, reporting on it in the person’s own language (Minichiello et al., 2008). Chapter Two highlighted the benefits of qualitative research in offering the capacity to explore reasons for participant answers, leading to deeper, explanatory contexts and understandings of data. With minimal literature specifically targeting young people living with cancer in nonmetropolitan areas, I designed a broad qualitative approach to elicit a thorough understanding of young people’s experiences through in-depth interviews.

3.2.1 Theoretical Framework

With this study, I aimed to explore the phenomenon of being a young person living with cancer from outer regional and remote Queensland. The best philosophical fit to underpin and guide my research was interpretive phenomenology (Creswell & Poth, 2018). Interpretive phenomenology is one of the research approaches under the epistemological umbrella of social constructionism (Crotty, 2020). Figure 1 depicts the study’s theoretical framework.

Figure 1

Theoretical Framework of Study



In philosophy, a person’s fundamental belief about the nature of knowledge is called ‘epistemology’ (Alston & Bowles, 2018). Epistemology, or the theory of knowledge, is embedded into the theoretical perspective, methodology, validity and scope of research (Crotty, 2020). Very simply, epistemology is the theory of knowledge underpinning research and, specifically, the researcher’s approach to the research they undertake. Social constructionism is the theory of knowledge underpinning this study. Constructionism is also referred to in the literature as ‘constructivism’ (see Creswell & Poth, 2018). Constructionism views all knowledge and meaningful reality based on human practices as constructed in and out of the interaction between people and their world, developed and transmitted in a social context (Crotty, 2020). Social constructionism holds that the way people make sense of the world derives from their social interactions within and because of their culture (Crotty, 2020). Essentially, meaning is socially constructed (Crotty, 2020). I previously explained how social workers endeavour to assist people in their interactions within their social environments (IFSW, 2023). People’s social interactions and culture are central to social constructionism (Crotty, 2020), which is central to social work (Connolly et al., 2019).

Researchers holding a social constructionist epistemology seek to understand a phenomenon from research participants’ views (Creswell & Poth, 2018). The researcher develops theories or patterns of meaning through the inductive development of participant accounts of that phenomenon (Creswell & Poth, 2018). Social constructionism is thus the epistemology (theory of knowledge) underpinning this study. Of the different philosophical approaches that fall under social constructionism's umbrella, phenomenology and specifically, interpretive phenomenology, informed my approach.

3.2.1.1 Interpretive Phenomenology. Defining interpretive phenomenology is a research exercise in itself. Amongst the major phenomenological philosophers, interpretive phenomenology has no simple definition. However, this does not preclude discovering the definition. Ironically, yet helpfully, the very act of trying to define *interpretive* phenomenology is rather like the methodological mission of *phenomenology*, which is essentially to bring to light something that was previously unknown about a phenomenon: “…to let what shows itself be seen from itself, just as it shows itself from itself. That is the formal meaning of the type of research that calls itself “phenomenology” (Heidegger, 2010, p. 35).

Heidegger (2010) defined a *phenomenon* as “what shows itself in itself, what is manifest. The ‘phenomena’ are thus the totality of what lies in the light of day or can be brought to light” (Heidegger, 2010, p. 26). Heidegger (2010) explains the need for phenomenology like this: “[I]t is precisely because phenomena are initially and for the most part *not* given that phenomenology is needed. Being covered up is the counterconcept to ‘phenomenon’” (Heidegger, 2010, p. 37).

Interpretive phenomenology, according to Heidegger (2010), involves “…the work of interpretation” (Heidegger, 2010, p. 38). My understanding as I immerse myself in Heidegger’s (2010) writing is that interpretation of phenomena occurs when phenomena are not necessarily apparent. Phenomena are either unknown or somehow covered up, which leads the enquirer to seek meaning or develop knowledge of the phenomena. In phenomenological research, the ‘essence’ is the ultimate outcome – something that conceptually captures and expresses the entirety of the experience under investigation (Larsen & Adu, 2022). Phenomenological research goes beyond participant descriptions of a phenomenon, seeking to inductively develop a pattern of meaning from interpreting research participant narratives (Creswell & Poth, 2018). Interpretive phenomenological research seeks to ‘bring to light’ what it *means* to experience that phenomenon and, thus, what the essence of the experience is. Essentially, interpretive phenomenology is a process where researchers interpret the meaning of the lived experiences of research participants who share that experience (Creswell & Poth, 2018; van Manen, 2016).

Interpretive phenomenology developed out of the philosophy of Edmund Husserl. Husserl urged phenomenologists to go “back to the things themselves” (Smith et al., 2009). Philosopher Martin Heidegger was a student of Husserl’s (Smith et al., 2009). Heidegger, whilst acknowledging “an intellectual debt to Husserl” (Smith et al., 2009, p. 16), diverged into interpretive or ‘hermeneutic’ phenomenology. Heidegger posited that the meaning of being could be found using the ‘interpretation of time’ as the ‘horizon’ through which being can be understood (Heidegger, 2010). In essence, Heideggerian phenomenological research examines human experiences over the course of time – the past, present and future (Adolfsson, 2010). My research also seeks to do this. I examine the experience of being a young person living with cancer from outer regional or remote areas by interviewing young people at a point in time (when treatment had finished at least six months prior) with them reflecting on three time points at diagnosis, during cancer treatment and after cancer treatment. I also asked young people what their life was like before they were diagnosed with cancer, exploring how having cancer and going through cancer treatment changed them and made them who they are now, at the point of the interview, in their own eyes. The interviews with social workers sought context on young people's experiences by asking for social work observations through young people's diagnosis, treatment and post-treatment cancer experiences and changes young people had shared that occurred due to their cancer experience.

Interpretive phenomenology introduced me to a research design embracing phenomenology and actively using interpretation in its processes. This is known as interpretative phenomenological analysis, or IPA (Smith et al., 2009).

3.2.1.2 Interpretative Phenomenological Analysis (IPA). IPA has been informed by three key philosophical areas – phenomenology, hermeneutics and idiography (Smith et al., 2009). The main philosophers informing IPA are Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2009). Hermeneutics, or the theory of interpretation, can be found in three hermeneutic phenomenologists – Heidegger, Schleiermacher and Gadamer (Smith et al., 2009).

IPA research aims for the phenomena to be expressed on its own terms and uses analysis as an interpretative process (Smith et al., 2009). In IPA, successful interpretation emanates from within participant/s text/s – the meaning is found in the text (Smith et al., 2009). IPA is sensitive to the need for analysing the text itself and not being influenced by the researcher's own conscious or unconscious 'fore-understandings', 'conceptions' or 'preconceptions' (Smith et al., 2009). Bracketing is, therefore, a goal for IPA researchers. Bracketing, introduced by Husserl and central to most phenomenological research, requires the researcher to 'bracket' or 'set aside' their own thoughts and opinions and be purely objective on what they are reporting (Moustakas, 1994). In IPA, bracketing during data collection events includes interviews with participants that enable "participants to express their concerns and make their claims on their own terms" (Smith et al., 2009, p. 42). Due to my clinical social work practice experience with young people in a regional context, I am "positioned within" the research (Creswell & Poth, 2018). My practice has shaped the research formulation and design. Acknowledging this, I explore the ways I managed IPA's goal of bracketing in my data collection and analysis in Section 3.3.4 on quality and rigour.

IPA examines how people make sense of their major life experiences (Smith et al., 2009). IPA's founding authors explain: "When people are engaged with 'an experience' of something major in their lives, they begin to reflect on the significance of what is happening and IPA research aims to engage with these reflections" (Smith et al., 2009, p. 3). IPA started in psychology, with early work in health psychology growing into related disciplines in human, health and social sciences around the world (Smith et al., 2009). IPA's core interests tend to be with the human predicament and, thus, it focuses on people engaging with the world (Smith et al., 2009). IPA studies typically have smaller numbers of participants and aim to find a reasonably homogenous sample, allowing an examination of convergence and divergence (Smith et al., 2009). The researcher interprets the accounts of participants to gain an understanding of their experience (Smith et al., 2009). Theoretical generalisability to a broader population is incumbent on the reader, who may determine transferability based on their existing professional and experiential knowledge (Smith et al., 2009).

Methodologies for approach in interpretive phenomenological research reveal differences of opinion amongst its major philosophers and scholars. Husserl and Heidegger are good examples of these differences, with Husserl focusing on descriptive phenomenology and Heidegger branching away into interpretive phenomenology (Smith et al., 2009). IPA is a type of hermeneutic (interpretive) phenomenological analysis that has drawn criticism from phenomenological scholars and researchers. It has been argued that IPA is not strictly "hermeneutic" in approach and, in fact, follows descriptive phenomenological techniques, for instance, in data analysis such as the method of 'reduction' (reducing research participant texts to 'themes') before the final phase of full interpretative analysis (Giorgi, 2010; Gyollai, 2020; Zahavi, 2019). Giorgi (2010) goes so far as to say IPA should actually be called "Interpretative Experiential Analysis (IEA)", arguing that IPA is not a phenomenological style of analysis and lacks scientifically sound processes in some of its methods.

I acknowledge that the field of philosophy in qualitative research enjoys a contested history, including interpretive phenomenology and the chosen method of data analysis and research design (IPA) that helped shape this study. Throughout my data analysis, I have had these criticisms of IPA in mind and tried to remain true to the hermeneutic intentions of interpreting the data in ways that embrace the phenomenological philosophical concepts historically outlined in this chapter.

3.2.1.3 Multiperspective Designs in IPA. IPA studies typically seek to explore a phenomenon from a reasonably homogenous sample (Larkin et al., 2019; Smith et al., 2009). Some IPA studies, like this one, are embedded within a conceptual framework that understands the phenomenon is not exclusively situated within the narratives of those who are directly going through the experience (Larkin et al., 2019). The phenomenon is also situated with others who belong to the person's world, including loved ones and those engaged in people's lived experiences (Larkin et al., 2019). Multiperspective IPA research provides an opportunity, through rigorous, epistemologically coherent designs, to capture more complex and systemic experiential phenomena using multiple perspectives to explore those phenomena (Larkin et al., 2019). As Larkin (2019) states, "The meanings of events and processes are often contested and can sometimes be understood in a more complex manner when viewed from the multiple perspectives involved in the system which constitutes them" (Larkin et al., 2019, p. 194). Social workers who work with young people from outer regional and remote areas have an immersive understanding of young people's experiences. However, due to not directly going through cancer diagnosis and treatment themselves, they are likely to have different views of it (Larkin et al., 2019). A potential advantage of multiperspective IPA designs is their capacity for greater impact, whereby "convergence and triangulation of viewpoints can be more persuasive than an analysis drawn from a single sample" (Larkin et al., 2019, pp. 194-195). A stronger, more persuasive analysis was deemed useful to increase the confidence with which the study could meet its aim of informing social work practice (Larkin et al., 2019).

Young people from nonmetropolitan areas experiencing cancer diagnosis have frequent contact with, and care in, health systems. They experience multiple contacts with practitioners involved in their care, including social workers. As shown in Chapter Two, a major gap in the literature is the voices of young people from nonmetropolitan areas who are living with cancer. Privileging young people's perspectives in this research was a priority. However, there is also a gap in social work knowledge and literature on practice with these young people. Social work perspectives could also meet the aim of informing social work practice, addressing that gap in the literature. These social work perspectives could offer context for young people's experiences, given social workers' direct psychosocial work with young people living with cancer. Therefore, the two perspectives chosen to meet the research aims and objectives were young people living with cancer from outer regional and remote Queensland and social workers experienced in providing psychosocial cancer care to young people from outer regional and remote Queensland.

Social work perspectives were included given the close, professional interaction social workers have with young people at various intersecting points with the health service. Thus, they were an ideal choice as a 'directly related group' (Eatough & Smith, 2017; Larkin et al., 2019; McInally & Gray-Brunton, 2021). The added context of social work accounts of the experiences of young people living with cancer from outer regional and remote Queensland has led to additional information in my study that was not available in the data from interviews with young people. One example is that young people recruited in phase one gave their accounts after their treatment had finished. Phase one's young participants, therefore, had curable cancer. Another example is that none of phase one's young participants identified as Aboriginal and Torres Strait Islander Queenslander. Social workers in phase two research, however, offered perspectives on their observations of the experiences of young people whose cancer was incurable and of young people who were Aboriginal and Torres Strait Islander Queenslanders. Research designs seeking to "give voice" to groups who might otherwise not be reachable or able to speak for themselves are possible through multiperspectival designs (Larkin et al., 2019).

3.3 Research Methods

3.3.1 Inclusion and Exclusion Criteria

Various inclusion and exclusion criteria were used to find participants in this study. The inclusion criteria for young people were that they must be aged 15–25 and have been diagnosed with cancer before the age of 25, and they needed to be living in Far North Queensland. Treatment must have finished at least 6 months prior to interview allowing enough time for the young person to have recovered from treatment, but not too long to hinder recollections of the cancer experience. Exclusion criteria included if the young person was currently undergoing treatment for cancer and if the young person between 15 and 18 years was assessed as not having the capacity to consent to participation in the research.

The inclusion criteria for social workers was that participants were Queensland Health social workers from CHHHS or QCH providing, or who had provided in the last 10 years, psychosocial support to young people living with cancer from Far North, outer regional or remote Queensland areas who travel or temporarily relocate to regional or metropolitan specialist cancer care centres for diagnosis or treatment. Social workers receiving clinical supervision from myself, the researcher, were excluded from participating.

3.3.2 Recruitment and Sampling Strategy

In qualitative research, recruitment and sampling is done purposefully (Creswell & Poth, 2018). Purposive non-probability sampling means the researcher chooses individuals and sites because they can purposefully provide knowledge related to the research problem and central study phenomenon (Creswell & Poth, 2018). The sample purposively chosen represents a perspective of the phenomena under study (Smith et al., 2009). For a multiperspectival IPA study, each perspective chosen needs to be represented by participants who have experience with the phenomenon in question (Larkin et al., 2019). Recruitment of participants to IPA studies is typically done via referral (through gatekeepers), opportunities (from the researcher's own contacts) or snowballing (referrals by research participants) (Smith et al., 2009).

The study's two participant groups were young people living with cancer from Far North Queensland (phase one) and social workers from CHHHS and QCH (phase two). A purposive sampling strategy was used with an IPA orientation to offer insights into the phenomenon (Smith et al., 2009) of experiences of living with cancer. Engaging with key clinical gatekeepers, clinical networks and snowball sampling (Smith et al., 2009) was used to identify and recruit participants. The interpretive tradition of phenomenology, including multiperspective design, uses in-depth interviewing as a research method, to explore and record participants' thick descriptions and understanding of the study phenomenon (Larkin et al., 2019; Minichiello et al., 2008; Smith et al., 2009).

Reflecting on experiences at different stages of treatment is consistent with Heidegger's (2010) interpretive phenomenological approach. Phase one participants were all interviewed at a single point in time, at least six months after treatment had finished. They were asked to recall their experiences at diagnosis, during their cancer treatment, and post-treatment. This included how they felt their experience was shaped by being from an outer regional or remote area.

Long time lapses between experiences and the qualitative interview are found in the literature (Bute & Jensen, 2011), including studies for young people living with cancer (Hendriks et al., 2024) and adults remembering childhood cancer experiences (Kadan-Lottick et al., 2002). Lapses in time between experiences and their narration has been theorised as important to the process of sensemaking in qualitative research (Sharf & Vanderford, 2003). Sharf & Vanderford (2003) postulate lapses in time between lived events and recounting them contribute to how people make sense of those experiences. A study by Bute & Jensen (2011) found their young adult participants, with an average age of 29 years, were more likely to be confident of their recollections when a greater time lapse had occurred between the experience and their interview. An IPA study exploring 11 young people's cancer experiences in the Netherlands (Hendriks et al., 2024) had an average length of time between diagnosis and interview of 5.3 years, with the longest time being 12 years. In my study, the average length of time between cancer treatment finishing and interview was 6.9 years. Quantitative research has shown knowledge deficits for adults diagnosed with cancer as children (Kadan-Lottick et al., 2002). Taking a balanced approach to these findings in the literature, the memories of young people's cancer experiences were strong enough for participants to be willing to engage with Hendriks et al.'s (2024) and my research. The purpose of IPA qualitative research is to gain an understanding of the lived experience of participants (Smith et al., 2009). The time lapse between this study's young participants' treatment finishing and interview did not prevent deep thought and consideration all gave to their cancer experiences and how they made sense of these, thereby meeting the aims and objectives of phase one of the research.

I asked phase one participants to reflect on what could be done by social workers and other health staff to improve their experiences. This could then inform social work practice. To further inform social work practice, phase two sought social workers' observations and recollections of young people at diagnosis, during and after cancer treatment. They were asked to share their experiences and views on how social work practice and services could be improved to better meet young people's needs from regional and remote Queensland areas.

3.3.2.1 Phase One: Young People Living with Cancer from Outer Regional Queensland. I chose a number of purposive recruitment strategies (Neuman, 2014; Ritchie, Lewis, Elam, et al., 2014) with young people. As noted, these included engaging with key clinical gatekeepers, clinical networks and snowball sampling (Smith et al., 2009). A range of strategies was required due to the sensitive nature of the research, the vulnerability of the research population, and the low number of young people who initially responded.

My first strategy involved placing flyers (Appendix A) in the paediatric and adult oncology clinics at Cairns Hospital and the Visiting Medical Officer (from paediatric oncology, Queensland Children's Hospital, Brisbane) clinic (which occurs twice yearly) at Cairns Hospital. This included a research protocol amendment to make the flyer more visually appealing. I presented the research plan to staff from these clinical areas to facilitate their understanding and support of the project. I also sought their assistance in ensuring flyers were made available to eligible potential participants. Nursing staff identified young people and provided them with a flyer. Three potential participants, as per flyer directions, contacted me, the researcher, directly. One of the three was interviewed soon afterwards. At the time of contacting me, two participants were still undergoing treatment. Once those two participants were six months post-treatment completion, they met eligibility criteria, consented to the study and completed interviews.

My second strategy involved attending the Visiting Medical Officer (VMO) clinics in March 2019, October 2019 and March 2020. The Regional Case Manager provided flyers to potential participants. I was located in a room nearby, where, if a young person indicated their interest in the study, they could come and find out more from me. At the March 2019 VMO Clinic, four young people indicated their interest in the study; however, at that stage, the research protocol asked that young people had been diagnosed between the ages of 15–25, so they were excluded.

My third strategy required a further protocol amendment due to low recruitment numbers, allowing any young person currently aged 15–25 at the time of their interview to have been diagnosed with their cancer any time prior to the age of 25 if treatment had finished at least six months prior. I then went back and received written consent from those four young people who had not been eligible at the March 2019 VMO clinic, three of whom completed an interview. One young person consented to and completed an interview at the last VMO clinic I attended in March 2020.

In consideration of the highly sensitive nature of the research and ongoing low recruitment numbers, my fourth strategy was to offer an opportunity to complete the qualitative interview questions in writing. Methodologies for conducting sensitive research with vulnerable populations allow approaches that ensure the voices of these populations are still heard (Liamputtong, 2006). Offering the written interview was a safe alternative to an in-depth interview for the vulnerable population I was trying to access. I weighed my decision against the need to access knowledge from a research population absent in the literature. One young person chose to complete the interview questions in writing.

My fifth strategy, through a further protocol amendment, entailed a mail-out conducted by nursing staff in the paediatric and adult oncology/haematology services. Flyers were placed in envelopes by oncology clinic nursing staff and mailed to all Far North Queensland young people identified through a central cancer patient database. This database was not available to me as the researcher to protect young people’s privacy. Two young people responded to this mail-out and were successfully recruited to the study.

My sixth strategy was snowball sampling (Creswell & Poth, 2018; Neuman, 2014; Ritchie, Lewis, McNaughton Nicholls, et al., 2014). I used snowball sampling by asking young people I interviewed if they knew of any other young people living with cancer who may be interested in taking part in the research and, if so, to pass on a flyer to them. I am unaware if any young participants did this.

I recruited a total of 10 young people for phase one research. None of these young people identified as being Aboriginal and Torres Strait Islander Queenslanders. One young person referred to me by an outpatient clinic nurse expressed interest in the study, consenting to interview with a relative in attendance. As the interview proceeded, I formed the opinion that the young person did not have the capacity to understand the questions being asked. The participant interview and data have not been included in this study.

3.3.2.2 Phase Two: Social Workers who Work with Young People Living with Cancer from Outer Regional and Remote Queensland. I chose a number of recruitment strategies (Neuman, 2014; Ritchie, Lewis, Elam, et al., 2014) for social workers. These included providing information about the study – verbally via an in-service to the QCH site over MS Teams 2 weeks prior to my research visit to that site and written through the dissemination of an email advertising the study with the flyer (Appendices B and C) attached at both the metropolitan and nonmetropolitan sites. Paper copies were provided to both sites, and these were left in common areas that social workers accessed at work. I also used snowball sampling (Creswell & Poth, 2018; Neuman, 2014; Ritchie, Lewis, McNaughton Nicholls, et al., 2014) by asking social workers who consented to the study to let other social workers know about the study if they wished. A total of six social workers were recruited to the study via these methods – two at the nonmetropolitan site and four at the metropolitan site. None of these social workers identified as Aboriginal and Torres Strait Islander people.

3.3.3 Methods

As noted, in-depth interviews are typically used in interpretive phenomenological and IPA studies to address research questions about people's experiences within the phenomenon in question (Larkin et al., 2019; Smith et al., 2009). In phase one, I used in-depth interviews with young people living with cancer conducted either in person, by video or by telephone as negotiated with participants. In phase two, I used in-depth interviews with CHHHS social work participants in person. For QCH social work participants, a choice of a focus group or in-depth interview was offered to all interested participants. It was intended that a focus group would be used if interested participant numbers were greater than three (Liamputtong, 2011). Only one social worker indicated a willingness to engage in a focus group for the interview, so a focus group was not conducted. Interviews were conducted in person or by video, dependent on room availability or participant preference.

The in-depth interviews were guided by an interview schedule (Appendices D and E). Phenomenology explores the lived experiences of individuals subjectively (their own experience) and objectively (an experience they share in common with other people) (Creswell & Poth, 2018). I, therefore, designed the interview schedule to ask participants what was different about being from outer regional and remote areas compared to metropolitan areas. I also asked participants what might improve young people's cancer experiences when from outer regional and remote areas.

3.3.4 Quality and Rigour

I conducted my study according to Smith et al.'s (2009) interpretative phenomenological analysis (IPA) processes to ensure quality and rigour. This encompassed Yardley's (2000) four broad principles of quality and rigour: 'sensitivity to context', 'commitment and rigour', 'transparency and coherence', and 'impact and importance' (Smith et al., 2009; Yardley, 2000).

I achieved 'sensitivity to context' by identifying the gap in the literature (Smith et al., 2009), which guided my understanding of the experience of young people living with cancer from nonmetropolitan areas in the literature review. IPA was identified as suitable for this phenomenological research to reach, engage with and report on this vulnerable participant group of young Queenslanders living with cancer and the social workers who work with them (Smith et al., 2009). Recruitment was via purposive sampling (Smith et al., 2009) of those who shared the lived experience of being a young person living with cancer from regional or remote areas or being a social worker who worked with this group. Rapport was established with social work participants and with key gatekeepers for the study groups of young people living with cancer, who are more difficult to access due to age and the highly sensitive nature of the study (Smith et al., 2009). For such a highly sensitive subject area, the interactional nature of data collection in interviews requires skill, awareness and dedication. It requires empathy, putting participants at ease, recognising interactional difficulties and negotiating power-plays between participant and researcher (Smith et al., 2009).

I achieved 'commitment and rigour' through my multiperspective IPA research design, allowing a detailed, multifaceted account of young people's experiences with deep attentiveness to participants and care undertaken during analysis (Smith et al., 2009). As discussed previously, 'bracketing' is central to commitment and rigour processes in all phenomenological research, requiring researchers to be aware of preconceptions (fore-structures of the researcher's knowledge) influencing the study (Smith et al., 2009). For example, a preconception I recognised at the commencement of this research was that travelling away from home for cancer care was hard for young people. Through bracketing, I was careful that the research design and analysis did not 'privilege' this preconception, instead focusing on the experiences and observations of the participants themselves (Smith et al., 2009). Interview questions were designed to be open-ended (Kadushin & Kadushin, 1997), allowing participants the freedom to respond in ways reflective of their thoughts and feelings on subjects. My interview style followed social work interviewing techniques conducive to eliciting open responses, such as remaining quiet whilst participants spoke, active listening, paraphrasing, reflection, empathy, sensitive mirroring of participant language and style (e.g., use of humour) and minimal prompts such as "uh-huh" and "I see" to encourage ongoing sharing (Kadushin & Kadushin, 1997). I kept my own opinions and thoughts out of discussions (Kadushin & Kadushin, 1997).

Smith et al. (2009) note IPA researchers are not always "able to access all [their] preconceptions at the start of the project" (Smith et al., 2009, p. 42). Preconceptions can emerge throughout the data analysis of research (Smith et al., 2009). A good example is my approach to social work perspectives. I was at risk of privileging social work participants and their narratives in the study by identifying with them as a social worker myself. I managed the risks of my preconceptions emerging during the research process through the use of structured supervision sessions, where I openly shared my thoughts and reflections. Rigorous, reflexive conversations with my advisory panel (Dörfler & Stierand, 2021) and my own reflexive processes, including journalling (Willis, 2019), enabled the identification of clear emergent themes from the data as opposed to, for example, broader views I reached that might be inconsistent with the data. For instance, I wanted to describe the respect I believe social work participants showed young people in the interviews as a 'guard of honour' during my analysis. Supervision discussions and personal reflection challenged me to return to the data itself, bracket my preconceptions and attend to words from the actual social work transcripts. Other opportunities to identify and challenge my preconceptions in research findings came through peer-reviewed publications of the literature review, phase one findings, and my PhD mid-candidature and pre-completion seminars.

Appropriate sampling allowed me to obtain rich data from different perspectives to answer the research questions and the quality of the interviews and completeness of analysis undertaken in phases one and two (Larkin et al., 2019; Smith et al., 2009). The analysis in phase one went beyond simple descriptions of what participants said to an interpretation of the essence of something about the themes that participants shared (Smith et al., 2009), resulting in the "connection" central concept linking the themes of what mattered most to young people (place, knowledge, people, support, peers and lifestyle). 'Connection' was also a 'gem' (Smith et al., 2009; Smith & Nizza, 2022) from young participants' themselves, who used the word to describe relationships important to them, including with health staff. 'Gems' in IPA are extracts from the data that make outstanding, resonant contributions to the analysis (Smith et al., 2009; Smith & Nizza, 2022). This in-depth interpretation continued in the synthesis of the data analysis for phases one and two in Chapter Six.

I achieved 'transparency and coherence' by reporting my findings with a clear audit of the steps undertaken and coherent arguments presented with logical thematic relationships (Smith et al., 2009). I demonstrate the 'impact and importance' of my study through the research being deemed of value, which the peer-reviewed publications of the integrative literature review and phase one results highlight. Further publications are planned, including based on the synthesis of the analysis of phases one and two. I am also leading a trial in the CHHHS paediatric and adult oncology/haematology services of an interventional resource tool for young people living with cancer from Far North Queensland (Appendix G), which I will detail in Chapter Eight.

3.3.5 Research Procedures Phase One

In phase one, my recruitment strategies led to young people contacting me if they were interested in participating. Young people aged 15–18 who were mature enough to understand and consent to participation in the research and were not vulnerable by virtue or immaturity in ways that would warrant additional consent from a parent or guardian were invited to participate in the study (paragraph 4.2.8 NHMRC, 2023). If I was to speak with a young person under the age of 16, Gillick competency was assessed. Gillick competency is assessed via a capacity assessment, where the assessor reflects on questions such as 'Does the person have the ability to understand information pertinent to the decision?' (Fenton, 2020). I assessed those aged 16–18 based on their having sufficient maturity and understanding of the study to be able to consent (Fenton, 2020).

When a potential participant contacted me, if deemed Gillick competent or sufficiently mature and able to understand the study, I provided them with a Participant Information Sheet (Appendix H) about the study. I answered any questions they had and asked them to sign a Participant Informed Consent (Appendix I) if they committed to participating. Participant Informed Consents were either emailed or mailed out (in which case a self-addressed envelope was attached to return it in) or completed at the interview. After providing a Participant Information Sheet, I allowed up to two months for young people to consider participating. I re-contacted young people, some multiple times, to ensure every opportunity was provided for them to participate. Once young people consented to an interview, I negotiated with them the type, place and time so that it was convenient for them.

My study design prioritised the perspectives of young people who had experiences living with cancer. The intention was to interview a young person on their own (subject to cultural safety considerations outlined below) so that they could express their views freely. Some chose to have a support person present (n=4), and this was always a relative. On occasion, young participants asked their support person to speak on their behalf or agreed with something their support person said on their behalf, which I assessed as representing the young person's thoughts and opinions.

I advised all participants that participation in the study was voluntary and if they decided not to participate, it would not impact their care. I advised participants they could withdraw at any time without giving a reason, and this would not impact the care or services they received from the health service. Due to the sensitive nature of the interviews with a vulnerable population, I provided participants with the name and contact details of support services (Appendix J) should they become distressed as a result of the interview. I provided participants with a $50 iTunes card or alternative to thank them for their contribution to the study, as advertised in the flyer. Participation compensation in studies with vulnerable populations is largely regarded as ethically warranted (Liamputtong, 2006). Compensation for vulnerable research participants validates their contribution as research partners whose data and time are of worth in the research process (Landrine et al., 1992; Paradis, 2000; Wiebel, 1990).

My recruitment required frequent engagement with some participants. Table 1 depicts the phase one recruitment strategies and response rates. Table 2 details the reasons for the non-participation of young people who initially expressed willingness to take part. Table 3 depicts the geographical locations of phase one participants at diagnosis using Australian Statistical Geography Standard (ASGS) remoteness classifications (Australian Government, 2022).

Table 1

Phase One Recruitment Strategies and Response Rates

Recruitment strategy	**Number of young people who responded to this strategy**	**Total recruited successfully via this strategy**
Flyers left in view for patients in paediatric or adult oncology/haematology clinics	3	**3**
Sitting in a room nearby VMO (Visiting Medical Officer) clinics to be immediately available to answer participants' questions	6 (4 young people were not eligible due to age at diagnosis not meeting eligibility criteria; one desired a written interview, but this was not an option at that time and respondent did not reply to further contacts when it was; one did not respond to further contacts from me)	**0**
Changing the eligibility criteria so those aged 15–25 years currently, but diagnosed at an earlier age, were eligible to participate	4 (1 young person did not respond when re-contacted due to meeting new eligibility criteria)	**3**
Attendance at additional VMO clinics	4 (1 young person withdrew consent later and one did not meet eligibility criteria)	**2**
Mail-out with flyer attached	2	**2**
Total	16	**10**

Table 2

Reasons for Non-Participation in Phase One Research

Reason for non-participation	**Number of young people**
Ineligible	1
Withdrew consent	1
Did not commit to interview despite initial interest in study	2
Did not commit to interview and would have provided a written interview, but this option was not available at the time & respondent did not reply to further contacts from me when it was	1
Did not commit to interview even though had provided informed consent	1
Total	**6**

Table 3

Australian Statistical Geography Standard (ASGS) Remoteness Code at Diagnosis for Phase One Participants

Address at time of diagnosis	**Number**	**ASGS remoteness area codes**
Outer Regional	8	Outer Regional Australia, Code RA 3 (2016)
Very Remote	2	Very Remote Australia, Code RA 5 (2016)

3.3.5.1 Data Collection Methods: Phase One. Ten young people agreed to participate and signed a consent form. I negotiated with each participant the time, method and venue of the interview or method of receiving the written interview that was most convenient for them. Six chose a face-to-face interview, two chose phone interviews (one was due to COVID-19 research restrictions), one chose a video-conference interview, and one chose a written interview. Bottled water and tissues were available for face-to-face interviews. An interview schedule (Appendix D) was used as a prompt to ensure data relevant to the research question was collected (Smith et al., 2009). The written interview appears in Appendix K. Interviews ranged from 45 minutes to three hours. All participants were provided with $50 to thank them for taking part in the study, with receipts or records of those transactions (if via bank cheque or inter-bank transfer) kept by me.

Phase one did not specifically target Aboriginal and Torres Strait Islander young people. However, I engaged the Senior Aboriginal and Torres Strait Islander Liaison Officer to assist me in designing the study to ensure it was culturally appropriate, safe, respectful and welcoming for potential Aboriginal and Torres Strait Islander participants. Design measures were undertaken to maximise a culturally welcoming environment for participation, detailed in the ethics section (3.6) of this chapter. As noted in my recruitment and sampling strategy section, there were no Aboriginal and Torres Strait Islander participants.

3.3.6 Research Procedures Phase Two

I commenced recruitment for phase two with discussions between Queensland Health Social Work Directors and Team Leaders to explain the research and seek their support and assistance in designing the recruitment methods used with clinical oncology social work staff. Letters of support for the research were obtained from three CHHHS Heads of Department (see Appendices L, M and N) and one Head of Department from the Queensland Children's Hospital (QCH) in Brisbane (Appendix O). A letter of support was also required for a site contact at QCH (Appendix P) by the Research Governance Office for Children's Health Queensland Hospital and Health Service (CHQHHS), under which QCH sits. Information was disseminated by the CHHHS Social Work Head of Department and QCH Oncology Social Work Lead to their social work teams.

The Director of Social Work CHHHS sent out emails with the phase two research flyer attached, inviting participation on three separate occasions over a one-month period. As outlined previously in section 3.3.2.2, I presented my research plan to the Social Work Department at the QCH prior to my site visit to conduct interviews, at which time I also had a face-to-face informal lunch with the team so staff could discuss the research with me and ask any questions. Flyers were disseminated electronically via email and left in common areas social workers used at both facilities.

Potential social work participants were asked to contact me directly if they wished to participate. When a social worker contacted me, I provided a Participant Information Sheet (Appendix Q) about the study and answered any questions. If the social worker wished to participate, I asked them to sign a Participant Informed Consent (Appendix R) either mailed out with a stamped, self-addressed envelope attached to return or completed at the interview. Interviews were conducted at a time, place and venue suitable to participants.

I advised all social workers that participation in the study was voluntary and if they decided not to participate, it would not impact their employment with Queensland Health. I advised social work participants they could withdraw at any time without giving a reason and that this would not impact their professional relationships with me. Due to the sensitive nature of the interviews, participants were provided with the name and telephone number of the relevant Queensland Health Employee Assistance Schemes for their hospital and health service. I provided social work participants with the Queensland Health Employee Wellbeing QHEPS page link to access other employee wellbeing information (see Appendix S – List of Support Services for Participants phase two). Table 4 presents the recruitment details of phase two's six social work participants.

Table 4

Phase Two Recruitment Details

Site	Number of social workers expressing an interest	Number who met eligibility criteria	Number who contacted after the study had closed	Final number recruited
CHHHS	3	2	0	2
QCH	5	4	1	4

3.3.6.2 Data Collection Methods: Phase Two. I conducted face-to-face interviews with social workers in Cairns and Brisbane after informed consent was gained in writing from participants. During the one-week research trip to the QCH in October 2022, I was provided with rooms for the sole purpose of conducting interviews. All but one interview with the Brisbane social workers was held during this week, with the last interview held at a later date over video interview after I returned to Far North Queensland.

I provided the ASGS Remoteness Structure Map (Appendix T) to social work participants at the interview. This map shows where outer regional and remote areas are located throughout Australia. To protect the privacy of participants, interviews were conducted in private rooms in CHHHS or QCH buildings. Video interviews were also conducted in these rooms. A plan was in place for COVID-19 restrictions, where applicable, for appropriate technology use to conduct interviews or focus groups (e.g., video interviews). I ensured bottled water and tissues were available for face-to-face interviews, including hand sanitiser (to mitigate risks of COVID-19 transmission).

3.3.7 Sample Size

IPA studies usually have small numbers (3–6) owing to the time involved for the required in-depth qualitative analysis of interviews (Smith et al., 2009). The main authors of IPA research, Smith et al. (2009), do not prescribe ideal numbers for data sets in PhD-level projects, although they offer some guidelines to help researchers decide. The authors note: “There is time to analyse more cases in a PhD but it is not especially helpful to think of satisfying the extra demands primarily through increasing numbers …. much depends on the research question and the quality of the data obtained" (Smith et al., 2009, p. 52). Studies seeking multiple perspectives, like this one, also benefit from lower numbers to allow for the in-depth, systematic and comprehensive analysis involved (Smith et al., 2009). To meet the purposes of the research aims and objectives, it was expected that meaningful data from a variety of participants could be achieved with between 10–15 participants in phase one, and up to 10 from QCH and up to five from CHHHS in phase two. If more participants than expected had expressed an interest, a plan was in place to thank them for their interest and advise them that data collection was complete and an offer made to provide a copy of the study findings, which occurred for one social work participant who contacted me after recruitment had closed. The thick, rich quality of the data from participants in both phases satisfied the aims and objectives of the research. Thus, recruitment ceased once numbers of 10 in phase one and six in phase two (with representative numbers from both sites) were reached. Phase one interviews occurred between October 2019 and August 2020. Phase two interviews occurred between April and November 2022.

3.4 Data Analysis

Data analysis in this study was guided by IPA (Smith et al., 2009; Smith & Nizza, 2022) and, within this, multiperspective IPA design (Larkin et al., 2019). I used IPA methods to analyse the data sets of young people and social workers, organising my interpretation through IPA processes of the development of codes (experiential statements), themes (personal experiential themes) and group experiential themes from rigorous, multiple reviews of interview transcripts (Smith et al., 2009; Smith & Nizza, 2022). Firstly, I analysed data from each phase individually, following a typical IPA analytical, iterative and inductive cycle (Larkin et al., 2019). This IPA cycle incorporated close, line-by-line analysis of participants' narratives. Next, themes were identified within each participant's narrative and then across all cases. I then developed an interpretative account of the data based on dialogue/s with participants. This informed a structure illustrating relationships between themes. Following on from identifying relationships between themes, I organised the material in a way that made the process from initial transcript comments and clustering to the final thematic structure evident. Through supervision, I was able to test and refine the plausibility of my interpretation. I then developed a full narrative with detailed commentary on the themes and accompanied this with a visual guides – a table and figures – to illustrate to the reader the interpretation/s made. My own self-reflection on my perceptions, conceptions and processes were recorded in a field journal I kept, with selected entries shared in supervision (Smith et al., 2009, pp. 79-80).

3.4.1 Phase One Data Analysis

With participant consent, I recorded the interviews on a digital recorder and transcribed them for analysis. The written interview response was also transcribed for analysis. Multiperspective IPA designs require separate, individual analyses of data sets forming each perspective (Larkin et al., 2019). Smith & Nizza (2022) have updated IPA thematic development terminology. The first level, emergent themes, has been updated to 'experiential statements'; the second level, superordinate themes, has been updated to 'personal experiential themes' and the third level, master themes, has been updated to 'group experiential themes' (Smith & Nizza, 2022).

I developed experiential statements (Smith et al., 2009; Smith & Nizza, 2022) from young people's perspectives that captured common themes across young people. Whilst undertaking coding from in-depth interview transcripts and developing experiential statements, I was mindful that I had two research questions to answer. The research questions encompassed 1) how young people from Far North Queensland described their experiences of living with cancer, and 2) what was important to them at diagnosis, during cancer treatment and after treatment or when they returned home. Through a process of reduction (Smith et al., 2009), I clustered experiential statements into personal experiential themes (Smith et al., 2009; Smith & Nizza, 2022). Again, with the study's research questions in mind, I explored IPA's objectives of developing group experiential themes (Smith et al., 2009; Smith & Nizza, 2022). This required finding the connections – the 'gestalt' (shape, form or 'essence') that emerged from the analytic process (Smith et al., 2009). I looked at Smith et al.'s (2009) IPA data analysis techniques – abstraction, subsumption, polarisation, contextualisation, numeration, function and 'bringing it together' – to deepen and broaden the analysis to develop "patterns and connections between emergent themes" (p. 96).

In keeping with the IPA approach, emergent themes were developed from the data around common narratives of ‘travel away is hard’, ‘talk directly to me’, and so on. These were then charted into a ‘coding tree’ of how the various themes fit together. The codes within emergent themes were scrutinised for divergence and convergence (Larkin et al., 2019). Transcript extracts, or quotes, were ascribed to the themes so that once I began reporting on the data, the participants’ words could be used to illustrate the findings (Smith et al., 2009; Smith, 2017; Smith & Nizza, 2022).

I developed an interpretation of what it means to be a young person living with cancer in Far North Queensland through the IPA processes of combining code and thematic development and my own psychological knowledge (Smith et al., 2009). This analysis led to the development of the essence of what it was that created a relationship between themes (Smith et al., 2009; Smith & Nizza, 2022), which was a word young people in the study themselves used on numerous occasions about “connection” with what was important to them. Choosing this word, ‘connection’, including the word itself, is what is called a ‘gem’ in IPA research – an extract from the data that makes a particularly resonant contribution to the analysis (Smith et al., 2009; Smith & Nizza, 2022). Within the six themes, it was important for young people that they were connected with that theme of place (treatment close to home), knowledge (being acknowledged and understanding their cancer), people (their connections with family, friends and health staff), support (being connected with coping strategies to deal with their cancer experience), peers (connection with other young people going through a cancer experience by sharing their experiences, including offering advice) and lifestyle (connection to lifestyle was about surviving cancer and how their cancer experience shaped them). I organised the material in such a way it was able to be audited, then discussed it with my advisory panel until agreement was reached. Once agreement was reached, I developed a full narrative written account supported by a simple diagram to illustrate the interpretation (Smith et al., 2009), leading to a publication of the findings. NVivo 20 qualitative software, regularly updated, was used to store data and facilitate analysis.

3.4.2 Phase Two Data Analysis

Phase two data analysis followed a process similar to phase one. I developed experiential statements (Smith & Nizza, 2022) from social work perspectives that captured common themes across social workers. I clustered these into personal experiential themes (Smith & Nizza, 2022). I asked myself the question, “What are the social workers telling me?” I simultaneously explored the IPA objectives of developing master themes of group experiential statements (Smith & Nizza, 2022). As for phase one, I inductively developed patterns and connections between themes that emerged from the data analysis (Smith et al., 2009).

3.4.3 Synthesis of Research for Phases One and Two

In multiperspective IPA studies, data synthesis occurs both *within* each sample and also *between* samples (Larkin et al., 2019). As Larkin et al. (2019) state, “Through the analysis and synthesis of multiple perspectives, it is possible strong and persuasive analytic accounts can be developed” (Larkin et al., 2019, p. 185). In my study, young people and social workers are directly related groups “immersed in the same experience, but are likely to have different views of it” (Larkin et al., 2019, p. 186). Young study participants shared their lived experiences of the phenomenon of going through cancer diagnosis and treatment as outer regional and remote Queensland residents. Social workers from outer regional and metropolitan Queensland sites shared their observations of how young people experience living with cancer through the common experience of young people’s contact with the health service when receiving cancer care. What these groups have in common is the shared experience of health care provision for young people living with cancer from outer regional and remote Queensland. Young people receive, and social workers provide, psychosocial health care.

In multiperspective IPA research, the research aim and questions are key to analysing and synthesising the data (Larkin et al., 2019). I needed to conceptualise what lay “between” participants and my interest in them (Larkin et al., 2019). The health care experience for young people was this common ground. However, in multiperspective IPA research, the researcher must be open to data emerging from studies that were neither anticipated nor conceptualised (Larkin et al., 2019). Across the whole sample, variations may be greater than in traditional, single IPA study samples, yet unveil insights and discoveries gained due to including additional perspectives (Larkin et al., 2019).

The data synthesis process of multiperspective IPA studies can be challenging (Larkin et al., 2019). These challenges revolve around what is, in effect, a "mini-meta-synthesis" (Larkin et al., 2019, p. 190) of samples where it can be difficult to determine "what to foreground, what to omit, and how to deal with areas of concern that do not overlap" (Larkin et al., 2019, p. 190). I used Larkin et al.'s (2019) analytical strategies to address these challenges.

To commence my data synthesis using Larkin et al.'s (2019) strategies, I compared both data sets side-by-side (see Chapter Six, Table 7), noting themes that were similar, different or stand-alone. Firstly, I identified *consensus overlap* or *consensual overlap* (Larkin et al., 2019). Consensus overlap relates to participants with different perspectives still expressing the same concerns (Larkin et al., 2019). For example, in this study, both young people and social work participants identified that young people's goal whilst away having cancer treatment is always to return home. Conceptual overlap occurs when a researcher identifies a *concept* underpinning participants' concerns, which in this study was the experience being in a 'liminal' (in between) state for young people – the liminal experience endpoint was when young people returned home.

The second analytical strategy was identifying *conflict of perspectives* (Larkin et al., 2019). In synthesising the analysis of both data sets, some information from each perspective differed. For example, only one young person in phase one discussed the issue of potential infertility from treatment, and this was not described in a way that indicated it was traumatic. However, social work participants who discussed fertility preservation described it as a traumatic experience for young people, involving loss of privacy and invasive procedures.

The third analytical strategy identified *reciprocity of concepts* (Larkin et al., 2019). Here, concerns are raised by each perspectival group that complement one another (Larkin et al., 2019). An example of this in the data synthesis was that both young people and social workers desire a connection with each other when young people are going through their cancer care. Young people wanted a connection with their social worker and to be checked in on regularly by them. Social workers also wanted a connection with the young people they helped, stating their helping relationship and, in particular, rapport-building were key to ensure young people receive the support they needed throughout their cancer experience.

The fourth analytical strategy was identifying *paths of meaning* (Larkin et al., 2019). These can relate to *shared experiences with divergent meanings* or *shared meanings attributed to different experiences* (Larkin et al., 2019). These strategies were used throughout the analytical work in the first three strategies outlined above, forming part of multiperspective IPA analysis processes (Larkin et al., 2019). Paths of meaning allowed me to identify and name the “enduring resilience” of young people in my data synthesis. For example, there were some divergent meanings ascribed by young people and social workers around young people having to travel away for treatment. Two young people (Mia and Andrea) said they understood needing to have their treatment away to save their lives, even though travelling away was hard for them. Some social workers, however, described having to travel away as something young people from regional and remote areas were accustomed to, with two (Emily and Riley) noting young people from nonmetropolitan areas were used to having to travel away for health care. Through data synthesis, I interpreted these differing perspectives or paths of meaning on needing to travel away as consistent with the enduring resilience in young people that was also evident elsewhere in both data sets. For instance, what Sage (social worker) interpreted as stoicism in a young person facing their end-of-life, with the benefit of data synthesis processes and paths of meaning formed, I interpreted as “enduring resilience”.

The fifth and final analytic strategy to assist data synthesis across multiperspective IPA studies is *lines of argument* (Noblit & Hare, cited in Larkin et al., 2019). Lines of argument are the development of stories or narratives that capture the analysis, relating to the most important aspects to emerge from the preceding four strategies (Larkin et al., 2019). My lines of argument are presented in Chapter Six, where I provide a narrative of the synthesised data analysis of both young people and social work perspectives.

3.5 Ethics

This section first outlines the ethics processes undertaken to conduct this research and the ethical considerations underpinning these processes. Next, I outline the ethical management of this study with participant safety, participant comprehension of the study and maintaining participants' privacy. Finally, I identify measures taken to ensure I was supported as a researcher of a potentially emotionally challenging topic.

3.5.1 Ethics Processes

The research presented and reported in this thesis was conducted in compliance with the Australian Association of Social Workers (AASW) Code of Ethics (2020) and Practice Standards (2023), the Code of Conduct for the Queensland Public Service (Queensland Government, 2024), the National Statement on Ethical Conduct in Human Research (NHMRC et al., 2023), the Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders (NHMRC, 2018a), the Australian Code for the Responsible Conduct of Research (NHMRC, 2018b) and James Cook University Code for the Responsible Conduct of Research (JCU, 2021). The study received ethics approval from the Far North Queensland Human Research Ethics Committee (HREC/18/QCH/90 – 1260), Children's Health Queensland Human Research Ethics Committee (HREC/22/QCHQ/82401) and James Cook University Human Research Ethics Committee (Reference Number: H7789).

3.5.2 Ethical Considerations

In this study, I followed principles of ethical practice espoused by the NHMRC (NHMRC, 2023; NHMRC, 2018b) and social work principles of ethical practice in research (AASW, 2020). Firstly, this study design and implementation of the research followed the Australian National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (NHMRC, 2023). The NHMRC Statement requires adherence in human research to merit and integrity, justice, beneficence and respect (NHMRC et al., 2023). Research merit and integrity require research to be justifiable by its potential benefit, methods appropriate for the research aims, based on a comprehensive and contemporary literature and research review, respect for participants is paramount, conducted or supervised by appropriately qualified people, using appropriate facilities. Justice in human research involves fair selection, inclusion and exclusion criteria of participants, fair recruitment processes, no unfair burden of participation in research on particular groups, fair spread of benefits of participation in research and access to the benefits of the research and no exploitation of participants, with clear, timely access to the outcomes of research for participants. Beneficence in research means the benefits of the research must justify any likely harm or discomfort to participants. Respect in research requires respect to all human beings involved in research including their welfare, beliefs, perceptions, customs and cultural heritage, the right to privacy, confidentiality and respect of cultural sensitivities, participant capacity and autonomy in decision-making, empowering those with reduced capacity and measures to protect them where necessary (NHMRC, 2023, pp. 10-11). I applied the NHMRC (2023) ethical principles as they specifically apply to research with children and young people (section 4.2) – these are detailed in the next section (3.5.3) on participant safety.

The second, concurrent principles underpinning the ethical conduct of my research were drawn from the AASW (2020) Code of Ethics. The AASW Code of Ethics requires social workers, in all areas of practice and engagement with service users, colleagues and the broader community, including in research, to uphold basic social work principles of respect for others, social justice and integrity (AASW, 2020). These principles include cultural safety and sensitivity, commitment to social justice and human rights, social work service and propriety (which includes trustworthiness and maintaining appropriate boundaries), professional competence, declaring conflicts of interest, and responsibilities to the profession to strive for and promote excellence in social work conduct (AASW, 2020). In all settings, including research, social workers are to prioritise the interests of service users, encourage service user self-determination, ensure informed consent is gained, that people's privacy and confidentiality are upheld, records are appropriately maintained in accordance with agency, government or research guidelines and that professional boundaries are upheld (AASW, 2020, pp. 12-22).

My discussion will now focus on declaring conflicts of interest in my own research (AASW, 2020). As a researcher positioned 'within' the health service, an 'insider researcher' working with both young people living with cancer and social workers, I need to address the role of self for academic rigor (Warner, 2024). IPA research has a rich tradition of emerging from clinical practice (Smith et al., 2009). Some of the young people in this study, including those who would have seen it advertised but chose not to participate, knew me as a social worker and in some cases I was their social worker. Likewise, some of the social workers who either participated or would have seen the research advertised knew me. Like Warner (2024), I believe I would have struggled to access study participants without my well-established clinical credentials within Queensland Health. It may have meant, for whatever their reasons, some young people and social workers wanted to participate (Court & Abbas, 2022). It might have hindered others from wishing to participate (Court & Abbas, 2022). For those in either phase one or phase two who chose to participate, they might have wanted to ‘please’ me and even anticipate answers I might like given our working history (Court & Abbas, 2022). This is of particular concern for the vulnerable nature of research with children and young people (NHMRC, 2023). Alternatively, knowing me may have acted as a deterrent for any number of reasons, including mistrust over how the information might be shared and my ability to keep results anonymous (Court & Abbas, 2022). Safeguards addressing these issues formed part of my research design, detailed in the next sections 3.5.3 – 3.5.7.

As an insider researcher, I also needed to honestly address how my working understanding and belief that travelling away was hard for young people could influence my research design, methodology and data analysis. In IPA research, this is called a ‘fore-structure’ of my knowledge (Smith et al., 2009). Reflective journalling and regular supervision with my advisory panel ensured these issues were managed as I progressed through my research, keeping me aware of my ‘positionality’ as an insider researcher (Court & Abbas, 2022; Warner, 2024). A robust literature review also highlighted gaps in research with young people living with cancer from outer regional and remote areas, which signposted the genuine gap my research was addressing (Smith et al., 2009).

3.5.3 Participant Safety of Young People

For any participants under 18, I abided by the National Statement on Ethical Conduct in Human Research section 4.2 “Children and Young People” (NHMRC, 2023). I made an assessment, as a senior social worker in paediatrics for over nine years at research commencement, as to participants’ capacity to understand the proposed research and consent to participate. I asked participants to reflect on their cancer diagnosis and how it had impacted them and their lives. This level of reflection had the potential to cause uncomfortable and upsetting feelings, given the often very invasive ways that cancers are diagnosed and treated. I relied on my skills as a social worker to identify when a person was becoming distressed, which did not occur for any participants. The interview would have been paused or stopped if the participant was too distressed to continue. As noted in the recruitment section, I made available a list of support services (Appendix J) for all participants, in which I entered specific information about their treating oncologist and local health service contacts, as well as other support services appropriate for this age group. I planned to refer any participant who I assessed as being distressed by the interview for face-to-face counselling with a qualified psychologist or social worker from the CHHHS. For those unable to attend face-to-face counselling due to geographical remoteness, I planned to refer them to an oncology social worker from Redkite (a childhood and young people's cancer support organisation) for phone counselling.

I checked on the welfare of some participants who disclosed, during the interview, that they were still struggling as a result of going through their cancer treatment by sending them text messages or an email enquiring how they were. All the young people whom I contacted expressed their appreciation for me doing this. One young person was still actively engaged with the counselling they had commenced prior to the interview for a health-related matter that triggered previous post-traumatic stress from going through their cancer experience.

3.5.4 Participant Safety of Social Workers

Discussing young people's cancer experiences may produce uncomfortable feelings. Additionally, the focus group setting can leave participants feeling more exposed (Kamberelis & Dimitriadis, 2013) by sharing their experiences with colleagues – potentially in ways they have not done previously. Despite not conducting focus groups, my research design prepared for this extra level of potential vulnerability. Participants' full participation and willingness to share depended on the venue, group process (had it been used) and facilitators' skills to promote a feeling of safety (Kamberelis & Dimitriadis, 2013). It was not possible to guarantee confidentiality in a focus group setting (Liamputtong, 2011). I designed the study so that focus group guidelines for safety would be negotiated with participants at the commencement of each group session, including conditions like not using young people's names and not sharing with others what was said in the focus group

(Liamputtong, 2011). As noted in the recruitment section, participants were provided with a list of support, including instructions on contacting the Queensland Health Employee Assistance Service for their hospital and health service (Appendix S). If any participants felt distressed during or after the interview, they would have been offered an opportunity to discuss this with me, including assistance to contact their preferred counsellor, clinical supervisor or the Employee Assistance Scheme for their hospital and health service.

3.5.5 Participant Safety of Aboriginal and Torres Strait Islander Young People

It was probable that incidental recruitment of young Aboriginal and Torres Strait Islander people would occur, given the study was being conducted in Far North Queensland and approximately 12% of residents in the regional site of phase one are Aboriginal people and Torres Strait Islanders (Queensland Health, 2022, p. 22). It was my intention to be inclusive of young people who identified as Aboriginal and Torres Strait Islander Queenslanders. I engaged the Senior Aboriginal and Torres Strait Islander Liaison Officer from Cairns Hospital as a cultural advisor in this study to ensure it was conducted in a culturally safe and respectful way for Aboriginal and Torres Strait Islander young people. Values of reciprocity, respect, equality, responsibility, survival and protection and spirit and integrity (NHMRC, 2018a) were observed in the study design. I planned to offer the opportunity to have an Aboriginal and Torres Strait Island Liaison Officer present when the Participant Information Sheet was provided to the participant. I then planned to offer the opportunity to have a family member or support person of the young person’s choosing or an Aboriginal and Torres Strait Islander Hospital Liaison Officer present during the interview. A time and place for the interview suitable for young participants would be negotiated. I would then discuss how to provide feedback about the results of the research in a way that was meaningful to the young participants. Lastly, I would provide the details of culturally appropriate sources of support in the young person's home community, such as their Primary Health Centre or a Community Health Worker, Aboriginal and Torres Strait Islander Liaison Officer and relevant specialised services (NHMRC, 2018a).

3.5.6 Participant Comprehension of Study

The age range of the study was young people aged 15–25 who were diagnosed with cancer before the age of 25. In phase one, any young person 15–18 years of age who I assessed as Gillick competent and of sufficient maturity to understand the nature of the research and the questions was eligible to participate (as outlined in Section 3.3.5). Questions were designed for a level of basic comprehension of English. For young people who identified as Aboriginal and Torres Strait Islander, I would have engaged a Senior Aboriginal and Torres Strait Islander Hospital Liaison Officer to assist with explaining the study and to be present for the interview (or for a family member to be present) so as to provide a culturally appropriate and safe interview experience. It was expected that a family member or the Senior Aboriginal and Torres Strait Islander Hospital Liaison Officer would assist me in ensuring the study and interview questions were suitably worded for the participant’s age, comprehension and cultural background. As previously noted, however, no young Aboriginal or Torres Strait Islander people living with cancer were successfully recruited to the study.

Young people living with cancer have dual vulnerability due to serious, life-limiting illness and mental health risks associated with age and developmental stage (Davies et al., 2021). It was important to me as a researcher that young participants felt supported and comfortable to do their interviews; hence, I welcomed family members if the young person chose to include them in the interview process. As noted previously, four young participants had a family member join for either all or part of the interviews.

3.5.7 Participant Privacy

To ensure the anonymity of research participants was upheld, I chose private rooms to conduct interviews, applied pseudonyms to research participants in my writing, removed identifying information about participants (such as their age, diagnosis or name of town they lived in for phase one, and location of social workers in phase two) and ensured the safe, secure storage of data on password protected computers and hard copies of data in a lockable filing cabinet only accessible to me (Heaton, 2022; NHMRC, 2018b). I removed any identifying details (AASW, 2020) in my reporting of the published findings with young people living with cancer. Pseudonyms were chosen rather than participant numbers to humanise the participants in my writing (Heaton, 2022). I did not invite participants to choose their own pseudonyms to protect other participants' privacy.

3.5.8 Researcher Safety

Due to the nature of this research, it was possible I may experience uncomfortable feelings or distress. The NHMRC requires both HRECs (Human Research Ethics Committees) and researchers to assess risks to researcher safety (NHMRC, 2023). Pinto et al. (2022) also address the ethical considerations for researchers of sensitive healthcare topics. These considerations include physical and emotional risks for researchers, such as traumatic or sensitive topics (Pinto et al., 2022). Support plans for researchers investigating sensitive topics are recommended (Pinto et al., 2022). I developed a support plan due to the sensitive nature of my topic. My support plan was incorporated into fortnightly academic supervision from my advisory panel, where issues regarding my personal safety and welfare were discussed. Identified issues led to establishing regular independent, external counselling for my psychosocial and emotional wellbeing. I also kept a personal, reflective journal. I recorded numerous responses and reflections in my journal, including poetry. These measures assisted me throughout the research process, ensuring risks to my mental health were managed.

3.6 Data Management

Once the study interviews were transcribed, I de-identified transcripts and allocated a participant code for storage on a password-protected computer and in a lockable filing cabinet, accessible only to me (JCU, 2023; NHMRC, 2018b). Participant names and contact information were stored separately from transcripts (NHMRC, 2018b). The data will be securely stored by me for five years from the date of submission and/or publications, after which paper copies will be shredded and electronic copies deleted (JCU, 2023; NHMRC, 2018b). Data management has been conducted in accordance with James Cook University's research data and information management requirements (JCU, 2023). Metadata records have not been kept due to the sensitive nature of the research involving a vulnerable population in phase one and an easily identifiable selection of participants in phase two (due to the small participant pool). The privacy of participant groups was paramount. This decision was made in conjunction with, and the approval of, James Cook University's eResearch

Specialist and Research Data Coordinator on 21st April 2023. It will not be possible to identify participants in my final thesis or publications.

3.7 Dissemination of Results and Publications

Heidegger (2010) states the role of interpretation is to disclose what has been discovered through research to other areas. This informs the commencement of disseminating this research. I provided copies of the published findings of phase one to young participants who asked for them. I have targeted my research dissemination to audiences and publications specialising in my field of study of young people living with cancer (Belcher, 2009; Gabriel, 2013). Initially, I led the publication of an international integrative literature review, current to the time of publication (2020), on the experiences of young people living with cancer in nonmetropolitan areas (Sariman et al., 2020). The literature review was published in an international journal dedicated to the field of adolescent and young adult cancer, the *Journal of Adolescent and Young Adult Oncology*. I also presented the findings of the literature review at the 2020 CHHHS Paediatric Oncology full-day workshop in Cairns.

Phase one findings on the perspectives of young people were published in the journal *Australian Social Work* in 2022 (Sariman et al., 2022). I chose this journal in line with my overarching research aim that the study findings should inform social work practice. Phase one findings were also shared in oral presentations at the CHHHS Research and Innovation Symposium, Paediatric and Psychology Departments and Cairns Hospital Grand Rounds. The Grand Rounds forum is a weekly, medical-orientated CHHHS-wide platform best suited to reach medical staff. I co-presented my research findings at Grand Rounds with the Clinical Director of Adult Oncology and an Oncologist (cancer doctor) who presented two case studies. Translating research into practice can be most effective when involving cross-discipline collaborations (Czajkowski et al., 2016). Collaborating and co-presenting with medical staff is a strategic way of being heard by the medical profession, an important audience I want my study findings to reach.

3.8 Conclusion

Chapter Three has outlined the philosophical and theoretical framework underpinning this study – interpretive phenomenology. I positioned my research and myself as researcher within social work theoretical frameworks and ideology. I have detailed the methods used, which are appropriate to the philosophical and theoretical framework, to address the research aims, objectives and questions. Consistent with interpretive phenomenology, I chose a multiperspective, interpretative phenomenological analysis (IPA) study design and methods, using in-depth interviews to collect data for both perspectives in phase one with young people and phase two with social workers. Multiperspective IPA adds depth to interpretative phenomenology studies exploring health issues, particularly for under-represented populations in research. Due to the dearth of published evidence to inform social work practice with young people living with cancer in nonmetropolitan areas, it was the method of choice for this study. Two perspectives were sought: young people living with cancer in outer regional and remote Queensland and, for further context, oncology social workers at outer regional and metropolitan Queensland sites. I have highlighted ethical considerations factored into my study design. The next three chapters present the findings of phase one's young people (Chapter Four), phase two's social workers (Chapter Five) and a synthesis of my analysis of both phases (Chapter Six).

Chapter Four: Findings – Young People's Perspectives

In the previous chapter, I detailed the philosophical and theoretical framework underpinning this study, outlining the methodology used to achieve the aims and objectives and answer the research questions. As explained, this interpretive phenomenological study uses a multiperspectival interpretative phenomenological analysis (IPA) design (Larkin et al., 2019; Smith et al., 2009). In this and the following two chapters, I present the findings of the two perspectives sought – young people living with cancer in outer regional and remote Queensland and social workers working with young people from outer regional and remote Queensland. This chapter focuses on the findings of the young people. It includes material that has been published (Sariman et al., 2022).

I formed two research questions to explore young people's perspectives in phase one of the research. The first question was "How do young people diagnosed with cancer from outer regional and remote Queensland describe their experience of living with cancer?" The second phase one research question was "What is important to young people living with cancer in outer regional and remote Queensland when they are diagnosed with cancer, during cancer treatment and after treatment or when they return home?" To answer these two research questions, I found a natural flow in my data analysis from how young people described their cancer experiences (question one) into what was important to them at diagnosis, during treatment and when treatment finished or when they returned home (question two). This flow of thematic development is depicted in Table 5.

Table 5

Theme Development into Group Experiential Themes for Young People's Perspectives

Experiential Statements *What it was like for young people*	**Personal Experiential Themes** *What was important to young people*	**Group Experiential Themes** *Spheres of connection for young person*
Travel away is hard → 1) Travel away is hard: - Easier when treatment can happen at home - Hard for young person - Hard for family (concern for family) - Relocating/multiple trips away for treatment 2) Travel negatively impacted my relationships, school & work 3) What makes travel easier 4) Difference between metro young people's experience and mine 5) Coming back home is (was) wonderful	**Treatment close to** → **home**	**Connection with Place** Treatment close to home 
Feeling unseen or heard → 1) I wanted to be in the loop 2) Regular check-ins 3) Talk directly to me	**Being seen and** → **heard** **and**	**Connection with Knowledge** Being acknowledged & understanding my cancer 
I needed to understand my cancer → a. At diagnosis b. During treatment: - What treatment was like c. After treatment	**Understanding my cancer**	
Relationships were important → 1) Relationships with family 2) Relationships with friends 3) Relationships with health staff	**Relationships with** → **family, friends and health staff**	**Connection with People** Family, friends and health staff 
Maintaining autonomy → - How I coped with having cancer	**Autonomy** → **and Support**	**Connection with Support** Coping strategies

I needed support → Where help came from		
Relationships with my peers → - Relationships with other young people living with cancer (peers)	**Improving young → people's/peers' experiences of living with cancer**	**Connection with Peers** Sharing my experience 
Improving young people's experiences → 1) Advice to peers (young people living with cancer) 2) Advice to social workers 3) Advice to health professionals		
Surviving cancer → 1) Who I am 2) Connection with me	**Surviving cancer → and** **How having cancer has affected my life**	**Connection with Lifestyle** Surviving cancer – how it has shaped me 
How having cancer has affected my life → 1) How cancer changed me – long-term effects: - Physical - Behavioural - Psychological/mental health/emotional - Spiritual/philosophical 2) Reflections on the whole journey		

Chapter Three outlined the IPA strategies used in analysing the data of young people's perspectives. This chapter presents the findings of the data analysis under the headings of the six group experiential themes, which I call "spheres of connection". These are place, knowledge, people, support, peers and lifestyle. Within these section headings, I use a narrative to present data from the personal experiential themes and experiential statements for young participants. Included participant quotes make the evidence base transparent (Smith et al., 2009). Following IPA methodology I developed a visual representation of the overall analysis. Figure 2 depicts this overall analysis in the "Spheres of Connection Important to Young People" model.

Figure 2

Spheres of Connection Important to Young People

4.1 Introduction of Participants

Ten young people living with cancer took part in the study: seven females and three males. Their pseudonyms are – Andrea, Brett, Brianna, George, Gracie, Layla, Mia, Raymond, Sharon and Sian. At the time of the interviews, participants were aged between 18 and 25 years, with an average age of 20. Participants' ages at diagnosis ranged between 22 months and 19 years. At diagnosis, six were under 15, and four were aged 15 to 25. Eight young participants' home addresses at diagnosis were in outer regional areas and two in very remote areas – see Table 3 (Chapter Three). An average of 6.9 years had passed since participants' treatment had finished. Nine young participants relocated to an outer regional or metropolitan city for initial specialist cancer care for between three weeks and nine months. All participants travelled to specialist outer regional and metropolitan cancer care centres on multiple occasions for treatment, medical procedures, and specialist appointments. The average distance from their home at diagnosis to the specialist cancer care site was 1,704km. No young study participants identified as Aboriginal and Torres Strait Islander. Results were therefore unable to reflect the increased health vulnerability of First Peoples Australians (AIHW, 2020a).

4.2 The Spheres of Connection Important to Young People

In phase one, I found that young participants from Far North Queensland described experiences where what was important to them was connection: connection with place, knowledge, people, support, peers and lifestyle. 'Connection' was a word used by some of the young participants to describe things important for them to have a relationship or relate with, and is therefore a 'gem' – a data extract which contributed deeply to the analysis (Smith & Nizza, 2022). Young participants desired these connections at all stages of the cancer care experience – diagnosis, during treatment and after treatment finished or when they returned home. These connections form the six group experiential themes of the findings, or 'spheres of connection'. The following sub-sections explore the findings within each sphere of connection in detail.

4.2.1 Connection with Place: Treatment Close to Home

The first sphere of connection is connection with place and the need for treatment close to home. Within this sphere, the analysis showed that participants viewed travel away as hard and coming home as wonderful. They also noted a difference in their experiences compared to young people from metropolitan areas.

4.2.1.1 Travel Away is Hard. All ten of the young people in the study had to travel away from the town they lived in to another rural, regional or metropolitan town or city for symptom management, diagnosis or treatment. They spoke of the health and psychological hardships relocation brought. All ten had to temporarily relocate to other towns or cities for periods of between three weeks and nine months, dependent on diagnosis and treatment type, with nine transferring to a regional or metropolitan city providing specialist cancer care services and all receiving multiple follow-up care trips or appointments at specialist cancer care sites. The distances the young people had to travel to relocate ranged from 347km to 2390km, with nine participants travelling by plane. Having to travel far away for treatment was met with many unknowns for participants.

> [The health staff] told us we had to go down to [the city] and they weren't sure at the time how long that would be so, you know, I kind of found it hard leaving friends, not knowing how long that would be for. (Raymond)

Participants found travelling away hard emotionally and physically, as it disrupted school and work and separated them from loved ones back home. They also noted it was hard on their families, and they found it easier when treatment was able to be transferred back from the metropolitan areas to facilities closer to home.

4.2.1.2 Coming Home is Wonderful. All ten participants spoke of how happy they were to return home either when their treatment finished or because ongoing treatment could happen closer to home. They spoke of how good it was to be back in their familiar space, and statements like 'sleeping in my own bed' emerged as important physical and emotional comforts about home.

> I think just the fact you can be in your own home in your own bed. I guess if you're feeling unwell even with the flu, it's nice to just be at home in your own house with your own things. So, I think that to me was the biggest relief. (Gracie)

Cancer treatments were uncomfortable at best for participants, involving pain and other distressing symptoms or side effects to manage. Considering this, Gracie's statement exemplifies why being in one's own bed and home mattered to participants and why coming home was wonderful – home was familiar, comfortable and safe at a time when cancer treatment was often causing severe physical and psychological suffering and torment.

4.2.1.3 Differences Between Metropolitan Young People's Experience and Mine. All phase one study participants noted key differences between themselves and young people who lived in the metropolitan or outer regional cities that had specialist cancer centres. The differences they spoke of were that, for young people living in the cities, faster diagnoses and treatment/s were available. They were able to go home at the end of a day of treatment to their own homes and beds. It was easier to stay connected with loved ones, school and friends. They were more familiar with the staff working at the specialist cancer care centres and with the city itself, and it was easier for staff to care for the young person communication-wise in just one place. Layla noted that young people living in the city where the specialist cancer care site was located would have their family present, know the doctors and be familiar with the city. However, Layla did not know anyone where she was having treatment:

> Somebody down there would know [city] – they'd probably know doctors there. They'd know the people doing the [treatment] … some of the nurses, I'm pretty sure, rotate throughout where you have chemo so they would know the nurses and that, too. (Layla)

For Andrea, having to leave home and community involved not knowing if she would be cared for:

> You're being taken out of your community; taken out of your home. There's, you know, for a lot of people, that's like, a huge deal – coming out of home, coming out of the community to go to another, to a big city to get treatment from doctors who you don't know … you think in your head – you're just: "How am I going to get the same caring treatment … the same care?" (Andrea)

These differences that the young people described highlight why connection with place mattered to participants. Mia explained it like this: "So, I didn't really know much about [city] other than the hospital. It wasn't home" (Mia). Those last words, "It wasn't home", summarise the significance of that difference between young people who have to travel for treatment and those living where they are receiving it, and why connection with place matters – for the young person in the city, they were home; Mia wasn't.

4.2.2 Connection with Knowledge: Being Acknowledged and Understanding My Cancer

The second sphere of connection is connection with knowledge. This encompasses young people being acknowledged and understanding their cancer at diagnosis, during treatment and after treatment.

4.2.2.1 Being Acknowledged. Being acknowledged by health staff and included in their care plan was important to young people in this study. They spoke of how staff tended to talk to their parents rather than the young person themselves.

> We also like to know what's happening. My family's not experiencing it. It's me that's experiencing it … just because the person being diagnosed is young … doesn't mean they're completely unaware of what's happening, because they do want to know … knowledge is a powerful thing. (Mia)

Young people said they wanted to be spoken directly to. Raymond called this keeping him 'in the loop': "I wanted to be in the loop, you know, so I knew what was happening next, and what I needed to be prepared for and everything" (Raymond). One participant experienced not only himself being unacknowledged when he asked questions but also his own mother being ignored by an ICU nurse – he explained his frustration at this behaviour from the nurse: "It's: 'No, that's my Mum. If I don't get to know, then at minimum, she gets to … Why am I not allowed to know? You're bloody doing this *to me*'" (George).

Given the importance of feeling a connection with staff through being acknowledged by them, not surprisingly, it was viewed favourably when doctors 'acted on a hunch' to investigate symptoms. For example, Goerge spoke of how a doctor stated, "16-year-old's should not be getting crush fractures". Another memorable statement recalled by a participant that a doctor said to them, which led to successful diagnosis for the young person, was, "You know, with your symptoms, if you were a 50-year-old male I'd think you had bowel cancer" (Gracie). They appreciated good advice from doctors, such as when a doctor said to a parent, "If this was my child, I'd send them to [city]" and even being "fought for" to have treatment provided by the specialist cancer centre in the city:

> … and the doctor [at outer regional hospital] said: “Look, there’s a really good doctor down there in [city] that is basically fighting for your case. She is basically sitting there with a broom fighting off all the doctors saying: ‘No, he is my patient now.’” (George)

Andrea recalled the excellent care she received from the Visiting Medical Officer (VMO) who comes to the outer regional city to do clinics twice a year, saying, “when we found [VMO], or when she found us, um, that’s when all the support started coming in.” These examples highlight how important being acknowledged by health staff was for young participants.

Participants also felt invisible at times and unacknowledged. They spoke of wanting to be offered support: “It sucked ‘cos I didn’t feel supported … down there (in the city) you don’t really see them (the nurses) until you buzz them … It would have been nice to actually know that they were there” (Layla). They also wanted staff to admit when things go wrong: “I want them (doctors) to accept they’re not Gods. I am not mad they made a mistake. Just admit you made a mistake” (George). They also noted that being treated normally was helpful: “…they just don’t want to be treated like they’re any different” (Sharon). Acknowledgement as a theme came through in the analysis of four young people, who expressed they were also glad of the opportunity to help other young people by participating in the study: “… it was good to be able to talk and give advice” (Brianna).

4.2.2.2 Understanding My Cancer at Diagnosis. Participants wanted to understand their cancer at diagnosis. Participants’ clearest memories of diagnosis included delays in being diagnosed, what they were told by health staff and family, the research they did and what they found out, the impact of their diagnosis on them (which involved fear and wondering if they were going to die for half the participants), the impact of their diagnosis on family and friends, and ways they felt living in a regional, rural or remote area negatively affected their diagnosis experience.

To understand their diagnosis, the young people and their families needed to know they had cancer in the first place. Two participants who lived in very remote locations when they were diagnosed both experienced delayed diagnoses, and a third living in an outer regional area delayed getting the test her doctor ordered because “I think I just sort of had in the back of my mind that ‘it’s gonna be something bad’, so I didn’t wanna get the lump that I found biopsied” (Layla). One of the two who lived in a very remote location, Andrea, described her experience of being informed that the tumour they had removed three months earlier was cancerous and that this not only meant a delay in her diagnosis but the doctor delivering the news said he didn’t know anything about the type of cancer and that she should “Google it”:

> I got a phone call, and I was at home, from the doctor. And he said to me: “Andrea, you need to get your Mummy because we’ve found something in your test, and you need to come to the hospital.” So, we went and did that. And they said that for the last 3 months that they had missed the … test …and they said: “Oh, we’ve missed this – we’re very sorry … here’s what you have.” And then he (the doctor) turned around and told me to Google it … he said he had “No idea. Ah, Google it. You’ll have to Google it.” (Andrea)

The other participant living very remotely who received a delayed diagnosis explained:

> I feel like because we were so remote and probably because [the remote staff] didn’t have the knowledge, that was probably why it took so long for them to figure it out … if we were in more of a, like, less remote location, I feel like we probably could have caught onto it a little bit earlier. (Sharon)

Andrea explained that the delay in her case was due to the surgeon who performed her surgery going on leave and not being backfilled. Andrea was told by the doctor who delivered the news of her diagnosis that due to the surgeon being away, “We had missed these results”, and that it was “…when they were catching up and going back through that they’d found this report …” (Andrea). She went on to explain:

> … in the (regional or city) hospitals, if the doctor goes away, someone else comes to pick up, you know, where they left off. And the fact that that surgeon went away, and no one was there to follow-

> up from him, ah, in a normal health service that wouldn't be on … you know, imagine if that had've been an aggressive tumour and they hadn't got it all and find out 3 months after … I could've been head-to-toe riddled with cancer. (Andrea)

Andrea's alarm at what could have been the case, being "head-to-toe riddled with cancer" if it had not all been removed by the surgeon, leads to another issue raised by half of the participants around fear of dying. Five participants expressed either fear or thoughts they had at diagnosis that they might die. George stated, "I didn't really show that I was absolutely terrified because obviously watching TV cancer is often portrayed as fatal." Gracie considered not surviving her cancer: "You're faced with your mortality at a very young age" (Gracie). Mia also associated having cancer with dying after an internet search: "I just remember connecting cancer with death. And just wondering, like: 'Is this gonna happen to me?'" (Mia). Raymond said, "…my main question was, like, 'Is it fatal?'"

Young people's ideas gained from incomplete and possibly incorrect diagnosis information led two participants to search the internet. In Andrea's case, she was literally following doctor's orders, having been told by her doctor to "Google it". This was the impact her internet search had on her: "I didn't wanna die … all I saw was cancer and all those things that pop up and I just, just thought I would die 'cause you know … [I was] this young child looking at all that" (Andrea).

Andrea and Mia, in discussing their fear around dying arising at the time of diagnosis, explained how they searched the internet for answers owing to a lack of explanations given to them on their cancer. Mia said, "I remember just sitting there. Like I said, they didn't really explain things to me. So, I had to rely on the internet to realise: 'Oh, well, what exactly is [Mia's cancer diagnosis]?'" Mia went on to explain that her internet search gave her the information she needed about how chemotherapy worked. Mia lamented:

> I had to go to the internet for that, which given our health care system now, shouldn't be the case. There should be that connection between the health care provider and the patient. Having to give that information for the patient is really important. To, I guess, have that autonomy to knowing what to do with their care. (Mia)

For these two young people, the failure of their health provider to give accurate information at diagnosis about their cancer led to them searching the internet, one literally due to ‘doctor’s orders’, which resulted in serious psychological consequences of being afraid they would die.

4.2.2.3 Understanding My Cancer During Treatment. Participants wanted to understand their cancer during treatment. A lack of explanation from health providers was an issue during treatment as well, with participants finding it hard and scary not knowing what treatment would be.

> I wasn’t prepared for how sick I was going to get … it was honestly the worst experience ever … I wish I had been more informed. I did try Googling some stuff, but I didn’t really find too much out about it. (Layla)

Gracie said: “I definitely was scared … I think it was mostly the unknown for me – that was the scariest.”

Participants found many aspects of their treatment negative. Their varied responses stated that it was boring, created hunger, was tiring, scary, sad, caused high fevers, rendered participants unable to go places when their immunity was low and that chemotherapy side-effects were harsh – in one case resulting in broken bones whilst still going through treatment. In another, extreme fatigue was a frightening experience:

> Throughout the treatment there is days that I’d go to sleep thinking: “I hope I’m just gonna wake up tomorrow” … I think your body just gets so fatigued and just so drained that, you know, it just felt like you could just easily go to sleep and just not wake up. That part was a bit scary, as well. (Gracie)

Other negative impacts included pain – George said of his treatment that although he was told by health staff he had a curable type of cancer: “You’re telling me ‘The cancer is weak’, but the chemo isn’t. Just because you can get rid of it doesn’t mean it hurts any less.” Two participants spoke of their concern about the impacts on their siblings: “[my sibling] was pretty lonely down in Brisbane …” (Sharon); “They did get worried at times”, said Raymond.

4.2.2.4 Understanding My Cancer After Treatment. Participants wanted to understand their cancer after treatment. All but one of the participants was still engaged in follow-up appointments with a cancer or haematological specialist when they consented to participate in the study. Participants described their experiences when treatment finished with mixed feelings. They were glad treatment was finished but also unsure of what the future held. Andrea said, "… it's just that, you know, 'great unknown' feeling …"

Participants noted many after-effects of their treatment. Physical after-effects included being unable to go back to work, cognitive delays, short-term memory loss, hearing loss and potential infertility. Behaviourally, one participant liked to joke about having had cancer and was more careful now with what he eats and "not doing anything too dangerous," given health providers did not know what caused his cancer (Raymond). Two participants did not like being separated or far from their parents due to anxiety (Sian and Brett). Psychologically, there were no long-term negative after-effects on one young person and their family (Sharon); however, another noted a realisation that "cancer can happen to me" (Raymond), and two stated not wanting to speak about having cancer with others (Sian and Mia). One participant discovered only recently, prior to the interview, that she had been on a drug trial during treatment, which was almost like a violation for the young person when she found out:

> …they didn't talk to me, and like say: "Oh, um, there's a trial on this drug. Did you want to be a part of it?" … which is kind of very unusual … what if I didn't want it and then you just went ahead with it? … it's my own body … (Mia)

There were also mental health after-effects and spiritual or philosophical realisations for participants. Mental health after-effects included getting anxiety, having a "late mental break" a year after treatment finished (Andrea), getting "post-traumatic stress" (Brianna) and having a fear of needles (Layla). Finally, some spiritual and philosophical realisations included: "you only live once (Brianna)", "I have a faith … you rely on that more and it makes you stronger (Gracie)"; "it strengthened [my faith] a bit (Raymond)" and "after having cancer I realised anything can happen" (Raymond).

4.2.3 Connection with People: Family, Friends and Health Staff

Connecting with people, in particular family, friends and health staff, was a third sphere of connection evident in the data. Missing family and loved ones were significant issues for all young participants. Gracie said of living away, "[Y]ou're more isolated from your family and friends". Keeping those connections going through communication was important: "I ended up having Facebook … Mum set it up so I could message friends" (Brianna). Some participants felt their friendships suffered through having cancer: "[N]obody sort of really came around as much" (Layla). George said, "Showed who the real friends were. The real ones, who actually messaged me and continued chatting with me, are the ones that I still chat to today."

Having a good connection with the staff treating them was important – at either the specialist cancer centre in the city or their home treating team. George remembers the psychologist in the city he went away to for treatment: "[The psychologist] sort of became one of my friends in the hospital because he … had the same sense of humour as me". Four participants spoke of the connection they had with a particular key case management health staff member in oncology. Mia explained the importance of this connection:

> 'Cause she just remembers you. She remembers what you like and all these other things. Which – yeah, it's really good. There was a connection between the two of us … a therapeutic relationship, I would say. (Mia)

Mia's words, and that she and three others spoke of this staff member, validates the importance of the key case management staff who assist young people in navigating their cancer care treatment and journey.

4.2.4 Connection with Support: Coping Strategies

A fourth sphere of connection that became evident through the analysis was connection with support. For young people in the study, being diagnosed with cancer, having to travel away and treatment itself brought negative experiences. Young participants spoke of needing coping strategies. They talked of the strategies they used themselves to deal with either the physical or psychological hardships they faced and noted where help did or didn't come from.

Young people's coping strategies included coming up with a solution to something they thought was going to happen (asking for a guide dog if he lost the sight in his eye – Brett); finding their own way of dealing with it: "[W]atching the needle go in made it easier than eyes closed" (Layla); and helping others and connecting with others who have cancer: "I think you make friends quite quickly when you can share experiences … not everyone has had that experience [cancer] … there was someone I met at Canteen – [he was] so like me …" (Brianna). Other ways of coping included staying connected with loved ones back home and using humour during treatment:

> I liked messing with my siblings about it … you know … to make fun out of it, 'cause they're not sure what's going to happen, they're always getting a bit scared, so you'd go "oh, oh, oh no" [Raymond grabs his chest and makes a sound like he can't breathe with a dramatic, scared look on his face, then laughter] (Raymond)

Use of humour whilst sharing their experiences also occurred during the interview on occasions: "It was a tiny little twin-prop plane. Bumpy as hell. It was quite a rainy night. It was dark, gloomy, rainy … quite fitting" (George, speaking on the Royal Flying Doctor Service flight to the city which he found extremely difficult physically and psychologically).

For the young people in this study, help came from anti-anxiety medication, family, friends, psychiatrists, psychologists, the young person's school, clown nurses, social workers and local community fund-raising. Andrea, although being in the health system, got psychological help through her school: "The school started noticing my mental health going down … through the school I got support – not through health" (Andrea). Andrea's statement highlights that it really does "take a community" to raise and support children and young people – what health services had not picked up on, her school did. Sian's family had their local community help with fund-raising: "Financially it was tough. Our local town fundraised which was so lovely" (Sian's parents). All of the participants emphasised the importance of support from family, especially whilst away. This was possible through publicly subsidised travel and accommodation. Participants' general recollections of having a support person with them is reflected well in Mia's statement: "It was really good, actually. It means I had someone there in an unknown situation. Like, [I] had someone familiar with me, which was really good … it was huge, I guess" (Mia).

Relatives who assisted the young people through the study stepped in at crucial times during their cancer journey, and during the interviews, to assist with gaps in memories/recollections. Parental oversight of care at diagnosis, during and after treatment led to ensuring their child was safe – even from other family members, averted eye surgery in one case where the parent demanded a second opinion given their child was going to lose their eye if the surgery went ahead (resulting in a good outcome – the young person still has their eyesight) and correcting health staff when things were not done properly or where their child was put at risk. Some of the young people noted, with thanks, their relatives' input at those key times during their journey: "They're my Mum and Dad. They're not going to choose something that'll make me die" (George).

4.2.5 Connection with Peers: Sharing My Experience

The fifth sphere of connection was connection with peers, or other young people living with cancer. Being connected with other patients was something young people spoke about as being important, either as a positive thing that helped them or missing it if they did not have it – including when other patients died. It was another patient who let Gracie know about volunteer assistance in the metropolitan city to get from the airport to the hospital:

> … he was getting treatment down in [city] around that time as well. He'd just finished treatment and he said: "Get in contact with the Cancer Council because they have volunteers who will pick you up from the airport and take you to the hospital that you need to go to." (Gracie)

All the participants offered ideas on ways to make young people's experiences of living with cancer (their peers) better. They gave advice for young people with cancer themselves, social workers and health staff.

4.2.5.1 Advice for Young People Living with Cancer. Nine participants offered advice for young people from Far North Queensland who may be going or will go through a cancer experience. Their advice can be categorised under five spheres of connection of the results – connection with place, knowledge, people, support, and lifestyle.

Advice falling within the sphere of connection with place included recommendations for the hardships of being separated from home when they had to travel away for treatment to southern cities. These included trusting their regional health care team: “Definitely trust in the people who are taking care of you in the regional area ‘cause they’re not the people where you might be having your treatment but, yeah … definitely keep your trust” (Raymond). Another recommendation was to prepare for travel to the major hospitals where the specialist cancer treatment was to take place. Raymond advised to take any games or the things young people might want with them when they go: “Actually don’t pack lightly … bring as much as you can! Especially if you don’t know how long it’s gonna be. It’s always good to bring lots of books, games, whatever. ‘Cause you’ll probably miss it if you forget it.” Staying in touch with family and friends back home was recommended: “Stay in touch and know … you are gonna see everyone again” (Brianna). One participant wanted young people to know that “processes are much better these days. Travel and everything’s … a way better experience with how far the health system’s come in the last 10 years” (Andrea).

Advice in connection with knowledge and understanding their cancer was to *get knowledge*. The ways participants suggested gaining knowledge were firstly to listen to health staff:

> … if you’re old enough to comprehend it, listen to everything they say, because knowledge is comforting. If you know what's happening, you'll know what's gonna happen next. So, nothing will be a shock, nothing will scare you … as long as you know, and as long as you listen, and as long as you comprehend what is happening, nothing will surprise you, nothing will scare you. (George)

A second piece of advice was to research about your cancer. Layla explained that before she even saw the cancer specialist, she Googled about her cancer:

> I know Google's not exactly that reputable, but I was on Google or googling everything about my cancer – what it was; there's not really any cause for it, it just happens, cancer … but, like, what it was; what I could do to help my body fight it … (Layla)

The third point of advice participants offered was to ask doctors and health staff any questions young people have about their cancer, at any stage of the cancer journey, with Layla going on to suggest young people write down questions and answers so they are not forgotten:

> … writing down my questions that I wanted him to answer, because you'd forget them otherwise. He'd be like: "You got any questions?" and you'd be like: "Not really." But then, you'd get home and you'd be like, "Oh, I wanted to ask him that". Write it down. Take it with you. (Layla)

Advice under connection with people centred around young people maintaining connections with their family and loved ones, including by being in contact with those still at home whilst they're away having treatment: "[S]urround yourself with your family as much as you can" (Sharon). Another suggestion was to be with other young people going through cancer for support and understanding: "Being with other people who are going through the same experience as you and know what you're going through." (Mia).

Advice under connection with support firstly came from six participants who said young people going through a cancer experience could build on their personal autonomy and ensure they have the support they need. These suggestions included 'speaking up' and asking for help for any physical or psychological issues they may have:

> You don't have to put up a facade and say you're not in pain. If you're in pain, tell them. Because if you do tell them you're in pain, they'll more than likely give you some pain meds to help with it. (George)

Andrea stated that "talking to someone is the key … your mental health is the key to getting through" (Andrea).

Participants also thought young people could help themselves psychologically by thinking positively: “[D]on’t think about bad thoughts” (Brett). Mia suggested, “not dwelling on the negative thoughts on what they see on the internet and yeah – just having that preoccupation of your mind with really good things as well, and your mental health especially.” Mia went on to suggest, as other participants did, asking for help if those psychological strategies were not working.

Participants suggested practical ways young people could build on their autonomy, including doing puzzles to keep the mind active: “[C]hemo messes with your brain … I wish I had done brain teasers or something to stimulate my brain more” (Layla). George suggested having interests: “Find a hobby … make sure that you know something that can distract you and can distract you for months” (George). Layla suggested keeping a journal to help with memories, given chemotherapy had affected her thinking: “[M]y memory and my brain just – it all gets muddled up sometimes.” Ideas to ensure young people have good support included joining childhood cancer support organisations to be with other young people who understand what they are going through, and proactively building a support network: “[T]ry to find a good support system” and “take one day at a time” (Sharon).

Advice within the sphere of connection with lifestyle included ways participants got through and were able to stay connected with life and themselves – the things that helped them personally survive their cancer. As part of these deep reflections, young participants advised that other young people going through cancer would do well to remember that they are not alone: “[T]hey’re not alone in their experience – they have someone. They have people to rely on” (Mia). One participant shared a song that he felt embodied the shared experience young people have going through cancer, highlighting these particularly poignant lines and how they make him think and feel:

> ‘We are the ones who will never be broken. With our final breath, we will fight to the death. We are soldiers.’ Like obviously it’s a bit morbid to think “yeah, its cancer patients fighting to the death”, but it’s sort of like we are. It’s like, no matter what, we’re still fighting. But sometimes we may lose. Thankfully, I didn’t. (George)

George is not the only participant to reflect on the cancer journey being a ‘fight’. Layla’s reflection brought with it advice for other young people to not give up that fight: “And just fighting – just not giving up would be my advice. Just don't give up" (Layla). Brianna, too, noted the importance of having hope: "[K]now that there is a light at the end of the tunnel."

4.2.5.2 Advice for Social Workers. All ten participants had advice for social workers on how to help young people from outer regional and remote areas going through cancer, with eight having had some level of contact with a social worker whilst going through their cancer treatment. Their advice addressed two of the study's spheres of connection: connection with people and support. Young people saw a key role for social workers to either be the support or connect them with needed support to go through their cancer experience. Participants provided advice on interventional methods that would connect the young person with their own autonomy and the support they required. They also recommended methods that the young person would find helpful in the therapeutic relationship with the social worker.

Participants noted the biggest way social workers could help is by being there in the first place, with one participant having no recollection of any social work support from the health teams in either their hometown or in the city they travelled to for their treatment. Another participant only saw a social worker once in their hometown, and two other participants recalled social work support in the city they travelled to for treatment: "I do remember social workers, but not psychologists. At least I was able to talk to people about what was happening, which is good" (Mia).

Availability of social workers and connecting regularly was important: "… just being a little bit more readily available … just to check in a bit more often … I think I met maybe one in the whole time …" (Gracie). Raymond said social work access was more readily available for him: "[T]trying to stay in touch as much as possible – you guys do that quite well … you connect with parents as well, which is good" (Raymond).

Offering psychosocial support was seen as an important role for social work: "[S]upport them and let them know that there's a lot of people there for them" (Brianna). One participant noted how offering support, especially for "the mental part of it," was important to help young people process what they are going through: "Because kids can't process that kind of stuff" (Andrea). One participant reflected on the psychological help he got, stating, "I wish it had happened a year earlier. Much earlier" (George). Another participant reiterated the importance of offering support:

> I mean, we are limited in what other things like Canteen or Camp Quality … that we have here [in geographical area Gracie is from] … but maybe being able to give them more access to support systems of someone who can answer their questions if they have any questions. (Gracie)

Offering support and arranging appropriate referrals for that support was a key social work role for these participants.

Participants also saw a role was for social workers to educate nursing staff about young people's needs and how to provide their care in the most optimal and supportive way, including allocating to the young person's care the nurses the young person feels most comfortable with, having a list of nurses who know how to "needle a port" as this particular procedure is painful and "When they miss it hurts, 'cause then they have to poke you again" (Brianna), or training nursing staff to do this procedure. Brianna suggested social workers could "talk to the nurses about being more supportive rather than being, like, 'this is just another patient'" (Brianna).

Participants also noted methods that they think social workers can use to connect therapeutically with and support young people psychosocially through their cancer care. One participant stated that being kind to the young person was a start: "Don't be so strict on them when they do something wrong" (Brett). Persistence was also seen as a favourable trait – to not give up on the young person if they refused help initially:

> I'd say that it's really important to try and get through, even if kids shut down, you know, a lot of kids will for the first session or whatever and will just sit there and they'll just shut down, but … try and deal with them – try to talk about something just randomly different to get them feeling a bit more confident. Just make the effort. Don't put it in the 'too hard' basket. (Andrea)

It was also seen as desirable to get to know the young person and understand that all young people are different and to be aware of each one's unique qualities: "That every kid's different, and to, ah, learn how they are to be able to work with them in a certain way" (Brianna).

Two participants suggested going at the young person's pace: "[T]ry to let people talk at their own pace", suggested Brianna. Sian's parents thought it was important to understand how traumatised both the young person and parents are and that to "go at their pace when discussing things" allowed the time required to process information given the trauma they are going through. Brianna also noted that choosing a place where they feel comfortable to talk or providing an opportunity to talk alone was important: "Even considering who's around them and they might not want to talk in front of (them) about things."

When asked what the best way was to get to know a young person, one participant replied to "ask how they're feeling", "find out how they're going with things" and "what they're looking forward to" and "who they've been hanging out with" (Brianna). Brianna also suggested finding out what makes the young person happy and assisting them in pursuing those things: "[W]ith kids that are coming back to oncology and stuff, maybe asking them if they like helping out. Like, helping other people, or whether they'd want to … 'Cos that (helping people) makes me feel happy."

One participant thought knowledge of the young person's cancer and what the young people who have travelled away are going through with being separated from home and loved ones was important for social workers to understand:

> … them having knowledge of the cancer and what they would be going through would be good … the social worker didn't know what I was going through … Just them trying to understand more where we're coming from … Like, their family environment. If they're coming from somewhere regional and they've been surrounded by all their family and all their friends and they're coming to any major hospital, they wouldn't have them with them. So, just understanding that and knowing where they're coming from and how they're feeling more. (Layla)

One participant saw a role for social workers in keeping in touch with the young person's school when they would be returning home from treatment to let the school know how to set the young person up psychosocially for success with their re-integration into school life: "Keeping in touch with the school would be a good one … like people just coming out of treatment. I guess it depends what they have and how it affects them at school" (Raymond).

Parents involved in supporting their child in the study had some suggestions about ways social workers could better help young people living with cancer from nonmetropolitan areas, including listening and being non-judgemental. One practical suggestion was given regarding how feeling dislocated from "place" (home and community) was an issue for young people: "Find out what they love in their home environment and help to bring some of that to the child while away from home" (Sian's parents).

Finally, other feedback was that social workers were helpful for young people: "Just keep doing what you're doing, I think" (Raymond). However, one participant said there were not enough of them:

> I haven't actually had a social worker that's been non-helpful from either hospital (hospital at home or in the city). Like, they've all been nice and very quick to getting stuff that you need done, but … I wish there were MORE … so it wasn't so: "Ahh, dam they're busy", or "Ahh, dam it's their day off." (George)

4.2.5.3 Advice for Health Professionals. Nine participants offered advice for health professionals on ways they could assist young people living with cancer in Far North Queensland. These suggestions fall under four of the spheres of connection: connection with place, knowledge, people and support. This advice highlights that young participants believe young people need health professionals to assist them connect with knowledge about their cancer. They want supportive and helpful connections with the staff themselves and ways to maximise their autonomy and ensure support is offered. Treatment closer to home is also desired.

Under the sphere of connection with place, all ten participants would have preferred to have their treatment closer to home. One participant suggested making an easier and physically more comfortable way to travel down to the southern city and specialist cancer care centre:

> … (I was) still sore and everything, and I was having trouble standing up a bit … they did send me on a public flight, and it was a bit

> difficult on the plane … I think we had to get our own transport to the accommodation once we got to Brisbane and everything. That was a bit difficult for me and my parents, because I was really still tired from that week of being in the hospital (and having surgery) … I was still sore and couldn't walk for long periods of time. A way to make that easier would have been nice. (Raymond)

Another participant suggested a bigger facility that could treat young people in Far North Queensland so that they did not have to travel away: "[H]aving a bigger facility in [Far North Queensland city] would be nice" (Mia).

Under the sphere of connection with knowledge, delayed diagnoses were an issue for three participants and thus advice for timely diagnoses were provided. Andrea put it this way:

> Just make sure it's not being missed, because it really does impact … it's a big thing for kids. Any result or finding is good … keep that follow-up. Keep it up to date. Don't go on holidays for 3 months … (and if they do) … Please do a hand-over! (Andrea)

Correct information about treatment, including what to expect, was suggested as an important way of connecting young people with knowledge about their cancer. "Explain the procedures to them. Just don't leave them out because they're young. Because they do understand. They do want to try to understand, anyway", Mia said. Layla believed she wasn't prepared enough for the reality of what her treatment whilst away would be like:

> I wish I had been more informed … I think I would have been more prepared … It was a bit traumatic … I knew it was gonna be heavy, but I didn't realise … I couldn't eat for days … I just couldn't eat anything.

Layla explained that "I did try Googling some stuff, but I didn't really find too much out about it." Layla had also been told by the doctor from the hospital in the outer regional city that she would be able to leave the ward whilst on treatment to see her family staying in the unit near the hospital in the city; however, in reality, this was not possible. This incorrect information from her home hospital set her up with an expectation for something that could not happen, making her travel away for treatment and separation from her family even worse at a time when she needed it most.

Under the sphere of connection with people, knowing, understanding, listening to and acknowledging young people going through cancer treatment are all what participants wanted from health professionals. George's words are a sobering reminder of why acknowledging the young people you are treating is important and why being ignored has a negative impact: "There was one nurse … she refused to tell me what meds she was giving me, she refused to acknowledge that I was even there, even though she was sticking a needle in me" (George). Layla's experience of feeling ignored was due to staff not regularly checking on her whilst she was having treatment. When asked what the nurses could have done so she did feel acknowledged and supported, Layla said: "Maybe even just talking for a little bit. Or coming in every couple of hours. Or making sure you've got water." Mia reiterated that she felt ignored when staff spoke to her parents and not her, and that staff need to talk directly to the young person themselves: "Just keep talking to them." Participants recommend acknowledging the young person by speaking directly to them, explaining the procedures that are happening to them and regularly connecting with them to enquire how they are going to make young people's cancer treatment experiences and relationships with staff better.

Knowing and being able to 'read' the patient was also suggested. Brianna spoke of how nurses knowing her meant her physical and psychological care needs were better met by them: "Some nurses would know you and you could ask them: 'I need to go soon – here' and they'd be able to tell you. Some nurses wouldn't even know who you are, and they wouldn't really know what to do." George thought if staff "read" their patients better, they'd pick up on the types of things that might put the young person at ease, like humour:

> If you can tell that they've got a really cool sense of humour or something, don't be afraid to crack jokes – especially with me. If you can make me laugh, that's a good way to make the appointment a lot nicer and quicker.

Being treated normally and allowing more uninterrupted sleep in hospital was advised. Sharon said young people would not want to be "treated like they're any different" than others to normalise the experience of having cancer. Two participants noted that allowing young people uninterrupted sleep overnight in hospital when they are tired is something health professionals should consider: “[I]t bothered me a lot in the nights sleeping over … the machines would always beep … it woke you up a lot – you wouldn’t get much sleep in hospital” (Raymond). George said he literally sticky-taped a note to his chest which read,

> “No pain – please let me sleep” because I got sick of them constantly asking me, because they’d ask me every 20 minutes, for 8 hours … So, I just sticky-taped that to my chest and fell asleep in the hospital bed because at that point I was just done, I was like “don’t care”.

Feeling normal and having enough sleep mattered to these participants.

Under the sphere of connection with support, a need was seen for psychosocial support. All participants suggested it, with one noting in her advice to health professionals: “Maybe bringing in a psychologist would be nice … Because it can be really draining on your mental health, especially going through it at a young age” (Mia). Indicating appreciation they felt when they did feel supported, two young participants wanted to acknowledge the good work health staff do. In their own words: “I met a lot of lovely people along the way who did an amazing job, so, I definitely think they’re doing the best with what they’ve got to work with” (Gracie); “Just thank you to all the staff – all the health care workers – for all the work that they do” (Mia).

4.2.6 Connection with Lifestyle: Surviving Cancer – How it has Shaped Me

The sixth and final sphere of connection emerging from the analysis was connection with lifestyle. It mattered to young participants that they survived. They reflected on a rich and varied array of ways their cancer experience changed them and made them who they are now. Some of the ways they felt they had changed were physical – wearing hearing aids, cognitive delays, potential infertility, not having any feeling in a body site, with one participant noting they now heal faster. Some were psychological or mental-health related – with anxiety, depression, fear of needles and ‘psychological problems’ topping the list. There was also a realisation of how many other people have cancer: “Once you get into that world of knowing about it, you realise how many people have it and how many people around you end up having it as well" (Brianna).

Participants noted things they can do because they had cancer, for example, tolerating pain better and being more resilient in online learning environments due to having to do school from a distance whilst away having their cancer treatment. They also noted things they cannot do now because of it. For example, some cannot work, are less active, do not talk about their cancer or sometimes choose not to talk as a way of avoiding how "I know (other people) will react" (Mia). They described who they think they are now because of having cancer as "a normal adult" (Andrea), braver, more sympathetic to others, more understanding, more health-conscious and more cautious: "[B]efore it was a pretty normal kids' life – doing what kids do, and the changes are I just stayed at home … being cautious about everything" (Brett).

Participants said they had done things because of their cancer experience like getting tattoos or becoming a nurse, or it had inspired them to do things like "go explore more or see more" (Layla). There were things they like to do now in relation to having had cancer, such as joking about it, helping others, having a "new-found love of food" (Layla) and listening to their bodies more. Other negative repercussions of having their cancer treatment were not getting a license and, as one participant put it, "I had to grow up a hell of a lot" (George).

One participant spoke of his relationship with his own body in relation to breaking his bones and other issues such as being hospitalised whilst still on treatment, like his body had 'let him down': "Well you sort of get like with, um, all of the medicine. You know it's [the body] going through a lot, but you're still like 'Come on you guys – you couldn't handle a little bit of running?' or 'You couldn't handle a slight temperature?'" (George).

There were spiritual and philosophical learnings for young participants – "I realise cancer can happen to me – I'm not invincible" (Raymond). Some shared having a stronger faith (Raymond and Gracie), realising that "life's short" and "you only live once" (Brianna). And they also noticed changes in their relationships with comments like "it made my family closer" (Mia). Conversely, some friends dropped away. Losing friends who died from their cancer, or knowing that other patients had died, was one of the hardest effects on their relationships of all: "[N]ot long after that he passed away, after having leukaemia for the third time…That really was hard, doing that – saying goodbye to people" (Brianna).

4.3 Conclusion

The phase one findings of this multiperspective IPA study indicate that young participants endured many hardships travelling away from home for their specialist cancer care at outer regional and metropolitan sites. Being separated from home, loved ones and their normal lifestyles was difficult. Young participants desired connection with and within six domains, represented and presented in the spheres of connection model. These six spheres were place (treatment close to home), knowledge (being acknowledged and understanding my cancer), people (family, friends and health staff), support (coping strategies), peers (sharing my experience) and lifestyle (surviving cancer – how it has shaped me). Their strongest desired connection in the sphere of 'place' was with home. The spheres of connection model offers a foundational way to understand what is important to young people living with cancer in outer regional and remote Queensland. The model can assist young people in maintaining and building connections with the things that are important to them. This understanding can inform social work and health practice with young people from nonmetropolitan areas. In the next chapter, I present the findings of the social work perspectives.

Chapter Five: Findings – Social Work Perspectives

Following from Chapter Four, which presented the findings of phase one on young people's perspectives, this chapter presents the findings of phase two on social work perspectives. Two key experiential themes emerged from the analysis: 'cumulative loss' and 'cumulative trauma'.

One key research question guided this phase of the study: "What are social workers' perspectives on the experiences of young people living with cancer from outer regional and remote Queensland and their encounters with the health system at diagnosis, during cancer treatment and after treatment or when they return home?" Interpretation of the data revealed that young people from outer regional and remote Queensland experience many losses and traumas, according to social work participants. Two group experiential themes of 'cumulative loss' and 'cumulative trauma' emerged. Social work participants also discussed the support young people require, which is presented in Chapter Six. The thematic development into social work perspective group experiential themes of 'cumulative loss' and 'cumulative trauma' are depicted in Table 6.

As outlined in Chapter 3, I used IPA for my data analysis of social work perspectives. In following IPA methodology (Smith et al., 2009; Smith & Nizza, 2022), I developed a visual representation of the overall analysis (see Figure 3).

As with Chapter Four, narrative is used to present data from the group experiential themes (cumulative loss and cumulative trauma), including personal experiential themes and experiential statements within these. Participant quotes are included to help illustrate the thematic data and make the evidence base transparent.

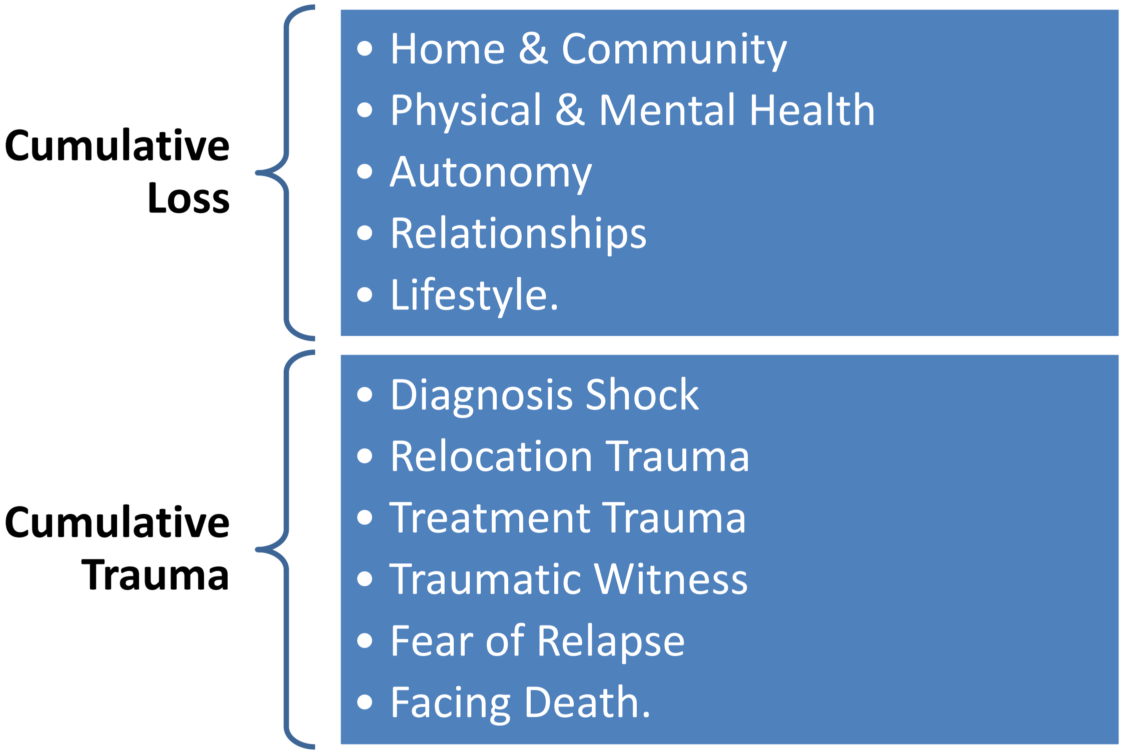
Table 6

Theme Development into Group Experiential Themes for Social Work Perspectives

Experiential Statements	**Personal Experiential Themes**	**Group Experiential Themes**
Pining for home → - The grief of having to travel away - Home & going back to Country: experiences for young Aboriginal and Torres Strait Islander people - Returning home	**Loss of Home** → **& Community**	**CUMULATIVE LOSS**
Coming home when life is ending → - Wanting to get back home		
Community connection vs Isolation: Differences → **between metropolitan and nonmetropolitan experiences** - Community connection (metro young people) - Isolation (nonmetro young people)		
- Physical Losses → - Psychological, Mental Health & Emotional Losses - Spiritual, Philosophical & Perspectival Loss & Change	**Loss of Physical** → **& Mental Health**	
- Loss of independence → - Loss of own space - Health choice losses - Young people desire inclusion in health conversations - Young person and carer	**Loss of** → **Autonomy**	
Missing family, friends and loved ones → - Loss & grief for family - Separation from family and home - Concern for family - Loss of hanging out with friends	**Relationship** → **Losses**	
- Loss of connection with self and life goals → - Lifestyle losses due to travelling away for treatment	**Loss of Lifestyle** →	
Diagnosis Shock →	**Diagnosis Shock** →	**CUMULATIVE TRAUMA**
Transfer Crisis →	**Relocation** → **Trauma**	
“The doing to them” → - Maslow’s Hierarchy: Save life first - Invasive procedures	**Treatment** → **Trauma**	
- Traumatic witness of family reactions → - Traumatic witness of peers’ experiences.	**Traumatic** → **Witness**	
Fear of Relapse →	**Fear of Relapse** →	
Facing Death →	**Facing Death** →	

Figure 3

Cumulative Loss and Cumulative Trauma for Young People Living with Cancer from Outer Regional and Remote Areas – Social Work Perspectives



5.1 Introduction of Participants

Six social workers participated in this study. Their pseudonyms are – Ari, Caelan, Emery, Layne, Riley and Sage. Two were from an outer regional Queensland site, and four were from a major metropolitan Queensland site. All were current employees of Queensland Health who had worked with young people living with cancer from outer regional or remote Queensland at some stage in the 10 years prior to interview. Social work participants' experience working with young people living with cancer ranged from 12 months to 14 years.

5.2 Cumulative Loss

One of the key themes that emerged in phase two's analysis on social worker's perspectives was cumulative loss. Social work data indicated multiple, cumulative losses experienced by young people when travelling away for cancer care to specialist outer regional and metropolitan treatment sites. Cumulative loss can further be broken down into loss of home and community, loss of physical and mental health, loss of autonomy, relationship losses and loss of lifestyle.

5.2.1 Loss of Home and Community

'Loss of home and community' is the first cumulative loss to emerge in phase two. Social work participants spoke of young people pining for home, coming home when life is ending and community connection (for young people living in the city where their cancer treatment is available) versus isolation (for those in outer regional and remote areas who have to travel away for treatment).

Young people from outer regional and remote areas experience many losses when they travel away for treatment and miss their homes and communities, essentially creating an experience of 'pining' for home. Pining is akin to longing – feeling very sad because one wants something or someone they are not with or do not have (Merriam-Webster Dictionary, 2023). Experiential statements within 'pining for home' were: 'the grief of having to travel away', 'home and going back to Country: experiences for young Aboriginal and Torres Strait Islander people' and 'returning home'.

All social work participants discussed how being away from home communities for cancer treatment was isolating and overwhelming for young people, and they missed their normal lives and loved ones: "[T]hey just missed their life" (Caelan). The grief experienced by young people through these cumulative losses was summarised by Ari and Layne: "[T]hey're grieving so many different things, little things … they're grieving their lost life that they used to have because everything is completely changed being relocated somewhere else" (Ari). Layne said that "the diagnosis, in itself, brings huge grief and worry and uncertainty around their future, and then also all the kind of physical losses … There's just so many different layers of loss often for young people."

In this study, social work participants all stated that young people from outer regional and remote Queensland areas spent significant periods of time away from home communities. Four social workers (Ari, Emery, Layne and Riley) explained how relocating to outer regional or metropolitan cities for cancer treatment meant being away for “six to 12 months, depending on how treatment goes” (Ari). Riley noted young people were “always [away] longer than they expected.” Missing the physical spaces of home was observed by social workers: “I think it can feel a bit of a concrete jungle in [metropolitan city] … with all the cars, and I think it’s a very different feel to their communities …” (Layne). Layne noticed young people ‘missing out’ on their relationships, school or work whilst away for long periods of time: “[T]hey feel a sense of that they’ve missed out on a lot of time and a sense that they’ve missed out on a lot of what’s happened.” Riley highlighted how young people were often initially excited about coming to a larger city, but then reality hits:

> … a few weeks in, reality starts to hit that this is what it's gonna be like for the next six to 12 months. And this isn't fun, or this isn't the initial kind of weird adventure that they started with. Now they're feeling yuck. And now they're stuck here. And that's when they realise that they really don't want to be here.

Two social workers observed young Aboriginal and Torres Strait Islander people yearn going back to Country. Ari described that, for one young Aboriginal and Torres Strait Islander person, “home meant a lot … things are a bit different going back to Country.” Ari explained, “they needed to return home to be on their land, to be seeing their family; to see their grandparents; to see all of those people.”

Emery had extensive experience working with Aboriginal and Torres Strait Islander people, including in remote communities. Emery explained diagnosis was a scary time for young Aboriginal and Torres Strait Islander people, exacerbated by having to relocate to large regional or metropolitan centres for treatment. Emery said, “they get some very scary news and then they’re immediately removed from their entire support network, except one person [their approved escort/caregiver travelling with them] … it is a big, big deal.” Emery said, typically, in very remote communities, Aboriginal and Torres Strait Islander young people are “related and in touch with everyone in it. So, really quite a big social network … there might be 300 people in town, but you [young person] know all 300 people.” Emery explained it was isolating and overwhelming to have to relocate away from extensive home community social networks to places “much bigger population-wise, and there are also extra systems [to learn].” Emery said that Australian historically discriminatory and racist health and government departmental practices may make young Aboriginal and Torres Strait Islander people and their families reluctant to engage fully with the system trying to support them: “If you’re a patient, and your experience with systems – big systems and processes – is continued and systematic racism and oppression, then you can see where people would be reluctant to engage moving forward as well.” Emery also noted English was often a “second, third, fourth language” when from remote communities, adding to experiences in the larger health system of being intimidating, alienating and isolating.

Emery worried resources in outer regional specialist cancer care services do not comprehensively culturally support young Aboriginal and Torres Strait Islander young people from remote communities. Lack of appropriate cultural support means informed consent and important information sharing may be missed, according to Emery. Emery shared concerns when Indigenous Liaison Officers are not from, or don’t understand, the young person’s Aboriginal and Torres Strait Islander cultural group: “[I]f we don’t really have prompts to ask about cultural practices … if … we don’t have an appropriate ILO from that group.” Emery noted one young person they worked with who, due to several barriers including COVID restrictions, heavily relied on their parent “to be the voice.” However, their parent “was also new to all of these systems” (Emery). Emery noted feelings of fear, isolation, alienation and dislocation from home communities for Aboriginal and Torres Strait Islander young people and carers were exacerbated when required to relocate to more than one specialist cancer care site (e.g., Torres Strait Islands to Cairns and then to Brisbane), a common occurrence for this age group, particularly those from remote communities.

According to social work participants, returning home is complex for young people when care finishes or is transferred to health services closer to home. Young people are excited to be going home; however, anxiety is common regarding continued health management and re-integration back home. Four social work participants (Ari, Caelan, Layne and Riley) had observed excitement and anxiety in young people returning home. Layne described how “initially, young people and families – there’s a genuine excitement and relief” (Layne). However, transition home was also a time of anxiety for young people, with some also grieving the loss of their connections with services and staff in the metropolitan hospital (Caelan) and fearful of whether their local health service had the expertise to manage their cancer care (Caelan and Layne). Caelan said, “you go back and it’s just Mum and Dad … almost that sense of the grief … ‘I always had these people around, so if something went wrong, I had people to ask, whereas now it’s just us.’” Layne had also observed young people’s apprehension about returning home: “[I]t can be daunting going back to not being close to a big hospital and: ‘What if something were to happen?’ … will the local hospital respond in the way that they need?”

Layne and Ari had observed young people anxious about reintegrating into their community. Layne said, “I think young people and families feel very changed by the cancer experience … while there’s often excitement, there’s apprehension around: ‘how will we re-integrate back into our routine when feeling like life has sort of changed forever?’” Ari had known young people going back to school and their friends not acknowledging their cancer experience: “[T]hey almost felt not validated that this had even happened. It was like the world moved on, which is a really common experience for people to say: ‘The world moved on and nobody even noticed I was there.’” Ari, Caelan and Layne noted proactive parental support in returning home and re-engaging with school and local services was key. Ari, Caelan and Layne said continued connection and support from their community (e.g., fundraising, schools maintaining connection) was integral to young people feeling confident returning home. Layne said young people without home community support “might have been really disappointed in how they’ve been supported by their community and, more individually by friends, and their having to return back can be very daunting.”

Four social work participants (Ari, Caelan, Riley and Sage) reflected on the experience of coming home for young people whose cancer becomes incurable whilst away. Two (Ari and Caelan) noted the importance of returning home to Country for young Aboriginal and Torres Strait Islander people: “They wanted to go back home” (Ari). Caelan believes young people yet to return home, or unable for medical care reasons, are particularly vulnerable. Caelan considered the experience of young Aboriginal and Torres Strait Islander people unable to go home before they die:

> …there are …lots of gaps for young people … being disconnected from Country; being disconnected from their community; not having

> the ability for families and friends to come in and see them, to follow through with rituals, memory making – there's so many challenges with end-of-life care for those that can't get back home …

Sage provided insights from working with a young person with incurable cancer. What mattered to the young person at diagnosis, during and after treatment finished was "to get back home" (Sage). Sage explained going home after treatment finished for this young person brought "a sense of coming home. I think [young person] was much more comfortable being home." In this final time of the young person's life, it was their wish to die in their own home. However, for medical reasons requiring hospitalisation, they died in hospital. Sage, reflecting on this young person's experience dying in hospital, said: "The hospital is very impersonal – no two ways about that … even though they've got all the medicines and everything on board, and nursing staff and doctors, it's still not home." Ari offered the following perspective on why returning home is important for young people at the end of life:

> Being home is important because that's their life … they've grown up there, they're safe there. They have comfort there. They're surrounded by potentially more extended family. They've got their peers; they've got their normal supports and they've got their stability back home … sometimes some of them are going to school regardless of the fact that they know that they won't ever graduate because that's their safe place. And that's where they wanna hang out with their peers and just pretend that everything is [stops sentence] … Home, in these situations, everything's normal and it's like they're not sick. Because they're back at home … (Ari)

In Ari's interpretation of why going home is important, home means comfort and close proximity to loved ones, friends, support, stability, safety and normality. The negative aspects of having cancer are lessened for young people when they are back in the comfort and safety of home.

Social work participants described differences between metropolitan and nonmetropolitan young people's experiences, which led to two experiential statements of 'community connection' for metropolitan young people and ‘isolation’ for nonmetropolitan young people. Community connections of home were a defining difference social workers described between young people from outer regional and remote Queensland (nonmetropolitan) locations who have to travel away for specialist cancer care when compared with young people who can remain in their own cities (metropolitan) for cancer treatment. For those young people who stay in their own cities, community connections remain; for those who have to travel away, it is isolating without those connections.

All social work participants observed travelling away for specialist cancer treatment was difficult for young people from outer regional and remote Queensland. They compared this with young people who can still remain at home when living in the city where the specialist cancer service is located. Young people living within close proximity to the health service could maintain physical connections with friends and loved ones, were familiar with the city itself and had the scaffolding of their local community around them. All of these factors associated with care close to home offered a “dilution” of “normalcy”, according to Riley: “I want to say the dilution that happens when you’re in your own community … you’re also accessing your friends … you have pre-existing relationship … not everything is about health and cancer and these things.” The dilution of normalcy for young people living where their cancer treatment is available means young people have their normal lives there to immerse themselves in, which mitigates the negative impacts of their cancer experience. Catching up with friends, being in a familiar space, sleeping in their own beds at night, being able to physically visit their school and living “fairly familiar lives” (Riley) were seen as beneficial for young people living where specialist cancer treatment was available. The scaffolding of local community around them was a significant source of support:

> Their friends are coming in and out of the hospital; they're going home to their real home that they are secure with; they’re still attending school. I guess it's that sense of normality … they can still kind of stay engaged with their normal life, their normal routine. (Caelan)

Travelling away is isolating for young people from outer regional and remote areas as the scaffolding support of home and community is missing:

> They feel lonely and isolated because they're away from their family and away from their friends … They're angry that there isn't something close to home that they can get - somewhere like a health service - that they can get their treatment at. (Ari)

Emery explained that being separated from family, friends, home and community meant "that ability to find comfort in the familiar is kind of just not there." Sage perceived living away from home going through cancer treatment as isolating for young people:

> You don't go home to your own bed of a night-time. You're living in a motel. Your whole life's been up lifted. You're aware your parent's life has been up lifted … you're s'posed to pick up your life from [home community] and then land [at treatment city] in an unfamiliar territory and it becomes: travelling across the road to the hospital, back across to the unit. And so, in that ground-hog day sort of routine. Then what do you do outside that?

Two social workers (Ari and Caelan) spoke about young people not feeling safe without the normal comforts of home: "It's the isolation that's the major difference. We don't have the same capacity to have these people feel comfortable and safe in their own environment – they're not" (Ari).

5.2.2 Loss of Physical and Mental Health

'Loss of physical and mental health' is the second cumulative loss to emerge in phase two. Social work participants' accounts of losses within physical and mental health fell under three main themes of 'physical losses', 'psychological, mental health and emotional losses' and 'spiritual, philosophical and perspectival loss and change'. These losses occurred in the context of travelling away for cancer care and affected young people's connections with people, their lifestyle and temporarily or permanently returning home.

Three social workers (Ari, Riley and Layne) noted physical losses including reduced physical abilities, pain from treatments, and physically evident treatment impacts like hair loss. They also spoke of the resulting loss of independence and privacy caused by physical losses. Reduced physical abilities occur with certain treatments and interventions, such as having a port (device under the skin on the chest) or central line inserted into a vein (cannulas usually inserted in the arm) to administer medication. As Riley stated, “some of the lines you can’t swim with or get wet”, impacting on young people’s lifestyles. Vomiting and nausea from chemotherapy stops young people from being able to participate fully in their lives (Riley). Reduced physical abilities mean young people’s goals must change:

> … potentially they’re having surgeries and things that actually are impacting on their ability to do some things like be as mobile as they used to be …what they previously wanted to do doesn’t fit anymore with either their physicality or the way that they think about the world. (Ari)

Social work participants explained treatment caused physical losses like weakness, loss of privacy and looking different: “If they’ve needed to get cancers cut out of different areas they might have different physical impacts from those … often young people are in wheelchairs and things for a while … they don’t have the strength to be walking.” (Riley). Loss of privacy accompanied invasive physical examinations. For instance, Riley explained mucositis was a condition young people experienced due to treatment which causes inflammation in the gastrointestinal tract causing ulcers from the mouth through to the urethra, bowel and anus. This led to a loss of privacy for young people, who endure medical examinations in personal body areas so treatment can be provided: “[T]hat often leads to lots of examinations of those areas … because you’re a teenager, there’s a lot of privacy in all these sorts of things” (Riley). Layne observed treatments can leave young people fatigued and physically weak, remembering how this prevented a young person’s ability to play sport, with the young person being “in bed each day for about a month.” Layne described how weakness remained a problem for another young person who had returned home: “[They] finished treatment and went back home but still require a lot of physio.” (Layne). Returning home looking different was difficult for young people: “[Y]ou go back and you look different when you’ve had those physical impacts of treatment [tears] … yeah – they don’t look and feel like they’re them anymore” (Riley).

Social workers explained that treatment can affect young people’s psychological, mental or emotional wellbeing. As Layne stated, “they feel just like it’s very unfair and don’t understand why it’s happened to them.” Riley noted, “they’re still facing all of those same challenges … peers and bullying and self-identity and social media … with this increased risk around/to their emotional well-being about their own health.” Riley and Layne described ways physical health losses can precipitate a decline in young people’s mental health: “[I]t brings a sense of sadness and disappointment, and you sometimes see themes of helplessness” (Layne). Riley noted serious mental health conditions can develop: “It’s a tricky time to manage their emotional well-being and what is an emotional and mental health response to a health crisis, versus what turns into health trauma or a chronic mental health condition.” Riley explained trips home during the relocation period whilst at major regional and metropolitan sites were important for young people’s mental health: “[T]hose periods of going home and re-connecting just offer so much.” However, sometimes young people do not want to return to continue their treatment after trips home: “[T]here’s a difficulty for parents in getting them to come back … they don’t want to [return for] treatment. But they do” (Riley).

Spiritual, philosophical and perspectival loss and change were observed in young people by five social workers (Ari, Caelan, Emery, Layne and Riley). Emery noted social, emotional, mental health and spiritual loss for Aboriginal and Torres Strait Islander people in relation to their connection with Country: “It’s those broader and maybe more comfort cares, and social and emotional, mental health and spiritual wellness that is impacted on being away from home and loved ones” (Emery). Riley and Caelan observed young people questioning or abandoning their religious or spiritual beliefs because of their cancer experience: “One of my young people had such a strong religious faith – then wanted nothing to do with [their] church” (Riley). Caelan shared how one young person “disconnected from [their] religious beliefs based on the fact that [they] got cancer.” The young person had been told by relatives with a religious faith, “‘you’re going through this for a reason’ ‘… it happens to the strong people’ ‘you were chosen because you’ll get through it’”. The young person told Caelan, whilst processing these comments: “‘I cannot think of anything fucking worse. Like, if God existed, I wouldn’t have cancer.’” Perspectival shifts had been observed by Ari, who reported a young person saying about friends at their home community “‘Such-and-such is fighting about something really trivial. And I just think to myself, who really cares? Like, this is such an insignificant thing to fight about.'" Social work participants thought these physical and mental health losses, including spiritual, philosophical and perspectival shifts, meant young people returned home feeling different and missing the person they were before they travelled away for their cancer care.

5.2.3 Loss of Autonomy

'Loss of autonomy' is the third cumulative loss to emerge in phase two. The data analysis revealed five areas encompassing social workers' views on young people's loss of autonomy: 'loss of independence', 'loss of own space', 'health choice losses', 'young people desire inclusion in health conversations' and 'young person and carer'.

Young people, four social work participants explained, experience a "loss of their independence" (Ari) when having treatment away from home. Young people are "at an age where they're slowly getting some independence, earning some money … and you are throwing them back in to that environment where – our hospital; the cancer; the treatment; is now controlling their life" (Ari). Further, they now have a parent or carer "who is well-meaning as anything, but realistically is also in control of their life and is looking over them and constantly with them all the time" (Ari). Emery observed reliance on the health system, including for accommodation, and having only one escort with them adds to the loss of autonomy.

Social work participants noted reduced physical abilities disrupt physical pursuits including playing sports and educational and personal milestones normal for adolescence and young adulthood. Sage described this disruption for a young person they worked with: "[T]here was some trajectory that this young person was on, where they wanted to go. So, getting back to school was important so they could achieve those goals... and sport." For this young person, losing their independence to attend school and play sports were significant losses. Caelan noted a loss of "friendship connections at school", educational milestones like completing their grades and formals, and personal, developmental milestone goals like getting a licence. Depending on parents again in many areas was a struggle:

> … we're almost at this peak independence and then we're pulled back into: "No – I need my parents here." That seems to be quite tricky for the young people. So, just: "I nearly had my life together and now I've just been pulled back into feeling like I need people to help me. (Caelan)

One social work participant detailed how young people experience a loss of privacy and space to occupy as their own when they travel away for their cancer care (Riley). Riley described privacy loss in hospital and outpatient accommodation. Young people share these spaces with their carer and other patients/families, including patients much younger than 15–25-year-olds "and being teenagers or young people on a ward with babies and children, and then staying in accommodation [which] can often be the same." Riley offered an example of how this lack of space and privacy impacted young people trying to process their grief of a new cancer diagnosis:

> I remember one [parent] telling me, "I'm pretty sure we're taking turns in the bathroom to cry, because it's the only space we have that is away from each other … When I'm running the shower it's just giving myself a few minutes to grieve, and not do that in front of [young person]. And I feel like [young person] is doing the same."

Two social workers discussed the loss of choice around young people's health care. Firstly, young people have no choice to have cancer treatment to save their life: "[Y]ou often don't have a lot of choice … if it's life-saving treatment, it's not really a choice for young people, it's realistically – it just has to happen" (Riley). Secondly, young people have no choice but to relocate for cancer care, with treatment unavailable closer to home: "So, they have no choice. They have lost complete control over everything. They have no choice but to relocate to [major metropolitan city]" (Ari).

Riley noted a lack of health choices by comparing how young people normally make choices, such as dying their hair, to express their identity or connection with certain friends or same-age groups: "[T]hey do it in a way that is safe to them and that actually builds connection to the other people." However, young people do not choose to look different from cancer treatment: "[A] really obvious tube that is plastered to your face with some tape that then goes up and into your nose, screams sickness" (Riley).

Half of the social work participants acknowledged young people "want to be included in the conversation" (Caelen) about their health care with health staff. Including young people in healthcare conversations about their health care contributed to young people's need for autonomy throughout their cancer experience, according to social work participants. Young people need space for private conversations "away from Mum or Dad to talk to someone" (Layne). Young people's inclusion and centrality in health conversations communicates that "this is your health – you're the boss" (Emery). Inclusion in health conversations contributes to young people's autonomy over their health care, which young people value "because everything else has been taken away" (Caelan). Having control over their health care "is a life skill for young people [which] makes them feel like this is about them, that the parents aren't making decisions for them … they're making their own decisions" (Caelan).

All social work participants perceived that young people experienced autonomy losses through constantly being with a parent/carer whilst living away for treatment. Being with one carer constantly can strain that relationship: "[Y]ou can definitely see it with patients, getting more frustrated or wanting more time alone" (Ari). Layne, Ari and Caelan described the challenges of being with one carer constantly, summarised comprehensively by Layne:

> … they're spending a lot of close time together through treatment and it can be a lot of pressure on that relationship … prior to diagnosis they might have been moving away from … their parent, and then all of a sudden very much having to really rely on them and always being with them.

Carers influencing young people's level of autonomy was also considered by Sage, Ari and Emery. Sage pondered whether a young person they worked with may have been discouraged by their parent, whether intentional or not, to make autonomous health care choices or access psychosocial support. Sage tried initiating support, "As much as I could. As much as [parent] would allow me." Sage described the parent as "very protective, and I absolutely understand." However, Sage was concerned that the young person may not have had an autonomous, active voice regarding decisions around their health care and support/s.

5.2.4 Relationship Losses

'Relationship losses' represent the fourth cumulative loss to emerge in phase two. Four subsets of this loss revealed in the data analysis were: 'loss and grief for family', 'separation from family and home', 'concern for family' and 'loss of hanging out with friends'.

Four social workers (Layne, Ari, Riley and Sage) discussed that young people miss face-to-face contact with family, friends and loved ones, including pets, when separated for extended periods. As Layne mentioned, "there can be a big disruption to family life, and dislocation of family members from the family unit, and young people have definitely shared missing their other parent or close family members, and siblings as well." Ari described young people feeling "lonely and isolated because they're away from their family and away from their friends." Layne stated young people "do miss out on more, school-wise and socially … they're such key years for school and for socialising and for friendships." Layne explained young people taking part in team sports miss those activities and social connections they bring: "[Y]oung people can often be part of a team and then they don't see those team members [or] peers … having to be [away] for extended periods can be really disruptive to them."

Social work participants noted pets were also missed. Riley described the delight a young person experienced sharing footage of their dog's reaction after a trip home during treatment:

> … when they finally got to go home it was just incredible … (laughs) … they filmed the dog coming and the dog realising it was them and just losing its shit and, it was just so lovely for them to get that validation, because they had for months been showing us photos and having photos up in their room and talking about the dog …

Sage also shared a young person missing pets: "Animals – pets – were important." Sage explained that at diagnosis, a young person wanted to "get back home and be with the animals."

Two social work participants commented on loss and grief experiences for young people's families. Loss could be complicated by other losses, demonstrating this study's finding of the cumulative nature of losses. In one example, a young person newly diagnosed with cancer had recently been through another immediate family member's cancer experience: "[T]here was such complex loss and grief in that family in so many ways for all of them … [including] siblings … it might be happening to one, but all of them are impacted" (Riley). Another example was when a young person's cancer was incurable and the immediate and devastating effect this had for both the young person and parent: "Life had "shwooo" (sound made with fast moving hand gesture). The … rug had been pulled out from underneath them and they'd been dealt a card that neither [parent] nor the young person ever expected to get" (Sage).

Separation from family was a loss observed by social workers for young people when going through treatment away from home. Loss of social connection also occurs due to cancer treatments. If young people are immune compromised, it limits their social interactions as they need to avoid getting sick: As Ari explained, "they can easily catch viruses and a common cold can be deadly to them." Riley observed young people's struggles with feeling different to their friends due to having cancer: "That's really hard … to acknowledge that something is different about you than your friends." Changes young people feel from their cancer experience can cause feelings of separation from important others who may not understand: "And they feel like people won't understand... that there is a bit of a lack of understanding or awareness with the broader networks … they (friends) don't really understand what they're going through as well" (Layne).

Five social work participants (Ari, Caelan, Layne, Riley and Sage) observed young people were concerned for their families' welfare whilst experiencing cancer. Young people carried the burden of guilt of hardships their families experienced. Ari said: "They feel very sad and guilty and upset that they're putting their family through this … feeling like they're a burden on their family … and that they're splitting up their family." Caelan explained this burden of guilt manifests in concern displayed for young people's parents, prioritising parental needs over their own: "[T]hey're always so conscious of what the parents are thinking or feeling or doing or not doing … And I'm like: 'I'm not asking about your parents; I'm asking about you and where you are.'"

Three social workers (Caelan, Layne and Riley) discussed young people feeling “torn” between feeling they’re a burden on their family and needing familial care through cancer treatment. Riley’s comment captures these observations:

> The young person wanted both parents there but also then felt the pressure that someone should probably go home and earn some money, although: “I don’t really want them to because, you know, I need my parents.” …they’re often torn between having that greater understanding of impacts for the whole family and the stresses on their parents at the same time as being kids and being people that want people around them to look after them and make them feel safe.

Loss of physically being with friends was observed by all social workers. Young people sometimes felt friends did not understand what they were experiencing and were ‘moving on’ (Caelan). Caelan observed young people worrying, “‘My friends will forget about me.’” Caelan, Layne, and Riley observed how young people tried to stay connected with their friends while away. Caelan noted with the ease of phone contact and social media, connection via these technology mediums was “not a big impact. But they do miss seeing their friends.” Further, “there might just not be that same level of communication that they would usually have with them. And that leads to a sense feeling that those relationships are impacted by being [away] and the treatment.”

5.2.5 Loss of Lifestyle

‘Loss of lifestyle’ is the fifth cumulative loss to emerge in phase two. Data analysis revealed two main areas of lifestyle losses social work participants identified for young people: ‘loss of connection with self and life goals’ and ‘lifestyle losses due to travelling away for treatment’.

Three social workers viewed having cancer as interrupting young people’s connection with their life goals. Riley described how being disconnected from home communities and loved ones can negatively affect young people’s self-identity: “if you’re then disconnected for long periods … or you’re recovering from big surgery and you can’t hardly communicate … teens will say to me: ‘I don’t feel like I’ll ever feel like me again.’” Interruption to the means of attaining life goals were losses. Riley explained the importance of school for both social connection and achieving young people's goals: "They lost so much that to get to keep doing the things that they wanted to do – the subjects they wanted to do – like, one of my young people is one of the most beautiful artists."

All social work participants observed lifestyle losses, encompassing losses noted previously, which were centrally important in young people's lives. The whole-of-life, cumulative losses young people experience travelling away for cancer treatment is captured by Ari:

> …it took them away from their comfort and their safety. And it required them to 1) deal with the fact that they have a life-threatening illness; but 2) deal with that not being anywhere near their usual homes and comfort and safety and support system. So, I think overall that is the biggest thing is that we ask them to deal with the treatment, the side effects and all of the different things away from anything and everything that they love and feel happy and supported by.

Young people's experiences of life-threatening cancer, treatment and side effects are traumatic – endured far away from the safety and support of home.

5.3 Cumulative Trauma

The social work data analysis revealed multiple traumas, which accumulated over time, experienced by young people who travel away for cancer care to specialist outer regional and metropolitan treatment sites. Six cumulative traumas were identified: diagnosis shock, relocation trauma, treatment trauma, traumatic witness, fear of relapse and facing death.

5.3.1 Diagnosis Shock

Diagnosis shock' was the first cumulative trauma young people experience, according to social work data. In this study, all social work participants outlined ways receiving a cancer diagnosis was a shock for young people. Diagnosis shock was due to fear, apprehension, uncertainty, isolation and feeling overwhelmed. Young people sought knowledge about their cancer and relied on their parents or carers at diagnosis, including due to having to travel away for treatment. Riley said a cancer diagnosis was a trauma for young people: "I would call it trauma because anything that's a threat to your life is trauma and a cancer diagnosis, no matter what it is, feels like a threat to your life." Layne described a common theme for young people as "the shock of the diagnosis and the distress around that." Layne described it as "a very scary, distressing time that can be quite isolating for young people who come from more remote communities." Further, young people "are suddenly thrown into the hospital into the clinical environment where they might not have been to a hospital before" (Layne). Caelan described fear and uncertainty for young people from remote areas:

> …they haven't actually had the diagnosis, but they've had some investigations already. So, I think there's a lot of fear; apprehension; uncertainty; when they get to [specialist outer regional or metropolitan centre] about: 'Well I've had all these tests, but I don't have the answers yet. I don't know what's actually happening for me.'

Riley noted young people from outer regional and remote areas are health travel savvy, accustomed to travelling away for various health care needs due to living further away from major treatment centres and hospitals, which meant cancer diagnosis was usually unexpected:

> …often for a cancer diagnosis people are presenting with things that don't necessarily scream 'cancer' from the get-go … people from more regional and remote areas are quite used to having to go somewhere else for health care. The local clinic can't do it so they go to the next biggest town … it doesn't always indicate red flags for them because it's quite routine. So, then when they end up [at specialist outer regional or metropolitan hospital] with a really significant diagnosis, it's really hard to activate supports because they have so far to travel to be here.

Social work participants believed that with the shock of diagnosis, young people seek knowledge about their diagnosis and what they can expect over the course of their treatment. Social workers explained there is a greater risk of consulting unreputable sources of information on the internet if health services do not immediately provide reputable information. Riley represents these social work views, explaining regardless of what advice doctors or other health professionals give, young people will ‘Google’ their diagnosis. They are “being given incredibly terrifying news, and any doctor that says: ‘Now look, don’t go research …’ I can tell you; a teenager is on their phone two minutes later Googling whatever that doctor just said” (Riley).

5.3.2 Relocation Trauma

‘Relocation trauma’ was a second cumulative trauma young people experience, social work data analysis revealed. Social work participants explained relocation transfers usually happen immediately on diagnosis or suspected diagnosis of cancer. Social workers used terms like “uprooting their lives” (Ari), “remove yourself from your entire life” (Emery), and “suddenly picked up and plopped in a hospital in the city” (Riley) to describe the dislocation the relocation brings. Travel itself was seen as stressful and, at times, frightening for young people and carers. Layne noted how daunting it was to travel away, especially for those who may not have been to a large city before:

> I think we find that young people and their families, they might not have ever been to [major regional or metropolitan city] or been on a plane … if they’re helicoptered into [outer regional/metropolitan city] that might be their first experience of 1) being in [outer regional/metropolitan city] or 2) then being on a plane as well.

Riley identified travel as being very stressful for parents, giving an example of parents travelling by car to get to a metropolitan city after a young person’s cancer diagnosis: “I’ve had parents who were on the road for 13 hours straight just trying to get here, because they’ve then found out that there’s a cancer diagnosis.”

‘Transfer crisis’ is the experiential statement I identified under relocation trauma. Social work participants perceived the suddenness of diagnosis and transfer away for treatment as a time of crisis for young people from outer regional and remote areas. Riley explained young people might not have “been on a plane before”, or “seen an escalator before” or “seen a lift before” or “seen a two-storey building before and all of a sudden they’re … often have gone to another hospital before [city], and then [arrive in city] and it’s soo [with emphasis] overwhelming.” Riley noted emotional and psychological shock with relocation, including being overwhelmed by the new treatment site and city environments:

> … when you bring people who aren't generally used to living with fluorescent lighting and elevators and escalators and lots of noise and lots of different people and medical information and just the very environment can be over-stimulating and overwhelming and scary – incredibly scary. And if English isn't your first language and no one speaks your language, or no one looks like you as well for more remote, Aboriginal and Torres Strait Islander families – especially those from remote communities, it's just huge. It's just huge …

Riley, Sage, Ari, Layne and Caelan emphasised how the suddenness of relocation and learning new environments was shocking and unsettling for young people: "These are all really challenging systems to navigate when you are just suddenly picked up and plopped in a, you know, hospital in the city, to try and work out these things" (Riley). Sage and Ari made similar observations using similar descriptive words to denote the abruptness of transfer: "Your whole life's been up lifted" (Sage); "it means not just the patient, but another family member, friend, carer, will have to be there with them. So, two people are uprooting their lives, at least – minimum – and moving to [metropolitan city] to have this treatment" (Ari). Riley and Layne observed challenges learning the new environment: "'Where do I get food from?' and 'How do I – what in the heck is Uber eats?' and 'a taxi' and 'How do I …'" (Riley). Layne also stated, "I think the kind of thoughts around 'how do we get around?' and not knowing where things are can be difficult as well." Caelan observed young people not feeling safe in the new treatment city site due to not having physical connectedness and the familiarity of home: "[W]hen you're going to a new hospital and new environment – you don't have that opportunity to retreat to what feels comfortable and safe."

5.3.3 Treatment Trauma

'Treatment trauma' was the third cumulative trauma to emerge in phase two. Treatment trauma describes what young people experience through treatment. All social workers observed the trauma young people experience at this stage, including physical shock, pain or “the doing to them” (Riley), emotional and psychological shock and invasive procedures. ‘The doing to them’ is the experiential statement falling under treatment trauma. Riley described the trauma of treatment: “[W]hen the ‘doing to them’ starts, they get their blood tests and all of those sorts of things – I think that’s incredibly scary.” Treatments and interventions social work participants described that young people have which are painful or traumatic included cannulas, ports and central lines being inserted (for intravenous administration of chemotherapy or other medicines young people need as part of their cancer treatment), physical tests and investigations, naso-gastric tubes to provide food into the young person’s stomach when unable to eat due to side-effects of chemotherapy, fertility preservation processes, treatments causing ill effects like nausea and weakness and making them feel “yuck” (Ari), look sick, and have “no energy” (Ari).

Emotional and psychological trauma was described as accompanying physically shocking cancer treatments. Psychological trauma also resulted from the experience of pain during invasive treatments. Riley noted that some of these treatments, like getting a port or cannula inserted, are explained to young people in ways that under-represent how painful they are: “Apparently it’s ‘just a scratch’ – don’t you love that line they give [young people]? ‘It’s just a little scratch’ … Every time I hear them say that I think: ‘Yeah – no thanks. I wouldn’t put my hand up’” (Riley).

According to Layne, isolation during treatment through being disconnected from the young person’s home community was a factor contributing to the trauma young people felt. Layne explained that young Aboriginal and Torres Strait Islander people were particularly vulnerable when being ‘in isolation’ in a single hospital room (that is, in a room on their own due to needing to be protected from viruses or illnesses when they are immune compromised or undergoing a bone-marrow transplant process). Being in isolation involved no one being able to visit other than the young person’s carer and staff wearing full Personal Protective Equipment (PPE) every time they come in or out of the room. PPE encompasses wearing:

> … big yellow gowns – they cover most of your body – they go down to the elbow … and then the gloves will be purple gloves that a staff member would put on. Then also usually a mask as well which covers

> most of the staff member's face. And could also be that a staff member has to wear a shield as well that would go over their face. So, can be quite a lot of additional equipment.

Whilst one young Aboriginal and Torres Strait Islander person was in an isolation room, Layne observed the young person as having "low mood" which meant "they didn't show much emotion and could be quite hard to engage as well in conversation" with "parental concern as well around their mood."

Two further experiential statements within 'the doing to them' emerged. The first experiential statement was 'Maslow's Hierarchy: save life first'. Two social work participants discussed the priority of saving a young person's life. Emery described what was important to one young person: "[I]f we're looking at their hierarchy of needs … obviously, the life-saving treatment and curative treatment – of the first one – they received and received quite thoroughly." Ari also acknowledged how cancer treatment is offered to save young people's lives, even though it means having to travel away from home: "[W]e can't do their treatment closer to home." Caelan noted parity of care regardless of young people's home location, given that all receive the same care at specialist cancer treatment sites.

The second experiential statement under 'the doing to them' was 'invasive procedures'. Invasive procedures accompany many cancer treatments for young people, as observed by all social work participants. Some of these were noted under 'the doing to them', but here I elaborate on fertility preservation, which was raised by five social workers. Caelan described how "oncology treatment may impact the likelihood of them being able to have children later on in life when they're ready to have children." Fertility preservation is how health staff preserve young people's reproductive capability through pre-cancer treatment procedures to store eggs for females and sperm for males. Riley described fertility preservation as "very invasive" for females:

> …the internal ultrasound to check how close the eggs are getting ready to be collected is quite an intrusive examination, especially for a teenager …then to have the egg collection, you have to go under either a twilight sedation [partially sedated] or an anaesthetic [fully

> sedated], and they go in through the cervix and from there they go across to your ovaries and collect the eggs.

For males, Caelan described fertility preservation as a confronting, embarrassing process:

> … for the young men, you know, some of them don't want to talk about masturbating. They don't want to even consider thinking about that with their parents. And then having to, the day of being diagnosed and told that you've got cancer, to then have to go into a bathroom and do that is just – yeah – it's mind blowing.

5.3.4 Traumatic Witness

'Traumatic witness' was the fourth cumulative trauma revealed in phase two's data analysis. I identified two experiential statements under 'traumatic witness': 'traumatic witness of family reactions' and 'traumatic witness of peers' experiences'. In 'traumatic witness of family reactions', all social work participants noted young people's concern for family, covered in section 5.2.4 on relationship losses. Additionally, two social workers also noted distress for young people witnessing their family upset by their diagnosis and treatment experiences. Riley explained young people are "attuned to [caregivers], even when they don't seem to be." Riley shared observations from their practice that "I think they're very aware when their parents are distressed or scared … as best [caregivers] try and hide it, they [young people] know. They can read that." Caelan had observed young people anticipating family trauma for pending decisions they were considering, such as not wanting chemotherapy due to expected traumatic side effects, even though it would increase their chance of survival. Caelan had seen young people more worried about "'What will my Mum and Dad think if I was to say no to therapy and it would reduce my chances?'" Caelan described an occasion where a young person facing end-of-life care options decided against ongoing treatment, which would mean shortening their life:

> … they were just so worried. They weren't fearful of dying. They weren't fearful of being in pain. They weren't fearful of their treatment. They were just worried that their parents would think that

> they're giving up … everything that they were worried about had nothing to do with them. It was just around their family and impact this would have on their community back at home.

'Traumatic witness of peers' experiences' refers to trauma young people experience seeing other young people with cancer go through traumatic treatments or death. In this study, social work participants' perspectives were that staying in hospital or living in accommodation with other young people and building new connections is a positive and helpful way of establishing a supportive community at treatment sites. However, "often those friends and other parents are also going through all of the same things" (Riley). Riley explained this means young people witness traumatic experiences their peers go through, including dying sometimes. Riley offered some examples, such as being in a shared room in hospital and "you're hearing someone else get a devastating diagnosis, or being exposed to other children dying in hospital, or even just being exposed to other people's distress." Riley described how this is also traumatic for parents/carers "when you are trying to deal with your own child's health crisis, you're trying to support a friend whose child is dying." Riley explained that this could occur through sharing living spaces with others from regional or remote areas who have also travelled to the specialist regional or metropolitan centres for care: "[T]he downside to that is that all of the [young people] are sick. And some of the [young people] die." Riley elaborated on how being exposed to peers' trauma due to having treatment or living in close proximity to them is detrimental to young people and "means you are exposed to so much of that trauma and not a great deal of ways to process it."

5.3.5 Fear of Relapse

'Fear of relapse' was the fifth cumulative trauma emergent in phase two social work data. 'Fear of relapse' refers to the fear social work study participants perceived young people experience of their cancer returning (relapse). Return travel to specialist sites for cancer monitoring or follow-up appointments can bring a fear of relapse. Multiple trips away could be "daunting having to do all that travel again" (Layne) in the context of being fearful that scan results may bring news of their cancer having returned. Both Layne and Riley shared their perceptions that young people fear relapse when returning to specialist cancer sites for cancer monitoring. Riley said: “that’s incredibly scary because the first time it’s unknown … But once you’ve lived through it, you then know exactly what that means if that happens again. So, you’re not fearing the unknown, you’re fearing exactly what you know.” Layne noted fear of relapse as another layer of trauma young people experience: “[I]f they’ve finished treatment there might be a lot of worry around relapse. So, it’s another layer on top of everything else.”

5.3.6 Facing Death

‘Facing death’ was the sixth cumulative trauma identified in phase two social work data analysis. ‘Facing death’ relates to when young people’s cancer cannot be cured. In this study, three social workers observed this as a traumatic experience for young people and their families. Ari, Caelan and Sage explored their observations when young people’s cancer could not be cured. Sage said that for young people, the experience of knowing their life was going to end amounts to “confronting your own death process.” Sage described the trauma, shared previously, for both a young person and their carer when told the young person’s cancer was no longer curable as “overwhelming.” Sage likened the impact of this trauma on a young person and their carer as a “rug being pulled out from underneath them”. Inherent in Sage’s descriptions was the connection between the young person and their parent and the devastating impact of incurable cancer on them both. Final traumas Sage perceived as occurring included the young person being unable to die at home, which had been their wish: “So, it just adds to that whole trauma – something being taken away from them again is like a slap in the face.” Sage lastly reflected on the young person’s end-of-life experience in hospital and how this final stage of life appeared to be traumatic psychologically. Sage’s observations led to the belief that the young person “looked terrified …No one knows how to die … particularly when you’re a young person.”

5.4 Conclusion

This chapter outlined social work perspectives, interpreted by me as reflected by ‘cumulative loss’ and ‘cumulative trauma’ young people from outer regional and remote areas experience when they receive a cancer diagnosis and need to travel away from their home communities for specialist cancer care. Under cumulative loss, social work participants identified five key areas of loss for young people – home and community, physical and mental health, autonomy, relationships losses and loss of lifestyle. Cumulative traumas were diagnosis shock, relocation trauma, treatment trauma, traumatic witness, fear of relapse and facing death. Social work participants identified that going back home or having treatment as close as possible to home is young people's psychosocial goal. The next chapter synthesises the analyses of young people's and social workers' perspectives.

Chapter Six: Synthesis of Young People and Social Worker's Perspectives

In Chapters Four and Five, I presented my interpretative analysis of young people and social work perspectives on the experiences of young people living with cancer from outer regional and remote Queensland. In Chapter Four, my interpretation of young people's perspectives was that they desire connection with the things that are most important to them – place, knowledge, people, support, peers and lifestyle. In Chapter Five, my interpretation of social workers' perspectives was that living with cancer for young people from outer regional and remote Queensland areas is an experience involving cumulative loss and trauma. The purpose of Chapter Six is to present the synthesis of my analysis of both sets of data from these two perspectives, using a multiperspective interpretative phenomenological analysis (IPA) methodology (Larkin et al., 2019; McInally & Gray-Brunton, 2021).

The fourth research question designed to explore both the perspectives of young people and social workers was: "What do the perspectives of young people and social workers tell us about the experiences of young people living with cancer from outer regional and remote Queensland?" To answer this question, as outlined in Chapter Three in section 3.4.3, I used multiperspective IPA strategies including conflicts of perspective, consensus overlap, reciprocity of concepts, conceptual overlay and paths of meaning (Larkin et al., 2019). The narrative I present throughout this chapter, which informs the discussion in Chapter Seven and the conclusion in Chapter Eight, constitutes the 'lines of argument' resulting from my analysis – the development of stories or narratives capturing the entire analysis (Larkin et al., 2019). In this chapter, I present the findings of my synthesis as seven analytical 'discoveries'. The synthesis culminates in an overall interpretation, emerging from the seventh analytical discovery, that travelling away for cancer treatment is a liminal, life-changing experience for young people from outer regional and remote Queensland.

6.1 Discoveries from the Data Synthesis

The synthesis revealed that both young people and social workers identified support as central to improving the experience of young people throughout their cancer experience from diagnosis through treatment and after they return home. A third group experiential theme, "support required", emerged for social workers as I analysed both data sets, which I address in discovery five. Table 7 represents both young people’s and social workers’ perspectives in this study to aid in synthesising the phase one and two data analysis.

Seven discoveries were made when synthesising the data analyses of phases one and two. My first three discoveries come from information provided by the social workers that was not available in the data from young people, so these differed to the experiences young people shared in phase one. These three discoveries are in relation to young Aboriginal and Torres Strait Islander experiences, young people going through end-of-life experiences and fertility preservation experiences.

My fourth, fifth and sixth discoveries relate to connection through cumulative loss and trauma. These discoveries result from both young people and social work participants saying young people need support through their cancer experience, sharing ways support does or needs to happen. The fourth is ‘scaffolded support for young people’, the fifth is ‘spheres of connection model for providing scaffolded support for young people’ and the sixth discovery is ‘connection between young person and social worker’. In this study, both young people and social workers stated a desire to connect to facilitate the support young people require.

My seventh discovery, which brings together the data synthesis and study findings, is that travelling away for cancer treatment is a liminal, life-changing experience for young people from outer regional and remote areas. This discovery emerged from young people and social work participants stating the main psychosocial goal for young people from outer regional and remote Queensland was to return home permanently. This led to the interpretation that travelling away for cancer care is a liminal, life-changing experience for young people from outer regional and remote Queensland.

Table 7

Group Experiential Themes Generated for Young People and Social Work Participants

Young People	**Social Workers**
Connection with Place: Treatment Close to Home - Travel away is hard - Travel negatively impacted my relationships, school and work - What makes travel easier - Difference between metropolitan young people's experiences and mine - Coming back home is wonderful	**Cumulative Loss** - Loss of Home and Community - Loss of Physical and Mental Health - Loss of Autonomy - Relationship Losses - Loss of Lifestyle
Connection with People: Family, Friends and Health Staff Relationships were important with family, friends and health staff	
Connection with Knowledge: Being Acknowledged and Understanding my Cancer - Feeling unseen or heard - I needed to understand my cancer: a. At diagnosis b. During treatment - What treatment was like c. After treatment	**Cumulative Trauma** - Diagnosis Shock - Relocation Trauma - Treatment Trauma - Traumatic Witness - Fear of Relapse - Facing Death
Connection with Support: Coping Strategies - Maintaining autonomy - I needed support	**Support Required** - Safety Nets - Building the Helping Relationship - Ideas to Improve Young People's Experiences
Connection with Peers: Sharing My Experience - Relationships with my peers - Improving young people's/peers' experiences of living with cancer	
Connection with Lifestyle: Surviving Cancer – How it has Shaped Me - Surviving cancer - How having cancer has affected my life	

6.1.1 Discovery One: Aboriginal and Torres Strait Islander Young People

My first discovery was from information unavailable in and thus different to the young people’s data. None of the 10 young people I interviewed identified as Aboriginal and Torres Strait Islander Queenslanders. Social work perspectives, however, provided insights into some of the issues they believed young Aboriginal and Torres Strait Islander people from outer regional and remote areas experience. Three social workers (Caelan, Emery and Sage) reflected on the experience of Aboriginal and Torres Strait Islander young people. Two main themes emerged from this data: ‘disruption to connection with Country when travelling away’ and ‘intimidating health system processes’.

Under ‘disruption to connection with Country when travelling away’, three social workers (Caelan, Emery and Sage) connected home with “going back to Country” (Ari). These social workers had observed in practice that going back to Country is important for young Aboriginal and Torres Strait Islander people who must travel away for their cancer treatment. The connection with Country is disrupted by travelling away. Emery, informed by working extensively with Aboriginal and Torres Strait Islander people, recollected the fear associated with a cancer diagnosis and having to travel away for treatment.

Under ‘intimidating health system processes’, Emery’s belief was that health systems and processes are intimidating for young Aboriginal and Torres Strait Islander people from outer regional and remote communities. Emery connected intimidating health system processes with memories young Aboriginal and Torres Strait Islander people and their families had of historic traumatic and racist government departmental policies and practices in Australia, including the removal of Aboriginal and Torres Strait Islander children from families and communities. Emery advised that social workers need to be aware of Australia’s colonial history and its impacts on Aboriginal and Torres Strait Islander peoples and offer culturally safe, trauma-informed practice to encourage young people engaging with the health system and their health care for the best possible cancer treatment outcomes.

6.1.2 Discovery Two: End-of-Life Experiences for Young People

My second discovery was also from information unavailable in the phase one data from young people's perspective. None of the young people I interviewed were going through end-of-life experiences as their cancer had been cured. Young participants spoke of the trauma and grief associated with witnessing their peers die, and for half of the young people, their own fear of dying. However, they were not having end-of-life experiences themselves. Half of the social work participants had worked with young people having end-of-life experiences and provided their perspectives on this. Two main themes emerged: 'traumatic for young people and their families' and 'young people want to return home at end-of-life'.

In this study, the three social workers who discussed end-of-life said it was a traumatic experience for young people and their families, and in all case scenarios where young people's cancer could not be cured, young people from outer regional and remote areas wanted to return home. Ari shared how a young Aboriginal and Torres Strait Islander person "needed to return home to be on their land" for their end-of-life. Sage shared the experience of a young person who, despite knowing their cancer could not be cured and, therefore, their life would end, found comfort in being able to return to their outer regional home: "[Young person] was much more comfortable being home."

6.1.3 Discovery Three: Fertility Preservation Trauma

My third discovery was information from social work perspectives on fertility preservation that differed from young people's perspectives. The only young person who discussed fertility issues, (Sharon), did so in the context of being informed she may be infertile as an adult as a consequence of her chemotherapy treatment. At the time of Sharon's interview with me, she did not use any words or body language indicating that her knowledge of potential infertility was traumatic for her. No young study participants discussed fertility preservation processes.

Current Cancer Council Australia clinical guidelines state, "It is recommended that health professionals inform all people diagnosed with cancer (or their parents in the case of children) that there is potential for cancer treatment to impact their fertility" (Cancer Council Australia, 2024). By this definition, all the young people I interviewed in phase one were at risk of infertility. However, as noted, it was only raised by Sharon. Some of the young people were of an age where fertility treatment would have been discussed and offered, as they were old enough to understand and consent to fertility preservation. However, other than Sharon noting potential future infertility from her chemotherapy, fertility preservation procedures were not discussed by young participants. There are two potential reasons for this. The first could be that fertility preservation was not discussed with young participants during their cancer treatment. The second reason could be that young participants did not want to discuss the fertility preservation treatment they went through, perhaps out of embarrassment to discuss it with me during their interviews, noting some young people had a parent or relative with them.

Social work participants in the study described fertility preservation as a shocking and invasive procedure for young people to go through. One social worker's descriptions of what two young people went through for their fertility preservation captures both the shock of the treatment, as well as how it is an additional layer in accumulating traumas young people experience through their cancer treatment: "I remember them both individually saying: 'Oh my God, I didn't even have to … didn't know I would have to think about that. Like, cancer's enough', kind of thing. It was like: 'Why are we talking about babies?'" (Caelan).

6.1.4 Discovery Four: Scaffolded Support for Young People

In the context of experiencing cumulative loss and trauma, I reached an interpretation through my synthesis that connection forms the basis of support young people require throughout their cancer experience. Scaffolded support can assist in making these connections. I reached this interpretation given my analysis of both young people and social work participant data. In this study, both young people and social work participants identified that young people from outer regional and remote Queensland need support whilst going through their cancer experience. In this data synthesis, I have used a "gem" (Smith & Nizza, 2022) of the word *scaffolding*, which came from two social work participants (Sage and Emery), to describe the support young people require. I presented phase one analysis on connection with support in Chapter Four in section 4.2.4 'connection with support: coping strategies'. My interpretation of social work perspectives on scaffolded support is now presented.

Social work study participants spoke of the support they believe young people require, which I styled into personal experiential themes of ‘safety nets’, ‘building the helping relationship’ and ‘ideas to improve young people’s experiences’. There were three additional scaffolded support ideas from social work participants that were not contained in the young participants’ perspectives. Additional ideas for scaffolded support from social work participants were for those who are Aboriginal and Torres Strait Islander, those going through end-of-life experiences and the connection of social workers between nonmetropolitan and metropolitan sites. I now present these three additional scaffolded support ideas.

Emery believed social workers need to be aware of historical, discriminatory and racist practices in large government systems that can make engaging with a health service frightening and intimidating for young Aboriginal and Torres Strait Islander people and their families from regional and remote areas. For Emery, this cultural awareness means social workers should link young people in with culturally appropriate support, including Indigenous Liaison Officers. Emery explained that with young Aboriginal and Torres Strait Islander people, consideration should be given to cultural needs and health literacy, including attention to language barriers for health information being provided. Emery discussed a “teach-back method” they use with Aboriginal and Torres Strait Islander young people to check the young person understands the information provided, which involves saying “You tell me back what I’ve said.”

Sage believed preparing young people for what to expect when their cancer cannot be cured was important. For social workers, this meant “being able to get in there and try, as delicate and frightening as it is, it’s important … to give some form of structure around what this may look like for [the young person] … ‘may’ …” (Sage). This meant trying, wherever possible, to have conversations with young people privately so the opportunity for them to ask questions about dying or raise things important to them could occur. For this to occur, this might require social workers respectfully advising parents or carers of the benefits of allowing opportunities “to speak with this young person on our own” (Sage). End-of-life care also involved ensuring support was in place for loved ones, wherever possible “‘Cause they get exhausted” (Sage). Sage also advised bereavement follow-up with parents and families is important in comprehensive end-of-life care so social workers can support loved ones.

Caelan also reflected on end-of-life practices with young people and how they could be improved. Caelan had considered introducing ‘legacy boxes’. Caelan noted that ‘memory boxes’ were already used in practice – these contain items for loved ones to use to create memories with the young person at their end-of-life, such as resources to make hand and footprints. Caelan considered what was already in existence for young people 15–25 years of age for their end-of-life care and could see a gap:

> [W]hat would be important to have in that for them? So, things like Voicing My CHOiCES™[1] and maybe talking about their funeral and making a Spotify playlist … how can we promote and make end-of-life [practice] better?

In this study, social workers from nonmetropolitan and metropolitan sites valued connecting with one another for knowledge-sharing, collaborating for enhanced care for mutual young clients and collegial support. Connecting with one another as social workers from either the metropolitan or nonmetropolitan sites was seen as important for mutual support and sharing of information and resources that can benefit young people (Sage). Sage added that social workers from either the metropolitan or outer regional/remote site should share things that assisted them in connecting with the young person: “These are the ways that I was able to interact with them; these are the things that I found were difficult, were easy” (Sage). It was recommended for nonmetropolitan social workers to ask questions of metropolitan social workers, who have expertise with young people living with cancer, for advice and information on services and supports for young people. Building those connections can be done by having a “call and chat” (Riley), dialling into a team meeting, or visiting the hospital at the specialist site “so they can then explain it to families” (Riley).

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[1] Advance care planning resource for young people aged 15-25: Zadeh, S., Pao, M., & Wiener, L. (2015). Opening end-of-life discussions: How to introduce Voicing My CHOiCES™, an advance care planning guide for adolescents and young adults. *Palliative and Supportive Care*, *13*(3), 591-599. https://doi.org/10.1017/S1478951514000054

6.1.5 Discovery Five: The Spheres of Connection Model for Providing Scaffolded Support for Young People

In this study young people desired connection through what social work perspectives contextually revealed are cumulative loss and trauma experiences when travelling away for their cancer care. Young people from outer regional and remote areas, both young people and social work participants identified, also require support throughout their cancer experiences due to having to travel away. The spheres of connection model central to phase one findings (Chapter Four) represents scaffolded support desired by young people. Young people value connection with the things that are important to them – place, knowledge, people, support, peers and lifestyle. Social work participants also regularly spoke about the need for young people to feel connected (a relationship, bond, etc.) with the things important to them.

6.1.6 Discovery Six: Connection Between Young Person and Social Worker

Young people, within their narratives in this study, discussed what it was like being diagnosed, travelling away and going through cancer treatment. Those descriptions made it clear it was difficult and, at times, physically painful and shocking and mentally hard. Two things stand out in the data. Young people want social workers to connect with them at regular intervals, and both young people and social workers desire a connection in this dyadic, helping relationship.

This study's social work perspectives provided context for the young people they work with, observing the multiple, cumulative nature of young people's losses and traumas over time. The cumulative nature of losses and traumas perhaps provides context for why young people desired connection and said they needed support, wanting social workers to connect with them at regular intervals. If one considers the multiple and accumulating losses and traumas occurring for young people over time, it makes sense they desire the continuity of regular supportive contact to help deal with these. However, the data reveals even more – both young people and social workers desire a connection with each other as they work together throughout the young person's cancer experience.

This study's young participants and social work participants said a connection between them was important. Riley (social worker) explained, when reflecting on a young person sharing details of their life with Riley: “They really … wanted to share all of that, so that you had an understanding of who they were.” Even the language some social work participants used conveyed a sense of connection with the young people they worked with, such as using “my” when referring to young people they worked with, such as in this excerpt of a quote from Riley: “… one of my young people …” For social workers, their desire to connect with the young person was motivated by a belief that building rapport and having a good professional relationship with the young person was a key foundation for effective interventions to help the young person through their cancer experience. Social workers shared how they use their professional relationship to help young people, investing time in building rapport whilst acknowledging their “guest in the house” (Sage) status and allowing young people to “drive” (Caelan) how close that helping relationship is. Both sets of participants believe it is the social worker who needs to use their skills to build this relationship and connection between the young person and the social worker.

6.1.7 Discovery Seven: A Liminal, Life-Changing Experience

The seventh discovery I made from the data was due to both young people and social work participants all stating that the psychosocial goal for young people from outer regional and remote Queensland who travel away for cancer care is to return home permanently. Social work participants highlighted that returning home permanently remained the goal when young people were going home for the end of their lives when cancer became incurable. My deep, contemplative analysis led me to an essential interpretation that living with cancer is a liminal, life-changing experience for young people from outer regional and remote areas. ‘Life-changing’ is another ‘gem’ – an extract from the data that made a resonant contribution to the analysis (Smith & Nizza, 2022) – used by Layne (social worker) to describe the whole experience for young people living with cancer from outer regional and remote areas: “[T]hey have gone through something life-changing.”

A liminal experience is used in anthropology to describe transitional periods in a person’s life where they are ‘betwixt and between’ two states – no longer holding a former state/self but not yet developed into or having reached their new state/self at the end of a ritual or process (Turner, 1967). Young people living in outer regional and remote areas begin as the person they were before they got cancer, then go through their cancer diagnosis and treatment experience, including having to relocate for treatment, emerging when they return home permanently as different to who they were before the experience began. One of the young people in phase one, reflecting on the whole experience of going through cancer and having to travel away, offered a quote capturing the liminal, life-changing nature of what she went through: "[T]he whole experience changed me – quite a lot" (Andrea).

6.2 Liminal Experience: An Anthropological Term Encapsulating Young People and Social Work Perspectives

My attempts to reach and describe the essence, the "gestalt" (Smith & Nizza, 2022) of my overall interpretation through the data synthesis led me to an unlikely place – anthropology. Anthropologist Victor Turner used liminal experiences as a way of describing the rite of passage from child to adult (Turner, 1967). Rite of passage participants, in the middle or 'liminal' phase of the rite, no longer hold their pre-ritual status (child), but nor have they arrived at the status they will achieve (adult) once the rite is complete (Turner, 1967). The experience of a young person being diagnosed with cancer and having to travel away for specialist cancer care is not a rite of passage – it is a forced transitional, traumatic experience due to their cancer diagnosis, as identified by young and social work participants in this study. However, describing it as a liminal experience is useful because young people are not, and will not again be, their old selves – a new self emerges at the end, having been through their cancer experience, which necessitated them travelling away for their cancer care. This new self emerges once they have returned home permanently, with all the changes in their lives that have come through and because of that liminal experience.

In this study, the liminal experience of travelling away for cancer care was life-changing for young participants. Young study participants, whose treatment had finished at least six months prior to study participation, reflected on the entire experience, including having been home permanently for at least six months. Young people spoke of how the experience had changed them – they were no longer their former, pre-cancer diagnosis selves. The element of having to travel away for treatment is why interpreting it as a 'liminal experience' is especially fitting – all the young people interviewed and all the young people social work participants spoke about from outer regional and remote areas had to travel away for specialist cancer care. Travelling away for treatment was a defining point of difference between young people from outer regional and remote areas and metropolitan areas. The liminal experience involves not only all the aspects of cancer diagnosis, treatment and recovery all young people living with cancer go through, but it also involves a geographical move to have the treatment away from home, community and loved ones. The separation from home and community is a passage of time, usually extended due to the length of time involved in cancer treatment, where important developmental milestones and physiological changes occur for young people – but this happens away from home. Interpreting the experience as liminal befits the essential understanding gained from both young people's and social worker's perspectives.

The liminal cancer experience for young people from outer regional and remote Queensland is life-changing. Young people do not go back to who they were, to their old self or old life. In addition to Andrea's statement earlier about how the whole experience had changed her, other young study participants spoke of the life-changing nature of the experience. Brianna talked about not being so scared to take risks anymore due to her cancer experience, which made her realise "you only live once …" Raymond, on reflection, realised after going through cancer he was not invincible and, as a result, was more careful now: "[T]hey're always saying 'teenagers, especially boys, think they're invincible' and I think it made me realise 'oh, that's not true at all' … things can happen and you've got to be careful …" Representative ways social work participants spoke of young people's selves and lives changing through having to travel away for cancer treatment include: "[T]hey didn't feel like themselves anymore" (Riley) and how social workers remembered young people speaking about returning home, asking questions like "'how will we re-integrate back into our routine when feeling like life has sort of changed forever?'" (Layne).

My use of a term from anthropology is not something new to social work research. The social work profession has collaborated with other disciplines from its beginnings to address social problems (Gulbas et al., 2021). Drawing from other disciplines has supported social work's development as a profession and helped shape social work interventions (Mathias et al., 2021). A good example of social work and anthropology collaboration is around the phenomenon of culture (Mathias et al., 2021). A suggestion has been made for social work moving forward that dialogical engagement with other key anthropological concepts may be beneficial (Mathias et al., 2021). Conceptualising young people from outer regional and remote areas living with cancer who travel away for treatment as a liminal experience has assisted the interpretation of the findings of this study. My search to understand liminality then took me all the way back to Greek philosophy.

6.2.1 *Understanding Liminal Experiences and Their Endings with Greek Philosophy*

Liminality was explored in Greek philosophy. Liminal means to remove 'the limit' (Szakolczai, 2022). In "Philebus", Plato's general ontological process of defining the 'in between' (liminal) experience divides all that exists into four states: "the limited, the unlimited, their combination and the causes of their combination" (Szakolczai, 2022, p. 21). The liminal exists in the third state of 'their combination' (Szakolczai, 2022).

Plato (ca. late 350s B.C.E./1982) presents a dialogue where Socrates uses pleasure and pain, hunger, thirst, health and ill-health to help explain the liminal experience to his partners in the dialogue – Philebus and Protarchus. Socrates states, "It seems, then, that if anyone has a lack, he desires the opposite to his present state: I mean, whoever has a lack craves replenishment" (Plato, ca. late 350s B.C.E./1982, p. 92). I posit that the things young people 'lacked' or felt disconnected from throughout their cancer experiences were at least partially replenished by maintaining or building connections. Social work participants also recognised this in relation to the importance of young people staying connected with home and community. Having an established connection with home was important; young people and social work participants identified means available to maintain connections with home such as telehealth, telephone calls, social media and physical trips home or loved ones visiting the treatment site when possible.

Socrates leads his dialogue participants to determine when the liminal experience ends (Plato, ca. late 350s B.C.E./1982). Socrates asks about 'the in between' of a state of the lack someone feels now, and its future replenishment:

> But what about someone who has a lack for the first time? Is there any way in which he can comprehend replenishment, by sensation or by memory? Can he comprehend what he is not experiencing at the

> time and has never experienced in the past? (Plato, ca. late 350s B.C.E./1982, p. 92)

Protarchus agrees that no, he cannot. However, the dialogue moves to how people have memories of times when their current lack did not exist, which form their *desires* to replenish what they lack (Plato, ca. late 350s B.C.E./1982). Socrates' dialogue participants agree that replenishment of the lack concludes the liminal experience. For young people in this study, the lack of home is replenished once they return home. In the absence of being able to return home, young people desire a connection with home, even if only temporarily.

The endpoint of the liminal experience for any young person going through cancer and regardless of their location is, I propose, when their treatment finishes – ending with a cure or no cure. Only once treatment is complete is the result of a cure or no cure known. However, the liminal experience for young people living with cancer from outer regional and remote areas ends when they return home permanently. The difference for those from outer regional and remote areas is that, even if there is no cure for their cancer, they still have the end goal of returning home – this is where the liminality of their cancer experience concludes. In very rare cases, according to Caelan (social worker), returning home is unable to occur due to factors such as extreme remoteness and home community resources – usually medical and health services – being unable to support the young person's end-of-life care.

Philosophy, from its very beginnings, has always sought to think and understand things affecting the lives of human beings (Ragland et al., 2001). My research is a philosophical, academic endeavour, through interpretive phenomenology, to understand what it means to be a young person living with cancer from outer regional and remote Queensland. I have favoured a Heideggerian interpretive phenomenology due to Heidegger's temporality perspective of existence, where existence can be understood in relationship with time (Heidegger, 2010). I wanted to understand young people's experiences across a span of time (at diagnosis, during treatment and after treatment), given the limited research that had been done when I commenced my study. Interpretive phenomenology, using a multiperspectival IPA design (Smith et al., 2009), led me back to Greek philosophy. Socrates, courtesy of Plato's writing (Plato, ca. late 350s B.C.E./1982), brings me to understand liminality and that it ends when the pain of being in between states ends. In this study's findings, replenishment comes for young people from outer regional and remote areas through connection with things missing when they travel away for their cancer care. Returning home is paramount to young people, marking the endpoint of their liminal experience.

Returning to Greek philosophy in my data analysis also shed light on other findings. Reading the way Socrates explains how someone can know the end of their pain is possible alongside a memory of pleasure, but they are not there in that pleasure state yet, is relatable with young people's 'pining for home' as discussed in this study. While away, young people wish to be home but are not. However, their memories of home and maintaining or building connections with home, as well as all connections important to them, assist them through the liminal experience of being away.

6.2.2 Liminal Experience Within a Liminal Experience

Within my interpretation that travelling away for cancer treatment is a liminal, life-changing experience for young people from outer regional and remote areas, I realised that there were generally two liminal experiences for young people, sometimes more. The transition from child to adult occurs in this age group of 15–25-year-olds, a recognised, liminal experience or 'rite of passage' in anthropology (Turner, 1967). Travelling away for cancer treatment then becomes a liminal experience within a liminal experience. Alongside their liminal adolescent transition from child to adult (Turner, 1967), young people from outer regional and remote areas travel away for their cancer care from the midst of homes and communities they would normally undertake that transition of adolescence in.

Caelan and Riley's descriptions of this 'tricky' time of transition for young people is understood through the lens of this time being a liminal experience within a liminal experience. There is more than one liminal experience happening within the one prolonged event of diagnosis and having to travel away from home and community for treatment.

> … there's so much transition for this age group and we've literally thrown in another whole experience for them that they can't control, that they have to be a part of, whether they like it or not, and it impacts them because they can't maintain their routine; they can't

> keep their connections as well. They, you know, don't have the opportunity to go back and go to school each day if they were feeling alright on that particular day … It's normally in a period of their life where they're trying to graduate. They're looking forward to formals; they're looking forward to getting their licence. So, not being able to meet those normal teenage goals – things that we just expect happens naturally as they get older. (Caelan, social worker)

Part of the cumulative loss experience is not being able to participate in or reach these normal developmental and transitional milestones of adolescence into adulthood. At best, the milestones are delayed. At worst, young people die. In all instances, cumulative loss and trauma are felt by young people through their cancer experience.

In one young participant's case, a third liminal and traumatic experience occurred whilst they were going through their cancer treatment (de-identified to protect the young person's privacy). It was a traumatic experience for the young person still undergoing cancer treatment. The young person was removed from their parent's care by the Department of Child Safety. The young person was returned to their parent after a period of time. However, as with any liminal experience, their life prior to being removed and after they were returned to their parent was a time of change – of anticipating and waiting for the end of the experience when they would find replenishment through being reunited with their parent.

6.2.3 Returning Home Permanently – The End Point of the Liminal Experience

In this study, all young people and social work participants noted that going home was the ultimate goal for those who had to travel away for their specialist cancer care. Going home permanently, including having treatment close to home, therefore, becomes the end point of this liminal experience. Coming home for young people is something I interpret as being 'wonderful', another 'gem' (Smith & Nizza, 2022) from one of the study participants who described coming home: "Oh – was wonderful" (Gracie, young person). Five social work participants (Layne, Sage, Riley, Caelan and Ari) discussed their observations that young people feel anxious about going home due to concerns the care required would not be as specialised as that in the major regional or metropolitan centres or feel anxious about fitting back into their peer groups at home, especially school. Caelan's observations are representative of what social workers' shared, explaining young people feel uncertainty of "'Not knowing how I'll be received by people' … they might worry about them seeing them in a different way or maybe not including them as much." Mia's (young person) experience of young people at her school seeming to avoid her when she had to wear a mask to protect her through lowered immunity is a good example of why young people can be anxious about returning home. However, for young people participating in this study or whose experiences social work participants spoke about, this anxiety did not stop them from wanting to go home. In fact, it may indicate the great importance young people place on going home, that they are anxious about what it will be like when they do.

The liminality of young people's experiences, with going home as the end point, is poignantly captured by George (young person). George likened going through cancer as a young person to being a soldier, playing me a song called 'Soldiers'. Soldiers going to war is a liminal experience – they leave as a person they will never be again, confront the reality of war, the loss of home and community whilst away, and the trauma experienced whilst serving in battle. The soldiers who do not die return home. Their goal is to return home – that is the endpoint. Even those who die in battle are returned home to their loved ones wherever and however possible by their country's government. For young people living with cancer from outer regional and remote areas, their endpoint is also returning home. This is even in death, exemplified through the recollection of a social worker (Sage) on the experience of a young person. Returning home from the metropolitan city, and finally from the outer regional hospital, was the young person's goal, Sage shared. George finding resonance of his and other young peoples' cancer experiences with soldiers' experiences is a connection of two liminal experiences. In both experiences, for young people from outer regional and remote areas who travel away for their specialist cancer care and for soldiers who serve in battle away from home and community, the end goal is always to return home.

6.3 Beyond the Liminal Experience: A New Normal

Young people's new self and life emerge from this liminal experience once they are permanently home. In this study, young people's perspectives illuminated what it is like once they have returned home permanently into what I interpret as their 'new normal'. The term 'new normal' is often used in health social work, although unfound in a social work-related literature search. It typically describes a major life change for people brought on by a health event. The term is attributed to having arisen out of the 2008 world economic financial crisis (Corpuz, 2021). It became colloquially popular to describe the modern world post-COVID 19 pandemic – that we were living in a "new normal" because of COVID 19 (Carr, 2020; Corpuz, 2021). The difference between a liminal experience and a new normal is that, with a liminal experience, something new is coming, but the person (or society) needs to go through the liminal phase before reaching the 'new'.

Five of this study's social work participants did not share information about post-treatment social work care provision for young people living with cancer from outer regional and remote Queensland. However, the young people that were interviewed were all at a stage at least six months after their treatment had finished, and they were all being, or had been monitored by six-monthly or annual reviews in specialist outpatient clinics. I, therefore, interviewed young people during their 'new normal'. It is evident to me, on review of young participants' data, that loss and trauma continued into the post-liminal phase and new normal for some of the participants. All of the young participants described the resilience and new perspectives they had reached about themselves and life now they were past the liminal, life-changing experience of travelling away for cancer treatment. The following summarises young people's post-liminal reflections, which evidence experiences of both ongoing trauma effects and enduring resilience.

6.3.1 Ongoing Trauma Effects

Some of the study's young participants described either still dealing with the post-trauma effects of their cancer experience or that the trauma of their experience had changed them, and they were more cautious now. One young person's reluctance to discuss in detail their experience of being removed from their parent by the Department of Child Safety is one example of trauma effects persisting into the time of the interviews. It was significant enough to have been raised by the young person in the interview, but not wanting to discuss something traumatic is one of a normal range of responses for young people still trying to process traumatic incidents (Gillece, 2012). Trauma also influenced how much participants were willing to share about their cancer with the people in their lives. Sian’s parents advised that Sian does not like talking about the time she went through her cancer experience, hence their assistance to her with the interview. Sian’s parents said Sian was “anxious with things” during her teenage years as a result of her cancer experience, now feared needles and did not like speaking about having had cancer. Mia also spoke of not wanting to discuss her past cancer experience with people she didn’t know.

Andrea was seeing a counsellor due to the ongoing trauma effects of her cancer experience when I interviewed her. Andrea had experienced what she called a “late mental break” a year after she returned home from cancer treatment finishing. Andrea said she had, more recently and prior to her interview with me, received a new health condition diagnosis. Andrea explained that due to the trauma and post-trauma effects she went through during and after her cancer experience, those trauma feelings had resurfaced.

Brianna was another young participant who experienced post-traumatic effects, both physically and psychologically, after her cancer treatment finished:

> I actually ended up – the way chemo affects you, I ended up – I get short-term memory loss, and I ended up with post-traumatic stress a few years ago … I would wake up and start crying and feel like I was back there – back in [metropolitan city] and all, I was having an allergic reaction again sometimes. And I think that come along with the fear that because we don’t know how you get cancer, you don’t know whether you’re ever going to get it again or not.

Like Andrea, Brianna received counselling from a therapist who treated her for post-traumatic stress disorder (PTSD), which she found helpful.

I considered whether young participants were experiencing the ongoing effects of having been through trauma on re-analysis of their reflections on their entire cancer experience, for example, when George likened his cancer experience to being a soldier (see Section 6.2.3). Fighting at war or in active service is generally well-known as being a traumatic experience. As discussed in sections 4.2.6 and 6.2, both Raymond and Brett said they were more cautious now because of going through their cancer experiences. Raymond said: "[T]hey weren't sure what caused it [Raymond's cancer], so it's always good to be careful … eat the right stuff, don't do anything too dangerous …" (Raymond, young person).

6.3.2 Enduring Resilience

Enduring resilience encapsulates how all young participants in phase one reflected on their cancer experience. Young people and social workers described various hardships young people endured through the experience of travelling away from their home communities for cancer treatment. However, young people in this study demonstrated an understanding and resignation of requiring treatment to save their lives. This acknowledgment of needing to travel away for treatment is captured well by Mia and Andrea: "I guess it would have been better if … with the clinic then in [outer regional city], so that I didn't have to be flying to [metropolitan city]. But then again, [metropolitan city] – they're more specialised" (Mia, young person).

> …some things were missed, because you were from such a remote area. But in another way, when you got down to [major outer regional city & specialist cancer care service], nothing was missed … You feel like they're gonna look after you – you're a priority. And you get seen. You're gonna get that help you weren't getting … [stops speaking]. (Andrea, young person)

Two social workers (Riley and Sage) noted resiliency in the face of the losses and traumas they observed young people go through. For instance, Sage noted a young person whose cancer could not be cured remained "stoic – there was no chink in the armour" in the face of the disappointments, grief and loss the young person and their family must have been going through.

I interpreted elements of resilience as being evident in all young people's narratives. As outlined in Chapter Four, young people in this study found ways of coping with their cancer experiences, such as the use of humour, gaming, establishing new connections with other young people and patients with cancer and staying in touch with loved ones back home. At the time of their interviews with me, young people described being more compassionate and understanding, sometimes philosophically changed. Sian had moved on with her life and was now active in sports and study. Raymond used humour during and after his cancer experience to turn darkness into light. Layla had expanded her family and was looking forward to the future, including planning a holiday. Andrea was now working in health care, using the trauma of her cancer experience to inform her practice with clients with care, compassion and kindness. Gracie was now working for a helping service. Brett was happy being back home with plans for study. Sharon was now working and studying and also using humour to connect with other people in light of her cancer experience. Mia had also moved into a caring profession, inspired by the nursing care she received and now wanting to "give back" using what the experience had taught her by having "empathy and knowing what they're going through" (Mia). Brianna was working with animals and was very active in cancer fund-raising and public speaking to raise awareness about children and young people's cancer. George was glad to be home and contemplating future study as he recovered from ongoing physical impediments to both work and formal learning. He was enjoying spending time with friends, his favourite leisure activities, cooking and exercising a well-developed sense of humour, which was on display at various points during the interview, for instance, on being told he had cancer and knowing cancer is "sometimes portrayed as fatal," he said, "I might die. That's something new" (George).

The young participants showed resilience through how they incorporated their experiences into their post-liminal, new normal selves and lives. Andrea and Brianna needed to see a counsellor for the trauma symptoms they were experiencing. Research shows there are barriers for young people seeking mental health help, including stigma and embarrassment, problems recognising symptoms and a preference for self-reliance (Gulliver et al., 2010). Despite these barriers, Andrea and Brianna showed resilience in admitting needing and accepting help. It took considerable courage for all young participants to take part in this study – this involved spending, on average, a whole hour re-visiting a liminal, life-changing cancer experience marked by cumulative loss and trauma. Many of them said they did this because they wanted to help other young people, exemplified in Layla's comment at the end of her interview when I thanked her for her time: “No I’m happy to help. It’s nice to get my story out there a little bit – like, help people.” All ten young participants offered advice for young people and social workers on how the experience for young people living with cancer from outer regional and remote Queensland could be improved.

Reflecting on young study participants’ resiliency, George’s description of soldiers again comes to mind. It exemplifies strength through loss and trauma as he compares young people going through cancer with soldiers. The lyrics of the song George shared with me in his interview speak of great resilience. I insert here, in full, the dialogue between George and I as he talked me through the song whilst playing it to me:

> [George begins playing the song “Soldiers” on his mobile phone]
> George: [singing along to the song the whole time] – “…here comes a powerful bit …”
> [singing with the song]
> “We stand shoulder to shoulder
> We stand shoulder to shoulder
> We stand shoulder to shoulder
> You can’t erase us
> You’ll just have to face us …”
> [continues singing with the song, then says]
> “I just love this bit … hear the marching?”
> [marching drumbeats accompany this part of the song as the lyrics are sung]
> [George continues singing as this whole verse is repeated in the song]
> [George paused the song and explained the following]
> “Nothing can stop us fighting the chemo
> Even when we’re sleeping, we’re fighting it.”
> [as the song repeats another chorus, George says he likes these lyrics as well]

“We will not sleep

We are not sheep

We are soldiers

We are soldiers”.

6.4 Conclusion

In this chapter, I have presented a synthesis of the data analysis of both young people and social work perspectives. Seven discoveries were made in the process: specific issues for young Aboriginal and Torres Strait Islander people, end-of-life experiences for young people, the traumatic nature of fertility preservation for young people, scaffolded support required through the cumulative loss and trauma young people experience, spheres of connection model as useful for providing scaffolded support to young people, connection desired between young people and social workers in the helping process, and the liminal, life-changing experience for young people living with cancer from outer regional and remote Queensland. Young people’s goal when away for cancer treatment is to return home, which marks the end of the liminal experience. However, their new normal on returning home encompasses both ongoing trauma effects and enduring resilience.

I conclude that young people living with cancer from outer regional and remote areas go through a liminal, life-changing experience when they travel away for their specialist cancer care to major regional or metropolitan cities. Young people’s liminal experiences are marked by cumulative loss and trauma. What helps young people through their liminal experience is scaffolded support. This study has revealed a potential way, through the spheres of connection model, to provide scaffolded support to young people living with cancer from outer regional and remote areas. In the next chapter, I explore the literature on the major themes that have emerged from this analysis – cumulative loss, cumulative trauma, connection and the liminal experience.

Chapter Seven: Discussion

In this chapter, I discuss the four major themes that emerged from my analysis of young people and social work perspectives on the experiences of young people living with cancer in outer regional and remote Queensland. I examine how these four themes of cumulative loss, cumulative trauma, connections important to young people and the liminal experience build upon and add to existing literature in the field. I also explore literature related to discoveries made within these themes in the data synthesis on end-of-life care for young people living with cancer, experiences of young Aboriginal and Torres Strait Islander people and scaffolded support. I found that the study findings are consistent with the literature in some areas, extend the knowledge base with a nonmetropolitan perspective, and offer new knowledge for practice with young people living in outer regional and remote areas. Study limitations are then discussed.

7.1 Cumulative Loss

Cumulative loss is one of the contextual offerings to emerge from social work perspectives, with the study finding multiple, cumulative losses accompany young people's experiences of living with cancer from outer regional and remote Queensland. This section connects these findings from the social work perspectives with literature on grief and loss, including relevant grief, loss, continuing bonds and meaning reconstruction theories.

7.1.1 Non-Death-Related Grief and Loss Largely Unrecognised in the Literature for Young People Living with Cancer

Grief and loss experiences for young people going through cancer appear largely unrecognised in the literature outside of the death of loved ones, including peers, or facing one's own end-of-life experience. For instance, in an article on understanding and supporting adolescents and young adults who are grieving, only bereavements of loved ones are acknowledged as grief or loss experiences (Palmer et al., 2016). Articles on grief and loss for young people going through cancer focused on the death of loved ones, peers or young people with incurable cancer (see Drake & Urquhart, 2020; Knox et al., 2017; Mackland & Wright, 2022; Sansom-Daly et al., 2023). However, in this study, I identified multiple cumulative losses that young people living with cancer from outer regional and remote Queensland experience, which were not death-related. The absence of non-death-related grief appears to be an important omission from literature to date, which would benefit from further research.

Grief is evident in a book written and published by a young person about her cancer experience. The author, Mette de Fine Licht, was diagnosed with cancer at age 16. de Fine Licht lost her hair during her cancer treatment and wore a wig (de Fine Licht, 2017). In this excerpt from her book, de Fine Licht describes losing her hair as a major loss through her cancer experience. No one knew she wore a wig, and at a party on the dance floor, her wig came ‘flying off’ (de Fine Licht, 2017). In this extract, de Fine Licht describes the horrendous torment of the experience:

> The first place I find to hide is the coat room, where I collapse behind a shelter of jackets. Under a rack and behind a pile of coats, I lie in tears hyperventilating. My arm goes to my mouth to keep my sobs from sounding throughout the building.
>
> From the other side of the barricade, I hear voices.
>
> ‘Who’s there?’
>
> ‘Mette, are you here?’
>
> ‘Is she okay?’
>
> ‘What happened?’
>
> ‘Does anyone know what is going on?’
>
> ‘Get Julie! She needs to help!’
>
> I am completely indifferent to anything I hear. The feeling inside is of utter devastation. The worst and most embarrassing thing that could ever happen has happened. They have seen me. Or, rather, they have seen the cancer victim. The incident makes me sicker to my stomach than the ifosfamide. (de Fine Licht, 2017, p. 102)

De Fine Licht’s (2017) experience of losing her hair exemplifies the losses young people experience going through cancer.

Some of this study's young participants from Far North Queensland described experiences of witnessing their peers die. Mackland and Wright (2022) explored the bereavement support needs of young people living with cancer witnessing the death of their peers. Whilst not specific to young people from nonmetropolitan areas, Mackland and Wright's (2022) research identified that young people experience multiple deaths of peers, have long-term emotional responses, recognise their own mortality and fear new friendships as a consequence. Young people in their study wanted formalised, age-appropriate, specialist bereavement care when they experience the death of a peer by staff specialising in grief and require a dedicated space to grieve (Mackland & Wright, 2022). Mackland & Wright's (2022) findings resulted in an annual "Remembering Friends" bereavement event for young people whose peers had died. This study's findings extend the knowledge base into outer regional and remote Queensland, where peers dying from their cancer was shown to be both traumatic and resulted in grief experienced by young people living with cancer. Offering age-appropriate, specialist bereavement support to young people living with cancer from outer regional and remote Queensland when their peers die is supported by the existing literature.

In this study, half the young participants were fearful of dying themselves. Young people and their families find it traumatic when a young person's cancer cannot be cured, as social work participants in this study said. Whilst I found no studies specific to young people from nonmetropolitan areas in the literature, there were studies addressing end-of-life experiences and the needs of young people with cancer (e.g., Barling & Davis, 2016; Barton et al., 2022; Burgers et al., 2022a; Burgers et al., 2022b; Knox et al., 2017; Sansom-Daly et al., 2020; Sansom-Daly et al., 2023). Burgers et al.'s (2022a) findings appear to describe themes of grief, loss and trauma in their study of young people with an uncertain and/or poor cancer prognosis. Young people in their study experienced feelings of inferiority, isolation, ongoing confrontation of their life's impending end, grief, and loss of control over the future (Burgers et al., 2022a). Knox et al.'s (2017) study found similar themes in their study with young adults, where participants also were confronted by their life's impending end (but this often went unarticulated), forceful removal from the 'stream of life', and interrupted developmental tasks of establishing adult identity, becoming autonomous and forming new relationships (Knox et al., 2017). An Australian study found young people with life-threatening cancer wanted to discuss end-of-life choices, with an advance care planning document '*Voicing My CHOiCES™'* available, but conversations around cancer potentially becoming incurable do not happen often in practice (Sansom-Daly et al., 2023). Acknowledging young people's fears of dying from their cancer and assisting them through open discussions, introducing advance care planning and providing or referring for skilled counselling to address fears around dying would help young people.

Social work participants in this study said all young people living with cancer from outer regional and remote Queensland want to return home at end-of-life when their cancer is incurable. Whilst not specific to young people from nonmetropolitan areas, a study by Odejide et al. (2022) supports this finding. Odejide et al. (2022) explored patient, family and clinician perspectives on the location of death for young people living with incurable cancer. The authors cite high rates of hospital death for young people with cancer, with the reasons unclear (Odejide et al., 2022). The study found most young people and their caregivers preferred to die at home (Odejide et al., 2022). However, some young people and their caregivers in the study chose a hospital death due to caregiver burden or protecting siblings from perceived trauma of witnessing the young person's death at home (Odejide et al., 2022). The other main reason for a hospital death was the lack of required services to manage symptoms at home, including insufficient caregiver support (Odejide et al., 2022). This study's findings are consistent with Odejide et al.'s, extending to include outer regional and remote areas. In this study, social workers provided numerous examples of young people from outer regional and remote areas wanting to return home, or be on Country for young Aboriginal and Torres Strait Islander people, to die. Consistent with Odejide et al.'s (2022) findings, a medical crisis necessitated re-hospitalisation in this study for a young person who had returned to their outer regional home to die (as detailed by Sage, social worker). Study findings that young people wish to return home, and to Country in the case of young Aboriginal and Torres Strait Islanders, when their cancer is incurable, informs social work. Advocating for and/or assisting in coordinating young people's return home for end-of-life is a priority. Plans also need to be made with the young person and their family for the scenario of re-hospitalisation should acute medical support be required and they are unable to die at home.

7.1.2 Grief and Loss Theory to Inform this Study

Cumulative loss for young people from outer regional and remote Queensland was a major finding from social work perspectives in this study. Given these findings, this section explores the grief and loss theoretical frameworks that can inform social work practice. The social work literature on grief and loss and end-of-life practice reveals gaps in social work theoretical and practice literature. In a 2005 article in *Australian Social Work*, Goldsworthy (2005) explores grief and loss theory in social work practice. Goldsworthy conducted an extensive literature review which "produced a mere handful of social work articles on grief and loss", noting " this unanticipated dearth of social work literature was somewhat surprising considering that working with loss and grief has long been identified as one of the core skills of social work practice" (Goldsworthy, 2005, p. 170). In another social work literature review, Kramer et al. (2003) conducted an analysis of end-of-life (EOL) content in social work textbooks and found that ten essential elements of skilled social work practice in end-of-life care only comprise 3% of the total text, concluding that the results "demonstrate a significant opportunity for improvement of EOL content in social work textbooks" (Kramer et al., 2003, p. 299). Social work participants stated that grief and loss theory was a gap in their social work knowledge in my previous research (Sariman, 2017). Ongoing research and scholarly debate on integrating grief and loss theory into social work theoretical and practice literature seems warranted to assist social workers in recognising grief and providing targeted support and/or referrals for grief support for young people living with cancer.

Despite gaps in social work theoretical and practice literature, there are well-established grief and loss theories elsewhere in the literature that can assist the critical analysis of this study's findings. These grief and loss theories are drawn from Worden's (2009) four tasks of mourning, Klass et al.'s (1996) 'continuing bonds' and Neimeyer's (2006) 'meaning reconstruction' following loss. I will first explore Worden's four tasks of mourning.

7.1.2.1 Worden's Four Tasks of Mourning. Worden (2009) posits that to understand a loss experience, one must first understand attachment and the theories underlying attachment. The psychiatrist John Bowlby's (1973, 1980, 1982) attachment theory largely explains human attachment, commencing with infant and children's attachments to their primary caregivers, as coming from the need for security and safety developed early in life. Attachments form with people; however, they can also form with other phenomena, as I will explain under disenfranchised grief (Doka, 2002). When a person or attachment is lost, humans grieve (Bowlby, 1973, 1980, 1982; Doka, 2002, 2016; Worden, 2009; Worden, 2015). Attachment theory will also be dealt with in more detail in section 7.3 on ‘connections important to young people’. It is due to this attachment to the person or thing that is a loss for someone that Worden (2009) developed his four tasks of mourning. The four tasks of mourning are steps people can undertake to assist them through the pain of a grief experience (Worden, 2009). The four tasks are: accept the reality of the loss, process the pain of grief, adjust to a world without the deceased [loss] and find an enduring connection with the deceased [loss experienced] in the midst of embarking on a new life (Worden, 2009 [my alternate words]).

Worden’s (2009) four tasks are informative when considered alongside one of the main interpretations from the findings of young people’s perspectives – the spheres of connection model. Young people in this study desired connection with and within six spheres of place, knowledge, people, support, peers and lifestyle. These six spheres mostly represent areas of loss for young people, as highlighted through social work data analysis in cumulative losses of home and community, physical and mental health, autonomy, relationship losses and loss of lifestyle. If the fourth task of grieving is to find enduring connections with losses experienced (Worden, 2009), then young people’s desires for connection with and within the six spheres demonstrate a processing of loss through connection. Disconnection from the things they have lost or that are missing is a grief experience – finding ways to connect with those things would help young people. Connecting with things important to young people living with cancer from outer regional and remote Queensland leads into the next area of grief theory I will explore – continuing bonds and meaning reconstruction.

7.1.2.2 Continuing Bonds and Meaning Reconstruction. Continuing bonds are attachments to the deceased or loss experience that are maintained rather than relinquished in the resolution of grief (Klass et al., 1996). The idea grew out of research into bereavement in children’s grief and how continuing the bond with a primary caregiver after they have died helped children resolve their grief (Klass et al., 1996). A paucity of research evidence on whether continuing bonds are effective or maladaptive has led to disagreements in the grief and loss field on its usefulness for those grieving

(Root & Exline, 2014; Worden, 2009). However, continuing bonds were posited as natural, adaptive experiences following loss (Klass et al., 1996).

A large study of 506 undergraduate psychology students led by Robert Neimeyer, famous for his theory and work in meaning reconstruction as a helpful process in bereavement, found continuing bonds with the deceased following the death of a loved one predicted greater levels of trauma and separation distress (Neimeyer et al., 2006). However, this higher level of trauma and distress only occurred when the person grieving was unable to reconcile their loss in personal, practical, existential or spiritual terms (Neimeyer et al., 2006). This means that reconstruction in grief is a pathway to incorporating loss positively for people (Neimeyer et al., 2006). Positive integration of loss can also lead to post-traumatic growth (Calhoun & Tedeschi, 2014). Young people in this study desired connection with and within six spheres of connection. Young people’s experiences from outer regional and remote Queensland are marked by cumulative loss and trauma, yet staying connected with, or building new connections with and within the spheres of connection can assist young people continue bonds with what they have lost or what is missing for them within those spheres of place, knowledge, people, support, peers and lifestyle.

7.1.2.3 Disenfranchised Grief. Kenneth Doka is a noted grief theorist and writer who introduced into grief discourse the phenomenon of disenfranchised grief (Doka, 2002). Disenfranchised grief is defined as someone grieving an experience of loss, but the grief experienced is disenfranchised, whereby the person grieving is not allowed the “right to grieve” by society (Doka, 2002, p. 5). Doka goes on to explain that this means the person’s grief experience is “not openly acknowledged, socially validated or publicly observed” (p. 5). Doka further explains that grief experiences are not only connected with loved ones or pets dying, but also can be due to other loss experiences like the loss of a dream, property and possessions, divorce, relocation, job, incarceration and other non-death-related losses (Doka, 2002). Young participants and social workers in this study spoke of multiple losses brought on by a cancer diagnosis and relocation to cities with specialist cancer care facilities involving separation from home and community, family and friends, loss of developmental milestones, physical abilities and attributes in themselves that cancer treatment changed and many lifestyle losses. The absence of non-death-related grief and loss as a major associated experience for young people living with cancer in the literature, whether from metropolitan or nonmetropolitan areas, leads me to describe young people's loss experiences as forms of disenfranchised grief.

The disenfranchised grief of cumulative loss experiences young people have when travelling away for their cancer care could help explain some of the realities shared by young people in this study. As a young person said to Ari (social worker), "The world moved on and nobody even knew I was there." Friends not understanding what they were going through was expressed by some young study participants: "Showed who the real friends were" (George, young person); "…nobody sort of really came around as much" (Layla, young person). Perhaps this is at least partially explained by disenfranchisement – the lack of recognition and understanding – of the grief brought on by cumulative losses young people experience throughout a cancer experience, including travelling away for their cancer care. Acknowledgement from family, friends, social workers and other health staff of the multiple, cumulative losses young people living with cancer from outer regional and remote areas experience will legitimise young people's 'right to grieve' (Doka, 2002) throughout their cancer care trajectory.

This study's finding of cumulative loss for young people living with cancer in outer regional and remote Queensland suggests recognition is required of non-death-related grief. Open discussions with young people living with cancer, providing or referring young people for skilled grief support and educating staff and young people's loved ones on the cumulative losses involved for those from outer regional and remote areas are ways social workers can bring awareness of cumulative loss and legitimise young people's grief in practice. Providing or referring young people for skilled grief support over the cumulative losses they experience could assist them in coping with those losses. Information for young people and their family and friends on cumulative losses young people experience, including ways family and friends can help, could assist connections that might otherwise become fractured due to lack of understanding.

7.2 Cumulative Trauma

The second contextual finding to emerge from social work perspectives was that cumulative trauma is part of young people's cancer experiences from outer regional and remote Queensland. This section connects these findings from the social work perspectives with literature on trauma, trauma theory and trauma-informed practice.

7.2.1 Trauma Recognised in Literature on Young People Living with Cancer

Social work data analysis resulted in my interpretation that young people living with cancer from outer regional and remote Queensland endure multiple cumulative traumas throughout the course of their cancer experience. Trauma is a more recognised experience in the literature, often associated with getting cancer at a young age. Severe illness or injury is a recognised experience associated with post-traumatic stress disorder (PTSD), anxiety and depression (SAMHSA, 2023). Numerous adolescent and young adult researchers have been exploring trauma and distress for young people living with cancer for over a decade now (see Fisher et al., 2018; Kwak et al., 2013; McCarthy et al., 2016; Osmani et al., 2023; Sansom-Daly & Wakefield, 2013). Osmani et al. (2023) conducted a systematic literature review of the worldwide prevalence of psychological distress, anxiety and depression in young people living with cancer. They found higher risks exist for psychological distress, anxiety and depression in young people compared with their cancer-free peers or older people living with cancer (Osmani et al., 2023). They also found one in three young people living with cancer experienced psychological distress or anxiety, and one in four depression (Osmani et al., 2023). This study's findings are consistent with the literature, with three of the ten young study participants describing post-traumatic stress symptoms and two of those three requiring counselling for those symptoms. One young participant needed psychological counselling during their cancer treatment, lamenting not being connected with the psychologist sooner. Findings suggest young people from outer regional and remote Queensland should be regularly offered supportive or specialist mental health counselling to help them cope with the multiple cumulative traumas they experience.

Tools exist in adolescent and young adult cancer care for measuring distress (Patterson et al., 2021a; Sansom-Daly & Wakefield, 2013; Wakefield et al., 2013). It is, therefore, an expectation in adolescent and young adult cancer care that there will be some level of distress or trauma through young people's cancer experience. For this reason, the findings in this study regarding the presence of trauma in young people are consistent with the literature. These findings extend the literature into the outer regional and remote context. However, I found nothing describing the cumulative nature of trauma throughout young people's cancer experiences. Knowledge that traumas accumulate throughout the course of the cancer experience can inform social workers that assessment and re-assessment are regularly required to ensure young people can be connected with the support they require, as the need arises.

7.2.2 Trauma Theory

Bloom (2018) provides a comprehensive theoretical framework for trauma. Bloom (2020) also outlines helpful signs of how trauma may present in young social work clients. Bloom's trauma theory states that the earlier in life trauma starts and the longer it lasts, the more challenging and prolonged its effects will be (Bloom, 2018). Trauma effects can be physical (fight-flight, chronic hyperarousal, fear-conditioning, freeze and dissociation, tend and befriend) or psychological through information processing, affecting attention and focus, decision-making and judgement, learning abilities and memory (Bloom, 2018). Trauma produces emotional responses to danger, such as numbing, avoidance, contagion and social rejection (Bloom, 2018). Behavioural responses can include traumatic re-enactment and the compulsion to repeat trauma, self-harming behaviour and addiction, risky behaviours, addiction to trauma, revictimisation and trauma-bonding, including the possibility of becoming a victimiser of others (Bloom, 2018). Given the cumulative nature of trauma for young people going through cancer from outer regional and remote areas, highlighted by this study's findings, these trauma effects are concerning.

Bloom (2020) has drawn attention to indicators for young people experiencing trauma, which include difficulties in forming trusting relationships, being easily upset, provoked or reactive and displaying inappropriate emotions and behaviour. Young people may be 'triggered' by environmental cues, emotionally responding in unhelpful ways or having flashbacks (Bloom, 2020). If traumatised, young people's behaviour can be hyperactive, defiant, inattentive or hyperattentive to 'danger signals' that others are not aware of (Bloom, 2020). A final indicator can be dissociation, which can manifest behaviourally as lying or zoning out, both to mask incidents that are too difficult to recall or unimaginably horrific and, in defence, young people will become detached (Bloom, 2020). Trauma theory can inform social workers of behaviours that may indicate a young person is traumatised, even if a young person or others are not recognising the effects of trauma. Trauma-informed practice offers ways to approach working with young people who are traumatised, which is explored next.

7.2.3 Trauma-Informed Practice

This study found young people living with cancer from outer regional and remote Queensland go through multiple accumulating layers of trauma over time. From the pioneering work of Harvard psychiatrist Judith Herman (2015) to the present time, maintaining or creating a safe space for those who are traumatised is key in trauma-informed practice. Healing trauma involves creating a safe environment within which people can heal (Herman, 2015). The safe space may be created or found by the traumatised person themselves or through professional help (Etherington, 2005). Trauma-informed practice indicates that creating or feeling some level of safety is required when young people go through traumatic experiences. This study's findings, combined with the literature on trauma-informed practice, indicate young people living with cancer from outer regional and remote Queensland require safe spaces to deal with the trauma they experience throughout their cancer care trajectory.

7.2.4 Trauma and Working with Young Aboriginal and Torres Strait Islander Young People Living with Cancer from Outer Regional and Remote Queensland

Informed by this study's social work perspectives, connection to Country and disconnection from Country to relocate and attend specialist cancer care treatment is a significant cultural consideration for young Aboriginal and Torres Strait Islander people from outer regional and remote Queensland. The literature is rich with knowledge that can inform and deepen understanding of the importance of connection with Country and culture for Aboriginal and Torres Strait Islander people of all ages (Dudgeon et al., 2014; Hunter et al., 2021; Sanjida et al., 2022). Hunter et al. (2021) detail that the Australian Aboriginal and Torres Strait Islander population "have endured immense hardship since the colonization of Australia characterized by the loss of lands, language, leadership, and family that contributes to the health and social inequities experienced today" (Hunter et al., 2021, p. 726). The authors note culture is central to health and wellbeing (Hunter et al., 2021). Social and emotional wellbeing for Aboriginal and Torres Strait Islander people is "grounded within a collectivist perspective that views the self as inseparable from, and embedded within, family and community" (Dudgeon et al., 2014). A literature review by Sanjida et al. (2022) found negative experiences for Indigenous Australians accessing tertiary cancer care services, including feeling alienated, isolated and culturally unsafe. Findings in this study that disconnection from culture and Country for young Aboriginal and Torres Strait Islander people involves cumulative loss and trauma when travelling away for specialist cancer care adds to existing knowledge, broadening the perspective into outer regional and remote geographical contexts.

Australian research finding negative psychosocial implications for Aboriginal and Torres Strait Islander people disconnected from culture and Country can be found in the literature (Kennedy et al., 2022; Smallwood et al., 2023; Wallace et al., 2021). Disconnection from family, community and culture resulted in negative impacts on social and emotional wellbeing for Aboriginal and Torres Strait Islander people during COVID-19 in a 2022 study (Kennedy et al., 2022). Kennedy et al.'s study explored COVID-19 related negative impacts on 110 Aboriginal and Torres Strait Islander people aged 16 and over in three Australian states of Victoria, South Australia and the Northern Territory. The authors found that disconnection from family, community and culture was a serious repercussion of visitor restrictions during COVID-19 (Kennedy et al., 2022). Whilst not cancer-related, Kennedy et al.'s (2022) research highlights the negative impacts on social and emotional wellbeing for Aboriginal and Torres Strait Islander people when disconnected from culture and Country. Other research highlighting negative repercussions through disconnection with culture and Country can be found in Wallace et al. (2021) and Smallwood et al. (2023). Wallace et al. (2021) found young Aboriginal and Torres Strait Islander people in formal state care experienced loss of connection to culture and desired reunification with their families, community and Country when leaving formal care arrangements (Wallace et al., 2021). An Australian study with rural Aboriginal young people found connections, culture and community were crucial to young people's resilience and wellbeing (Smallwood et al., 2023). Smallwood et al. (2023) found distress results from the loss of these relationships and connections, concluding connections to culture, health and wellbeing are vital components of young Australian Aboriginal people's health care experiences.

My study findings from social work perspectives are consistent with the literature, confirming the central importance of connection to Country and culture for young Aboriginal and Torres Strait Islander people from outer regional and remote Queensland. Study findings indicate that it is traumatic to lose connection with Country and culture through having to travel away for cancer treatment. Acknowledging the trauma through loss of connection with Country and culture, and offering culturally appropriate support and referrals to young Aboriginal and Torres Strait Islander people from outer regional and remote Queensland is advised, based on study findings. However, without the voices of young Aboriginal and Torres Strait Islander people in this study, further research is needed to hear their voices and improve social work understanding.

7.2.5 Trauma Effects After Treatment Finishes and Post-Traumatic Growth

In this outer regional and remote Queensland study, some young participants described experiences of feeling traumatised after their treatment had finished (Andrea, Brianna and Sian). Hobbie et al. (2000) found 20.5% of survivors of childhood cancer experienced lifetime post-traumatic stress disorder (Hobbie et al., 2000). Kwak et al. (2013) found 39% and 44% of 14–39-year-olds experienced post-traumatic stress at six and 12 months post-diagnosis, respectively (Kwak et al., 2013). Survivorship models of care are thus important and acknowledged in the literature (Janssen et al., 2021; Kinahan et al., 2015). Where social workers are unable to provide survivorship care, referral pathways to services and resources are paramount (Baird et al., 2019). This study's findings are consistent with the literature, adding knowledge that post-trauma effects occurred for young study participants from outer regional and remote Queensland. Screening at regular intervals for post-trauma effects in young people after treatment finishes is warranted, with age-appropriate trauma-informed support and referrals offered for those experiencing trauma and post-trauma symptoms.

Zebrack et al. (2015) also found post-traumatic growth occurs in young people following cancer treatment. The authors studied post-traumatic stress and growth 12 months following diagnosis (Zebrack, 2015). They concluded that re-experiencing trauma, whilst a symptom of post-traumatic stress disorder, may also represent cognitive processes required to achieve personal growth (Zebrack, 2015). Bloom (2018, 2020) also recognises that traumatic growth can occur. Bloom notes that traumatic experiences change people, who, in post-traumatic growth, can go on and become leaders to help and inspire others who share their experiences (Bloom, 2018). Positive incorporation of loss experiences can also lead to post-traumatic growth (Calhoun & Tedeschi, 2014). Findings in this study showed young people were resilient and grew through their cancer and post-trauma experiences. Andrea (young person) was now using her experiences to empathise with and help the people she met in the service she worked in. Brianna (young person) went on to help others including public speaking about her experience and fund-raising to help other young people going through cancer. Sian (young person) described herself as fun and outgoing now, was involved in further study and enjoying time with her loved ones and engaging in a favourite hobby. This study's findings are therefore consistent with the literature but extend knowledge that post-traumatic growth occurs for young participants living with cancer in outer regional and remote Queensland also. Interventions to encourage post-traumatic growth and resilience would assist young people in outer regional and remote Queensland by finding meaningful ways to enjoy their 'new normal' selves and lives.

7.3 Connections Important to Young People

Young study participants in this study desired connection with place, knowledge, people, support, peers and lifestyle. They also experienced many hardships when having to travel away for their cancer care. In connection with place, young people's strongest valued connection was home. Treatment close to home was preferred by all young participants in this study. Whilst one United Kingdom (UK) study found young people were willing to travel for specialist cancer treatment if age-appropriate care was unavailable close to home (Marris et al., 2011), another, more recent, UK study found those from nonmetropolitan locations were less satisfied with treatments and said distance was a barrier to receiving supportive care compared with those from metropolitan locations (Murphy et al., 2021). My findings are largely consistent with the literature and the 'tyranny of distance' theme emerging from my literature review, where travelling away for specialist cancer care treatment was found to be hard for those from nonmetropolitan areas (Holland, Walker, et al., 2021; McGrath, 1999, 2015a, 2015c, 2015d, 2016a, 2017; Paul et al., 2013; Sariman, 2017; Sariman et al., 2020). This study's findings support Maidment and Bay's (2012) argument that social workers require a 'place-based' model of care when practising in regional, rural and remote areas. 'Place-based' social work practice acknowledges the centrality of geography in people's lives from regional, rural and remote areas (Maidment & Bay, 2012). I posit this study's findings suggests the place-based model of care is relevant for social workers working in both metropolitan and nonmetropolitan settings with young people living with cancer from outer regional and remote areas. This study's findings offer an understanding of how travelling away from outer regional and remote 'place' for specialist cancer treatment disrupts young people's lives. Travel away involves many hardships for young people due to being away from home, community, loved ones and lifestyles, often for extended periods. This study found young people's connections, especially with place – home and community – sustained them whilst away from their outer regional and remote homes.

Travelling long distances from outer regional and remote Queensland for cancer treatment disrupted young people's desired connections at a developmentally important time in their lives. The importance of connections for young people living with cancer within some of the spheres of connection can be found in the literature. Physical, mental and emotional health and meaningful, age-appropriate pastimes with others were important to young people living with cancer in one study (Schreiner et al., 2020). Another study, which summarised literature on young people living with cancer, found issues of paramount importance for young people were life-stage development, including peer and family relationships, engaging in education and employment, developing autonomy and the cancer treatment environment itself (Thompson et al., 2013). Fox et al. (2023) found in their systematic review of 44 articles on young adults living with cancer that social connectedness improved psychological well-being, although not in all cases. This study's findings add to the existing literature that shows young people benefit from connections important to them. However, a significant extension of knowledge has been made for young people living with cancer from outer regional and remote Queensland, who desire connection with and within six identified spheres. Using this knowledge with young people to assist them in making meaningful connections would help those from outer regional and remote Queensland. This finding may also inform the current gap in knowledge, informing practice frameworks regarding psychosocial care for young people living with cancer from nonmetropolitan areas.

Connection between young people living with cancer from outer regional and remote Queensland and their social worker also emerged as an important relationship in this study. This connection is something young participants believed is contingent on being established and developed by social workers. The connectedness young people feel with health care professionals was explored in a study by Phillips et al. (2017). Phillips et al. (2017) concluded that young people feel disconnected prior to treatment with health care professionals. Young people will, once the initial confusion and emotional turmoil of diagnosis passes, make attempts to connect with health care professionals (Phillips et al., 2017). The authors found young people judge whether health care professionals can be trusted based on behaviours that encourage connectedness, which include reciprocating young people's efforts to connect through humour, identifying common bonds or interests and persisting in spite of young people's non-verbal deflections (Phillips et al., 2017). This study's findings extend Phillis et al.'s (2017) research into the outer regional and remote context, with young participants advising that persistence is a favourable trait and social workers should not give up if young people refuse help initially.

My review of social work literature reveals that it is rich with information guiding social workers on the importance and use of the helping relationship in practice. Social work theoretical and practice texts (see Connolly et al., 2019; Connolly et al., 2018; Howe, 2016; Okun & Kantrowitz, 2008; Payne, 2020) address the importance of the helping relationship being the tool social workers use to help clients reach their intervention goals. Social work studies have shown building a mutual relationship with clients based on reciprocity and trust (Alexander & Charles, 2009) creates therapeutic, close, positive bonds (Knei-Paz, 2009), which is more likely to foster positive outcomes for clients. Social workers foregrounding the helping relationship from first contact with young people living with cancer from regional, rural and remote areas was a finding in my previous study (Sariman, 2017) with social work participants from regional North Queensland. Knei-Paz (2009) found that heavy workloads, bureaucratic processes and budget limitations often precluded the time required to cultivate quality bonds with clients. This study's findings extend the existing literature into the outer regional and remote context, with social work participants placing great importance on the benefits of time spent on rapport-building and establishing the helping relationship with young people; however, some participants also noted time constraints posed by busy workloads. Study findings suggest psychosocial benefit is gained by establishing the helping relationship as a priority, with time required to do this built into social work departmental workload management processes.

7.4 Grief, Trauma and Attachment Theory and Connection

Attachment theory offers ideas on why connections are important to young people from outer regional and remote Queensland. Bowlby's attachment theory (Bowlby, 1973, 1980, 1982) asserts that the attachments children and young people make with caregivers and people are a vital part of their growth and development. Attachments assist children and young people feel connection with, and safety in, their personal and social worlds (Holmes, 2014; O'Shaughnessy, 2023). Attachment theory underpins the therapeutic, evidence-based "circle of security" programs taught to parents and helping professionals in forming safe care-giving attachments with infants, children and young people (Powell et al., 2013). Attachment theory has also assisted in understanding attachment to physical places, like home, that are formed due to needs places meet within us (Counted, 2016). Place attachments commonly meet the needs of survival and security, goal support, a sense of belonging and self-continuity, enhancing identity and self-esteem (Counted, 2016, p. 10). In this study, young people's strongest desired connection with place was home. Attachment theory also advises that when attachments are disrupted or cease, grief and loss typically follow (Bowlby, 1980; O'Shaughnessy, 2023). Being disconnected from place (home and community), people and lifestyles when travelling away for treatment were significant losses for young people in this study. Acknowledging young people's losses when travelling away for specialist cancer care treatment would assist conversations and social work interventions to support young people's grief.

My study findings and analysis indicate being disconnected from things that are important to young people living with cancer from outer regional and remote Queensland is a grief experience. Grief, trauma and attachment theory are helpful in understanding why grief is the result of feeling disconnected from people, places and things important to young people. Worden's last of the four tasks of grieving states the grieving person needs to find an enduring connection with the loss experience (Worden, 2009). Young participants in this study valued connection with the things that are important to them. Those things – with and within the six spheres of connection – are things that, when disconnected from, caused them grief. As noted previously, identifying a safe environment within which to heal is something those traumatised may create or find (Etherington, 2005). Young participants in this study could identify the safe space for them throughout their cancer experience – with and within the six spheres of connection of place, knowledge, people, support, peers and lifestyle. Attachment theory helps an understanding that connections with people and places, especially home, are important in young people's feelings of safety and security in their personal and social worlds (Bowlby, 1980; Counted, 2016; Holmes, 2014; O'Shaughnessy, 2023). Grief and loss result when attachments are disrupted or end (Bowlby, 1980; O'Shaughnessy, 2023). These theories contribute to an understanding of how being disconnected from people, places and things important to young people from outer regional and remote Queensland is a grief experience. Acknowledging, validating and working with young people to identify the cumulative loss and trauma they experience and maintaining or forming connections that will help young people through their loss and trauma experiences would be responsive social work intervention goals based on these study findings.

7.5 The Liminal Experience

A major interpretation made from the data is that young people living with cancer from outer regional and remote Queensland areas who travel away for their cancer care go through a liminal, life-changing experience. Metropolitan-based literature supports there are life-changing aspects of young people going through cancer. For instance, Kelly (2008) recognised how getting cancer young interrupts young people's lives. Feelings of injustice and a loss of sense of security are common experiences noted (Kelly, 2008). Hendriks et al.'s (2024) qualitative phenomenological research with young people explored their experiences of how cancer changed their bodies (Hendriks et al., 2024). Six themes emerged: self-conscious body, vulnerable body, adapting to the body, uncontrollable body, remembering the body and shared bodies (Hendriks et al., 2024). The title quote from a young participant evidences body changes are life-changing: "There is still a part of me that would love to be the old me again" (Hendriks et al., 2024, p. 1). These studies indicate the life-changing nature of going through cancer for young people. However, they are not specific to nonmetropolitan contexts.

Living in a liminal space has been used to characterise oscillating between hope for a cure and facing possible death in a Canadian study of young adults living with advanced cancer (Avery et al., 2024). Avery et al. (2024) used the term to describe how participants' day-to-day lives were marked by uncertainty. In my study, the liminal experience encompasses a geographical move away from home at or close to diagnosis for cancer treatment, with return home marking the endpoint regardless of treatment outcome. Identifying the specific liminal phase in between diagnosis and having to travel away for treatment and then returning home as the endpoint aligns with Turner (1967) and Plato's (ca. late 350s B.C.E./1982) depictions of liminal experiences where people are "in between" their old state/self and not yet arrived at their new state/self (Turner, 1967). 'Replenishment' from the pain and discomfort experienced in the liminal phase (Plato, ca. late 350s B.C.E./1982) comes from returning home permanently. Returning home permanently is when young people from outer regional and remote Queensland begin living their 'new normal' lives. Based on this finding, I recommend that social workers discuss the liminal nature of the experience with young people from outer regional or remote areas. Discussing the in-between state they find themselves in where they have not yet returned home may help young people understand what they are going through and plan ways to manage being away from home. Managing the liminal experience is informed by this study's findings in seeking ways young people from outer regional and remote areas can maintain or build connections important and meaningful to them with and within the six spheres of connection.

In Chapter Six, my synthesis of the data analyses of young people and social work perspectives revealed that what helps young people through their liminal experience is scaffolded support. In this study, scaffolding is a metaphorical representation of support young people need going through their cancer experience, given the protective, safety features scaffolding affords. People going through traumatic experiences benefit from feeling safe (Etherington, 2005; Herman, 2015). People going through loss experiences benefit from having their loss recognised (Doka, 2002), forming connections that help reconcile or continue their bonds with the loss experience (Doka, 2016; Klass et al., 1996; Worden, 2009) and making meaning out of their loss experience (Neimeyer et al., 2006; Neimeyer & Thompson, 2014). The need for a network of support throughout a cancer experience for young people is well-recognised in the literature (Bibby et al., 2017; Dyson et al., 2012; Holland, Walker, et al., 2021; Lea et al., 2020). Holland et al.'s (2021) study of young people living with cancer in Queensland found access to psychological, emotional, relationship, carer, education, school, work, financial, relationship and peer support was important. This study's findings add to the existing literature, highlighting young people from outer regional and remote areas require a network of scaffolded support as they go through their cancer experience "away from their usual homes and comfort and safety and support system" (Ari, social worker). Knowledge from the findings that young people from outer regional and remote Queensland go through a liminal, life-changing experience marked by cumulative loss and trauma and require scaffolded support can inform social work practice. Trauma-informed interventions which acknowledge young people's grief and assist them maintain or build connections important to them with and within the six spheres of connection would improve young people's liminal experiences travelling away for cancer care from outer regional and remote Queensland, based on this research.

7.6 Study Limitations

This study's research findings need to be considered in the context of study limitations. In this study, young people and social workers represented a specific ethnic cohort. The voices of young Aboriginal and Torres Strait Islander people were missing in phase one, and no social work participants in phase two identified as Aboriginal and Torres Strait Islander. Possible reasons for lack of engagement with the research from Aboriginal and Torres Strait Islander people include not meeting the study's eligibility criteria, which may be partially due the research design not planning specifically for culturally inviting ways to engage (Lloyd-Johnsen et al., 2024). For example, co-design methodologies are valued by Aboriginal and Torres Strait Islander people due to partnering with First Nations consumers, families and communities (Butler et al., 2022). The Australian Cancer Plan acknowledges the critical role of the Aboriginal Community Controlled Health sector in leading improvements in health outcomes, including health research (Cancer Australia, 2023). A co-design methodology was not used in this study. Given Aboriginal and Torres Strait Islander people are often impacted by social determinants that cause poor health, and the higher percentage of the overall population of Aboriginal and Torres Strait Islander people at the outer regional site of this study (Queensland Health, 2022), this constitutes an important gap future research could address.

IPA research samples are typically small (Smith et al., 2009), including in multiperspective IPA studies (Larkin et al., 2019), to allow the in-depth, interpretative analysis between cases and perspectival groups. The small sample sizes in both phases of this study should be considered in the context of their appropriateness for IPA multiperspective design and methodology (Larkin et al., 2019; Smith et al., 2009). Further, sample sizes were appropriate based on guidelines on information power in qualitative interviews given narrow study aims, small sampling frames in both phases, and quality of the rich, thick participant narratives within the in-depth interviews (Malterud et al., 2015).

Caution is required in generalising the results due to limitations of the sample size. The sample is limited in diversity, included only specific locations, age and cancer types, and those who were willing to participate in the study. These experiences may not be representative of other young people living with cancer in outer regional and remote areas across Australia or outside this study's specific demographics.

Participant confidentiality was prioritised. Therefore, in phase one, participant ages or diagnoses were not reported, and in phase two, gender neutral pseudonyms and the geographical location of individual participants were not identified.

7.7 Conclusion

Study findings indicate young people living with cancer from outer regional and remote Queensland go through a liminal, life-changing experience when travelling away for their treatment at specialist cancer care sites. The liminal experience means young people are between states – who they were before they were diagnosed with cancer and travelled away and who they will be once they return home permanently. Young people's experiences from outer regional and remote Queensland are marked with cumulative loss and trauma. In relation to the finding of cumulative loss, I identified a gap in the literature in acknowledging non-death-related losses young people living with cancer experience, which I described as a form of disenfranchised grief – grief unacknowledged by society. In relation to cumulative trauma, distress and trauma are well-recognised experiences in the literature for young people living with cancer. The analysis of the cumulative nature of young people’s losses and traumas when from outer regional and remote Queensland adds to the literature.

Young phase one participants desired connection with and within six domains of connection when having to travel to specialist cancer care sites for treatment. Requiring support was a finding consistent with the literature on young people living with cancer, where it is also well-recognised that a network of support and support options are needed. However, the scaffolded support of the six spheres of connection adds to knowledge on support required by young people living with cancer from outer regional and remote Queensland in the context of understanding the cumulative loss and trauma experienced when travelling away for their cancer care. The spheres of connection model provides a baseline from which social workers can establish connections with young people from outer regional and remote areas to foster and build the helping relationship. In the next and final chapter, I summarise my thesis and original contribution to the social work literature, connect the study findings with the research questions, discuss implications for social work practice, offer suggestions for future research and provide a final reflection.

Chapter Eight: Conclusion

In this final chapter, I consolidate my research into six sections. Firstly, I provide a thesis summary, identifying the original contribution made to the social work literature. Secondly, I outline the study findings in relation to the research questions. In the third section, I present implications for social work practice. I then present a current quality improvement activity occurring in my health service informed by published phase one findings as an example of an implication for practice. In the fifth section, I present suggestions for future research. Lastly, I offer my researcher reflection, concluding how the study findings can inform social work practice with young people living with cancer from outer regional and remote Queensland areas.

8.1 Thesis Summary and Original Contribution

There was limited research exploring the experiences of young people living with cancer in nonmetropolitan areas, with the voices of young people themselves missing in qualitative literature when I commenced this research. As a regional social worker working with young people living with cancer, this meant there was a lack of evidence to guide my practice. To address this gap, I aimed to conduct an in-depth study of the experiences of young people living with cancer in nonmetropolitan Australia at key transition points of diagnosis, during treatment and after treatment to inform social work practice.

The theoretical framework underpinning this research is social constructionism (Crotty, 2020) and interpretive phenomenology (Creswell & Poth, 2018). Multiperspective interpretative phenomenological analysis (IPA) methodology (Larkin et al., 2019; Smith et al., 2009; Smith & Nizza, 2022) assisted me in meeting the study's aim of informing social work practice. The multiperspective IPA design, using in-depth interviews, allowed young people’s voices from outer regional and remote Queensland to be heard for the first time, with social work perspectives adding context to young people’s experiences given their direct work with young people at the outer regional and metropolitan sites chosen. Amongst interpretive phenomenologists, Martin Heidegger's (Heidegger, 2010) view that time is the horizon through which human experience is understood assisted my study design. I chose to cover the entire duration of the cancer experience from diagnosis through treatment and after. This decision was instrumental in my essential interpretation of the findings that young people from outer regional and remote Queensland go through a liminal, life-changing experience, with the endpoint occurring when they return home permanently. If I had not designed the study to seek reflections of the entire duration of young people's experiences, the importance of returning home permanently may not have been reached.

Liminal experiences in anthropology refer to the time between a person's former self or state before the experience started, then throughout the experience when they have not yet reached their new self or state that ends the liminal phase (Turner, 1967). Adolescence, the transition from childhood to adulthood, is an example provided by Turner (1967) of a liminal experience. This study's findings, from both young people and social work participants' perspectives, indicated travelling away for specialist cancer treatment is a liminal experience with the endpoint, or 'replenishment' from the pain and discomfort of the liminal phase (Plato, ca. late 350s B.C.E./1982) occurring when young people return home permanently. The study findings indicate that returning home is always the goal, even if the young person's cancer is incurable and that means returning home to die.

I found that travel away involved many hardships for young study participants living in regional and remote Queensland. Distance from specialist cancer care services emerged as a unique, defining point of difference for young people living with cancer in outer regional and remote Queensland compared with young people in metropolitan areas who live near specialist cancer treatment services. Travelling long distances to relocate for cancer care disrupts young people's lives, including important developmental milestones specific to adolescents and young adults. Phase one research revealed that young participants desired connection through their cancer experiences with and within six spheres – place, knowledge, people, support, peers and lifestyle. Context provided by social work participants revealed that young people face multiple, cumulative losses and traumas throughout their cancer experiences and travel away.

The original contribution this multiperspective IPA research has made addressed a gap in the literature, providing social work-led qualitative research into young people living with cancer from nonmetropolitan areas for the first time. The research findings revealed new knowledge that young people from outer regional and remote Queensland desire connection through their liminal, life-changing cancer experiences marked by cumulative loss and trauma. Young people require scaffolded support throughout their cancer experiences. Scaffolded support is informed by the spheres of connection model, which can guide social work practice with young people. Using the spheres of connection model as a guide can assist young people in maintaining or building connections with things important to them and assist in building connections between young people and their social workers. The spheres of connection model was published and has informed a registered quality improvement activity trialling an interventional tool (Appendix G) within the Cairns and Hinterland Hospital and Health Service. I will detail this quality improvement activity in section 8.4.

8.2 Addressing the Research Questions

In this section, I present ways in which the study findings address the four research questions. In summary, travelling away for specialist cancer treatment is a liminal, life-changing experience where young people desire connection through cumulative loss and trauma.

8.2.1 The Tyranny of Distance – Travel Away is Hard for Young People

I explored young people’s perspectives with the first research question: How do young people diagnosed with cancer from Far North Queensland describe their experience of living with cancer? My interpretation of the results identified that young people describe their experience of living with cancer in ways that highlight travelling away for specialist cancer care involves many physical and psychosocial hardships. Young people have to relocate for their treatment to major regional or metropolitan specialist cancer care centres for long periods, and being away from their home communities negatively impacts their relationships with home, loved ones, school, work and lifestyle. Young people often felt “out of the loop” (Raymond, young person) and that health staff were speaking with their parents/carers rather than them, which young people did not like: “I am the patient – you should be talking about this with me” (Mia, young person). Young people also felt they lacked knowledge and understanding about their diagnosis and treatment, partially due to health staff not speaking directly with them but also, from the young people's perspectives, due to health staff not providing reliable information to assist young people in understanding their cancer and required care.

Young participants formed relationships with other young people going through cancer experiences – their peers – and found witnessing their peers' treatment impacts or deaths confronting and distressing. Going through a cancer experience changed young people's lives, and their desire during treatment was always to return home.

8.2.2 Connection is Important to Young People

I explored young people's perspectives further with the second research question: What is important to young people living with cancer in Far North Queensland when they are diagnosed with cancer, during cancer treatment and after cancer treatment finishes or when they return home? I found that young people find it easier if treatment can happen closer to home. Young people described things that can make travel easier and how health staff can improve care. Young people provided advice for other young people living with cancer from nonmetropolitan areas to make it easier for them. Essentially, young people desired to remain or build connections with the things that were important to them – place (treatment close to home), knowledge (being acknowledged and understanding my cancer), people (family, friends and health staff), support (coping strategies), peers (sharing my experience) and lifestyle (surviving cancer – how it has shaped me). Summarising Chapter Four's findings, young people desire connection with and within these six spheres. These six spheres show travel away from home and community is hard for young people. Their relationships with people (family, friends and health staff) are important. They need to be acknowledged and understand their cancer. They need support. Relationships with their peers and improving other young people's experiences are important. Contemplative reflection on the whole experience reveals young people's lives have been both negatively and positively affected by going through and surviving their cancer experience.

Social work participants showed an understanding of young people's need to stay in contact (connected) with the things that were important to them whilst away. The importance of connection is evident through the areas social workers identified as involving loss for young people – home and community, physical and mental health, autonomy, relationship losses and loss of lifestyle, and in identifying the scaffolded support young people require throughout their cancer experience.

8.2.3 Cumulative Loss and Trauma

I explored social work perspectives with the third research question: What are social workers' perspectives on the experiences of young people living with cancer from outer regional and remote Queensland and their encounters with the health system at diagnosis, during cancer treatment and after treatment finishes or when they return home? The social work perspectives provided context for young people's experiences as involving multiple, cumulative losses and traumas.

8.2.4 A Liminal, Life-Changing Experience

This study's findings reveal that young people living with cancer from outer regional and remote Queensland who travel away for their specialist cancer care go through a liminal, life-changing experience. Young people start this experience as who they were prior to their cancer diagnosis, with travel away for specialist cancer treatment marked by cumulative loss and trauma. Young people's goal is to return home permanently. However, they return home changed – different to who they were before. Once home, their new normal is marked by post-traumatic stress and growth because of their liminal, life-changing cancer experience.

8.3 Implications for Social Work Practice

In Chapter One, I outlined my oncology social work practice with young people from outer regional and remote areas, including my time being weighted towards priority, crisis-based referrals of patients with immediate needs in the paediatric ward I covered. The busy hospital environment and lack of evidence to guide the time I did spend with young people living with cancer led to me feeling what I offered was inadequate. This motivated me to conduct this research. In this section, I present the implications for social work practice generated by the research findings in three areas: 'preparing for the liminal experience: before and during diagnosis'; 'during the liminal experience: connection through cumulative loss and trauma during treatment whilst away'; and 'beyond the liminal experience: after treatment'.

These implications for social work practice are derived from the study findings and are relevant for social work practice with young people living with cancer from outer regional and remote areas. The tyranny of distance for outer regional and remote young Queenslanders means they must travel and relocate for extended periods to major regional or metropolitan locations for their specialist cancer care. Young people receive psychosocial care from social workers at major Queensland regional and metropolitan relocation sites. Therefore, these practice implications are for social workers located in any remote, regional or metropolitan site who work with young people living with cancer from outer regional or remote areas. Key goals for social workers in all locations are establishing the helping relationship, maintaining connection with young people at regular intervals and assisting young people in maintaining, building or strengthening connections that are important to them. The spheres of connection model that emerged from this study provides social workers with a foundation to inform scaffolded support and the connection work they do with young people living with cancer from outer regional and remote areas.

8.3.1 Preparing for the Liminal Experience: Before and During Diagnosis

Proactively recognising loss and trauma and helping young people identify, maintain, build and strengthen connections may improve young people's liminal experiences travelling away for cancer care from outer regional and remote Queensland, based on this research. Regional and remote social workers should consider specific ways they can help prepare young people for their liminal, life-changing cancer experiences at their regional or remote sites before young people travel away. Transfers from outer regional and remote Queensland locations to specialist cancer care can occur quickly, including after-hours. Therefore, I recommend social workers in all locations assist young people from outer regional and remote areas to prepare for and manage the liminal experience by identifying, maintaining, building or strengthening connections important to them with and within the six spheres of connection that emerged from this study's young participant data. Theories informing grief, loss and trauma practice, identified in Chapter Seven, may also be helpful (Bloom, 2018, 2020; Bowlby, 1973, 1980, 1982; Doka, 2002; Klass et al., 1996; Neimeyer et al., 2006; Neimeyer & Thompson, 2014; O'Shaughnessy, 2023; Worden, 2009).

In this study, young people and social work participants desired a connection with each other and believed it was contingent on social workers to initiate and build the helping relationship. Rapport-building and establishing connections with young people living with cancer is important to ensure holistic psychosocial assessments occur for ongoing, flexible care specific to young people's needs and connecting them to supportive help and resources (Patterson et al., 2018). My study findings suggest psychosocial benefit is gained and should be prioritised in establishing a helping relationship with young people living with cancer from outer regional and remote areas. Further, maintaining regular connections with young people living with cancer from nonmetropolitan areas, using age-appropriate, trauma and culturally informed interventions, can build connections between young people and their social workers. Social work departments could consider workload management processes that support social workers to establish and connect regularly with young clients from outer regional and remote areas. Young study participants' advice to social workers, as provided in Chapter Four, may also inform practice methods to build and strengthen the helping relationship.

8.3.2 During the Liminal Experience: Connection Through Cumulative Loss and Trauma During Treatment Whilst Away

This study's findings indicate young people's liminal, life-changing cancer experiences from outer regional and remote Queensland are marked by cumulative loss and trauma, with young people desiring connection with and within six spheres of connection with place, knowledge, people, support, peers and lifestyle. Travelling long distances disrupted those connections at a developmentally important time in young people's lives. Social workers could use this knowledge to assist young people from outer regional and remote areas in exploring the cumulative losses and traumas they face throughout their cancer experience and assist them identify, maintain, build or strengthen important connections. Where psychosocial assessments identify significant grief, loss or trauma affecting young people's mental health, I recommend social workers ensure young people have skilled support by directly providing it or referring young people to staff or services who can provide it, such as psychologists, psychiatrists or mental health teams.

Phase two study findings from social work perspectives indicated that for young Aboriginal and Torres Strait Islander people from outer regional and remote areas it can be traumatic being disconnected with Country and culture through having to travel away for cancer treatment. I recommend social workers, in consultation with Indigenous Liaison/Hospital Officers, explore ways of mitigating trauma experienced by young Aboriginal and Torres Strait Islander people from outer regional and remote areas. Social workers could refer young Aboriginal and Torres Strait Islander people to culturally appropriate staff, such as Indigenous Liaison/Hospital Officers, and connect them with culturally safe and appropriate community services at outer regional or metropolitan specialist cancer care sites.

Study findings suggest that social workers require comprehensive knowledge of the supports and resources available to support young people from outer regional and remote Queensland. Social work participants suggested nonmetropolitan and metropolitan social workers can benefit from connecting with one another for knowledge-sharing, collaborating for enhanced care for mutual young clients and collegial support. Social workers could explore ways of connecting with their nonmetropolitan or metropolitan counterparts to achieve these goals.

The spheres of connection model that emerged from the study was developed by identifying people and things young studey participants desired connection with during their cancer experiences of having to travel away for treatment. I recommend social workers explore ways within their service frameworks that the spheres of connection model can guide practice with young people living with cancer from outer regional and remote areas. Social workers can assist young people from outer regional and remote areas to identify connections important to them, including how to maintain these whilst away, build those still needed and strengthen them, including at regular connection points with young people. Study findings indicated going home permanently is important to young people from outer regional and remote Queensland. Identifying connections important to young people and how these may be strengthened whilst away, may guide preparations for young people returning home. Young study participants valued autonomy. Therefore, encouraging ownership of young people's connections and how they will maintain, build and strengthen them is recommended. I present an example of using the spheres of connection model in practice in section 8.4.

Half of phase one's young study participants were fearful of dying. Phase two social work participants also explored scenarios of end-of-life experiences for their young clients from outer regional and remote Queensland. I recommend social workers recognise that young people from outer regional and remote areas may be fearful of dying from their cancer and assist them through open discussions and introduce advance care planning. Further, where social workers assess more specialised skills are required to meet the needs of young people fearful of dying or going through end-of-life experiences, I recommend referrals to appropriately skilled staff (e.g. psychologists, mental health experts or advance care planners) or services (e.g. palliative care). End-of-life care also involves ensuring support is in place for loved ones, wherever possible, including bereavement care after a young person dies.

Social work perspectives in this study indicated that young people wish to return to their outer regional or remote homes, or to Country for young Aboriginal and Torres Strait Islander people, when their cancer becomes incurable. Social workers can advocate for and support young people's psychosocial care needs when young people transition back home for end-of-life care. Transitions home for young Aboriginal and Torres Strait Islander people require culturally appropriate measures, including referral to Indigenous/Hospital Liaison Officers at metropolitan or outer regional specialist cancer care sites and home health services on Country to coordinate culturally appropriate care.

8.3.3 Beyond the Liminal Experience: After Treatment

Study findings highlighted post-trauma effects for young participants after returning from their cancer treatment to their outer regional or remote homes, with some young participants requiring counselling. Study findings also indicated young participants grew through their cancer and post-trauma experiences, which I interpreted as 'enduring resilience' and connected with post-traumatic growth described in the literature (Bloom, 2018, 2020; Calhoun & Tedeschi, 2014; Zebrack, 2015). I recommend social workers explore opportunities for regular connection with young people living with cancer from outer regional and remote areas post-treatment to support young people with post-trauma effects. These regular post-treatment connections between young people and social workers could also be used to help young people explore their post-traumatic growth so they might find hope, meaning and happiness in their 'new normal' selves and lives.

8.4 Outcome from Knowledge Dissemination of This Study: Interventional Tool Trial

In this section, I present an example of how knowledge from this study's findings can be used in practice with young people living with cancer from outer regional and remote areas, with a current quality improvement activity I am leading in my health service. The ultimate outcome of research dissemination is to inform and hopefully improve practice (Evans et al., 2014). As a result of my dissemination strategy to date, the published results of young people's perspectives have been used to inform a trial in the Cairns and Hinterland Hospital and Health Service (CHHHS). Senior clinicians from CHHHS adult and paediatric oncology services liaised with me to use phase one published research findings. The clinicians sought to develop a trial based on the spheres of connection model. The aim of the trial was to devise an interventional tool for young people 15–25 years old living with cancer in Far North Queensland. In February 2023, we formed a working group. The working group included representation from nursing, social work and Aboriginal and Torres Strait Islander staff. Nominated to lead the trial, I sought and secured CHHHS Executive Sponsorship from the Executive Director of Allied Health. I consulted with the Far North Queensland Director of Human Research Ethics Committee to ensure a trial based on published research findings was following ethical human research processes. Consistent with my research findings of a liminal experience for young people from outer regional and remote areas who travel away for their cancer care, our working group named the trial project "The In-Betweeners". The trial was supported by the medical Clinical Directors of CHHHS adult and paediatric oncology services. The trial was submitted and is now a registered CHHHS Quality Improvement (QI) Activity (see Appendix U). The Project Plan for the QI Activity can be viewed in Appendix V.

In the planning meetings, the working group made one change to the spheres of connection model. The working group thought young people from Far North Queensland, when diagnosed with cancer, would be very unlikely to know any other young people living with cancer (peers). It was decided to move "peers" as an addition into the *people* sphere. There are, therefore, five spheres of connection in our trial: place, knowledge, people, support and lifestyle. Blank pages were included with headings "Questions I need answers to" and "Other things that matter to me". These were important additions because, whilst the trial was informed by this study's findings, the five spheres in the booklet are not exhaustive regarding what may be important to young people from the Far North Queensland region. The working group also included a list of age-appropriate support organisations with contact details in the "Support" section to facilitate young people's awareness of support services available and autonomous access if desired.

An important element of pre-trial preparations was consumer feedback from young people living with cancer. We asked young consumers to review the booklet and offer suggestions. Three young consumers (one from Far North Queensland) thought the trial booklet was good and were supportive of using it in a trial. Two young Queensland consumers for the Youth Cancer Services consumer-led Youth Advisory Group gave similar feedback which is captured in the written feedback of one of these consumers: "I think the Connection Tool is good … I wish I had something like that when I went through" (name withheld for privacy). Young consumer feedback was incorporated into the booklet prior to trial commencement.

The interventional tool trial successfully commenced in the CHHHS adult and oncology services on 5 February 2024. The interventional tool booklet (Appendix G) developed by the working group is called "My Connections". The booklet is provided to young people aged 15–25 years diagnosed with cancer from Far North Queensland to use during their cancer experience or for review if their cancer treatment has finished. Young participants of the QI Activity are provided with a survey, which can be completed by hand or QR code (Appendix W). The trial will run for six months. On trial completion, survey results will be analysed. The plan is to embed the tool into practice once modifications from the trial results are incorporated. I plan to lead the dissemination of the trial results through service-wide education sessions and a publication.

8.5 Suggestions for Future Research

The voices of Aboriginal and Torres Strait Islander young people and social workers are missing in this research, a limitation I identified in Chapter Seven. Due to Aboriginal and Torres Strait Islander people often being impacted by social determinants that cause poor health, and the significant population percentage occupied by Aboriginal and Torres Strait Islander Queenslanders at this study's outer regional site (Queensland Health, 2022), the lack of young or social work

Aboriginal and Torres Strait Islander voices in the study is concerning. Social work's anti-racist, social justice agenda has not always translated well into social work research (Rowe et al., 2015). Rowe et al. (2015) argue that social work researchers require a paradigmatic shift to learn from Indigenous approaches. Although I made every effort through my involvement of an Aboriginal and Torres Strait Islander Senior Hospital Liaison Officer to design and conduct this study in culturally appropriate, safe and inclusive ways, I am a white researcher whose participant base contained no Aboriginal and Torres Strait Islander people. Scholarly reflection informs my recommendation that to capture the voices of Aboriginal and Torres Strait Islander people in research exploring experiences of young people living with cancer in nonmetropolitan areas will ideally involve a co-design approach. Co-design is recognised as a valued research method by Aboriginal and Torres Strait Islander Australian communities (Butler et al., 2022; Cancer Australia, 2023). The Australian Cancer Plan states the primary goal of cancer care in Australia is to achieve equity in cancer outcomes for Aboriginal and Torres Strait Islander people, equal to all Australians (Cancer Australia, 2023). I recommend co-design research approaches partnering with Aboriginal and Torres Strait Islander consumers, families and communities in future research exploring experiences of young people living with cancer in nonmetropolitan areas.

The study findings also revealed that non-death-related grief and loss are often not acknowledged in the literature as part of young people's experiences going through cancer. This study identified multiple cumulative losses young people living with cancer from outer regional and remote Queensland experience, which were not death-related. The absence of non-death-related grief for young people living with cancer appears to be an important omission from literature to date. Further research targeting non-death-related, disenfranchised grief and loss for young people living with cancer from both metropolitan and nonmetropolitan areas is recommended.

To address current disparities in cancer outcomes between those living in metropolitan areas and those from outer regional and remote areas (Cancer Australia, 2023, 2024), future research could focus on a comparison of the metropolitan and outer regional and remote Australian experiences of young people living with cancer.

Findings from this study provide information that may guide social work practice with young people living with cancer from outer regional and remote areas – an example of this is the quality improvement project trialling the interventional tool in my hospital and health service. Further research using appropriate methodologies to engage with young people and other stakeholders to develop resources and practices that aim to improve the quality of cancer care for young people from outer regional and remote areas could also be considered.

8.6 Researcher Reflection

In Chapter One, I identified gaps in my knowledge as a regional paediatric oncology social worker. The gaps in my knowledge provided the motivation for me to choose to research the experiences of young people living with cancer in nonmetropolitan areas. I hoped to discover, through the research process, ways to inform social work practice with young people from regional and remote areas. As I reflect on my research journey and the findings from this research, I can identify times in my practice when I attempted to 'connect' young people with things they needed and that mattered to them. However, it was not done in a systematic way informed by research. Young people who travel away for cancer treatment were shown in this study to highly value and desire a connection with the things that are important to them. Those important connections were place, knowledge, people, support, peers and lifestyle. I believe this is important information for social workers in any location to understand when working with young people living with cancer from nonmetropolitan areas.

I have also reflected on gaps in social work theoretical and practice literature on grief and loss and end-of-life practice (Goldsworthy, 2005; Kramer et al., 2003). Due to extensive experience in palliative care preceding my paediatric role, I had well-established bereavement practices for death-related grief young clients experienced. However, perhaps one of the reasons I did not recognise or respond well to non-death-related, disenfranchised grief in the young clients I worked with was due to gaps in my social work education and the social work literature.

The spheres of connection model that emerged from this research has practical use for young people from regional and remote areas who are going through cancer experiences. Young people who have reviewed the “My Connections” booklet being used in the trial I am leading in my hospital and health service have provided some initial feedback that the booklet is useful, with some wishing they had a tool like that when they went through their cancer experience.

Young people’s resiliency and post-traumatic growth shone through in the last section of Chapter Six. Their bravery and determination to go forward were evident after the liminal, life-changing experience of getting cancer and the cumulative loss and trauma endured through travel away for their cancer treatment. They strived to maintain connections important to them, even in the absence of any formal practice/s or knowledge yet available to assist social work or other health professional/s to purposefully help them maintain those important connections.

This research is the story of young people living with cancer from outer regional and remote Queensland (the phenomenon), brought “into the light” (Heidegger, 2010) by the findings. These findings were a gift from the young people and social workers who generously participated. Phase one findings are now being used in a trial in my hospital and health service. I have plans to disseminate the overall findings and continue to tell this story. My hope is that the findings will help young people going through cancer from nonmetropolitan areas and the social workers who work with them. The research can assist connections between young people and their social workers so that both are better informed and prepared for the experience.

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Appendix A: Study Flyer for Young People

Attention - Young People

- Do you live in Far North Queensland?
- Are you aged 15-25 and were diagnosed with cancer prior to the age of 25?
- Has your treatment finished?

If you answered yes to all these questions, then you are warmly invited to take part in a study to share your experience as a young person living with cancer in Far North Queensland.

$50 iTunes card or alternative will be provided as a thank you for taking part in the study.

For more information or to register your interest, please text, phone or email me:

Jodi Sariman
James Cook University, North Queensland
jodi.sariman@my.jcu.edu.au

Queensland Government

JAMES COOK UNIVERSITY AUSTRALIA

Young People with Cancer FNQ Flyer V3 22 October, 2019

Appendix B: Study Flyer for Social Workers CHQHHS

Attention – Qld Health Social Workers

- Have you worked with Children's Health Queensland anytime in the last 10 years?
- In the last 10 years, have you provided any support to young (15-25 years) clients living with cancer from Far North, regional or remote Queensland?
- Did any of those young clients have to travel away or temporarily re-locate to regional or metropolitan specialist cancer care centres for diagnosis or treatment?

If you answered yes to all these questions, you are warmly invited to take part in a study to share your perspectives as a Social Worker providing psychosocial support to young people living with cancer from Far North, regional or remote Queensland.

For more information or to register your interest, please text, phone or email me:

Jodi Sariman
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Young People with Cancer FNQ Flyer V1 25 Oct 2021

Appendix C: Study Flyer for Social Workers CHHHS

Attention – Qld Health Social Workers

- Have you worked for the Cairns and Hinterland Hospital and Health Service anytime in the last 10 years?
- In the last 10 years, have you provided any support to young (15-25 years) clients living with cancer from Far North, outer regional or remote Queensland areas?
- Did any of those young clients have to travel away or temporarily re-locate to regional or metropolitan specialist cancer care centres for diagnosis or treatment?

If you answered yes to all these questions, you are warmly invited to take part in a study to share your perspectives as a Social Worker providing psychosocial support to young people living with cancer from Far North, regional or remote Queensland.

For more information or to register your interest, please text, phone or email me:

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Young People with Cancer FNQ Flyer V1 25 Oct 2021

Appendix D: Interview Schedule for Young People

Interview Schedule

Welcome participant.

1. Please tell me a little about yourself.
Prompts:
- how would you describe yourself?
- what are your likes/dislikes (eg. music, movies), friends, school/work/college/TAFE/Uni, family, interests

I want you to think back to the beginning of this experience of having cancer.
2. What are your clearest memories, both positive and negative, about that time?
Prompts:
- how were you told you had cancer and who told you?
- who did you speak to about your diagnosis?
- what were people's reactions?
- what were your interactions with health/hospital staff like?
- what were you thinking or feeling?
- what did you want to do?

3. What was most important to you at that time?
Prompts:
- practical issues (finances, housing, school/college/TAFE/Uni)
- relationships with friends and family
- what was going to happen to you
- if life was going to change.

4. How do you think living in (home town) affected what happened after your diagnosis?
Prompts:
- travel
- financial costs
- work
- school/college/TAFE/Uni
- friends and family - did they come with you?
  - were you separated from them?

Now I'd like you to think about the period of time when you were having treatment.
5. What are your clearest memories about having treatment?
Prompts:
- where you had your treatment
- treatment itself (side effects, physical reactions, pain, discomfort etc.)
- the staff you had contact with
- the significant people in your life (eg. family or friends) and your relationship with them while you were having treatment
- physical separation from friends and family and home town
- work
- school/college/TAFE/university

6. How do you think being from (home town) made things different for you during treatment?
Prompts:
- what was different for you compared to young people who lived in the city where you had treatment?

Please think about when your treatment finished, or when you were able to return home (if you did).
7. What was it like when your treatment finished or you returned home (or both)?
Prompts:
- what happened when treatment finished, or when you returned home
- what you were thinking or feeling
- your relationships with other people - family and friends, hospital/health staff
- work
- school/college/TAFE/Uni
- what you did.

Please think about what your life was like before you got cancer.
8. What changes do you think happened for you because of getting cancer?
Prompts:
- changes in life in general
- changes in you and how you see the world now
- changes in friends and family (and your relationships with them)
- changes in work, school/college/TAFE/Uni
- changes in your own physical abilities.

Please think about the whole experience from your cancer diagnosis to now.
9. As you look back on all that has happened for you with getting cancer and having treatment, how do you think being from (home town) affected your experience?
Prompts:
- your access to treatment - how easy or not it was to get to treatment
- your relationships with your friends and family
- work
- school/college/TAFE/Uni
- financially.

10. What advice would you give another young person living in a regional, rural or remote area if they got cancer?

11. What advice would you give social workers or other health staff about helping young people from regional, rural or remote areas when they get cancer?

12. This brings us to the end of the interview. Do you have any further comments you would like to make?

Thank you very much for your time.

Appendix E: Interview Schedule for Social Workers

Social Worker Interview Schedule
Welcome participant/s.

#Interview and focus group participants: please do not disclose names or any information that might identify a patient or their relatives/loved ones. In an effort to ensure this does not occur, please try to focus on common or broad issues you have observed in practice for young people from Far North, outer regional or remote areas, rather than individual patients
#Focus group participants: information shared in focus group/s is to be kept confidential to protect the privacy of participants, patients and relatives/loved ones of patients
Cue word: "wait" (interviewer will use if concerned a patient or their loved one's identity may be revealed)

(A) Can you please tell me a little about your practice experience working with young people (15-25 years) living with cancer from Far North, outer regional or remote Queensland? (ASGS: Remoteness Structure Map attached)
Outer regional – eg. Mackay, Townsville and Cairns

(B) I want you to think about a case or cases that stand out to you when you think about working with young people living with cancer from Far North, outer regional or remote Queensland.

a) Please think about what you observed happening for the young person/people at diagnosis, or what they shared with you about when they were diagnosed. Please remember not to use the patient or their relatives/loved ones' names or provide any other information that might identify who they are.

1. What do you recall was important to the young person/people when they were diagnosed?

Prompts:

- Practical issues (finances, housing, school/college/TAFE/Uni)
- Relationships with friends and family
- The welfare of their siblings, family or friends
- What was going to happen to them eg. treatment, physical changes
- If life was going to change; Having to travel away for treatment

2. How do you think being from Far North, outer regional or remote Queensland affected what happened after they were diagnosed?

Prompts:

- Travel
- Financial costs
- Work
- School/college/TAFE/Uni
- Friends/family: did they go with them if they had to travel away for treatment? Was the young person separated from family & friends?

b) Now please think about what you observed happening for the young person/people during treatment, or what they shared with you about when they were going through treatment. Please remember not to use the patient or their relatives/loved ones' names or provide any other information that might identify who they are.

1. Please describe the location/s the young person/people had their treatment (eg. remote, outer regional or metropolitan) – noting if they had treatment in more than one town/city/location.

2. What do you recall was important to that young person (or young people) during treatment?

Prompts:

- Physical (where, side-effects)
- Relationships with staff, significant others (family/friends)
- Physical separation from friends/family/hometown if they had to travel away
- Work
- School/college/TAFE/Uni
- Thoughts, plans (including fears) for the future

3. If the young person/people had to travel away to a specialist cancer care centre for treatment, how do you think being from Far North, outer regional or remote Queensland made things different for them?

Prompts:

- What was different for them compared to young people who lived in, or within driving distance of the city where the specialist cancer care centre was?

c) Now please think about what you observed happening for the young person/people, or what they shared with you about when treatment finished or they were able to return home? Please remember not to use the patient or their relatives/loved ones' names or provide any other information that might identify who they are.

1. What was it like for them when they finished treatment or returned home (or both)?

Prompts:

- What happened for them when treatment finished, or they returned home?
- What do you recall them saying they were thinking and feeling?
- How were relationships with other people – family, friends, hospital/health staff – affected by their treatment finished and/or returning home?
- Work; School/college/TAFE/Uni
- What did they do at that time?
- Thoughts and feelings they shared about wanting to know plans or timeframes for when they would return home

d) Please think about anything the young person/people shared with you about how getting cancer changed their life. Please remember not to use the patient or their relatives/loved ones' names or provide any other information that might identify who they are.

1. What changes did they say happened to them because of getting cancer?

Prompts:

- Changes in life in general
- Changes in them and how they saw the world having had cancer
- Changes in friends and family (and their relationships with them)
- Changes in work, school/college/TAFE/Uni
- Changes in their own physical abilities
- Physical changes due to having cancer
- Spiritually or philosophically

e) Please think about the whole experience of the young person/people from their cancer diagnosis to after treatment finished.

1. As you reflect on their entire cancer journey, how do you think being from Far North, outer regional or remote Queensland affected their experience?

Prompts:

- Their access to treatment – how easy or not it was to get treatment
- Their relationships with their family and friends
- Work
- School/college/TAFE/Uni
- Financially
- Being homesick when away
- Spiritual or philosophical needs

(C) Please reflect on your experience working with young people with cancer, what they have shared with you about what is important to them and what you have observed as being important to them.

a) What advice would you give a young person living in Far North, outer regional or remote Queensland areas if they got cancer?

b) What advice would you give Social Workers or other health staff in Far North, outer regional or remote Queensland areas regarding how to best assist young people diagnosed with cancer from those areas?

c) What advice would you give Social Workers or other health staff working in specialist major regional or metropolitan cancer care facilities regarding how to best assist young people diagnosed with cancer from Far North, outer regional and remote Queensland areas?

(D) This brings us to the end of the interview. Do you have any further comments you would like to make?

Thank you very much for your time.

Appendix F: Table of Interview Questions for Young People and Social Work Participants

Young People Living with Cancer	Social Workers
1. Please tell me a little about yourself.	1. Can you please tell me a little about your practice experience working with young people (15-25 years) living with cancer from Far North, outer regional or remote Queensland?
	****I want you to think about a case or cases that stand out to you when you think about working with young people living with cancer from Far North, outer regional or remote Queensland.***
I want you to think back to the beginning of this experience of having cancer:	*Please think about what you observed happening for the young person/people at diagnosis, or what they shared with you about when they were diagnosed:*
2. What are your clearest memories, both positive and negative, about that time? 3. What was most important to you at that time? 4. How do you think living in (hometown) affected what happened after your diagnosis?	2. What do you recall was important to the young person/people when they were diagnosed? 3. How do you think being from Far North, outer regional or remote Queensland affected what happened after they were diagnosed?
Now I'd like you to think about the period of time when you were having treatment:	*Now please think about what you observed happening for the young person/people during treatment, or what they shared with you about when they were going through treatment:*
5. What are your clearest memories about having treatment? 6. How do you think being from (hometown) made things different for you during treatment?	4. Please describe the location/s the young person/people had their treatment (e.g. remote, outer regional or metropolitan) – noting if they had treatment in more than one town/city/location. 5. What do you recall was important to that young person (or young person) during treatment? 6. If the young person/people had to travel away to a specialist cancer Care centre for treatment, how do you think being from Far North, Outer regional or remote Queensland made things different for them?
Please think about when your treatment finished, or when you were able to return home (if you did):	*Now please think about what you observed happening for the young person/people or what they shared with you about when treatment finished or when they were able to return home:*

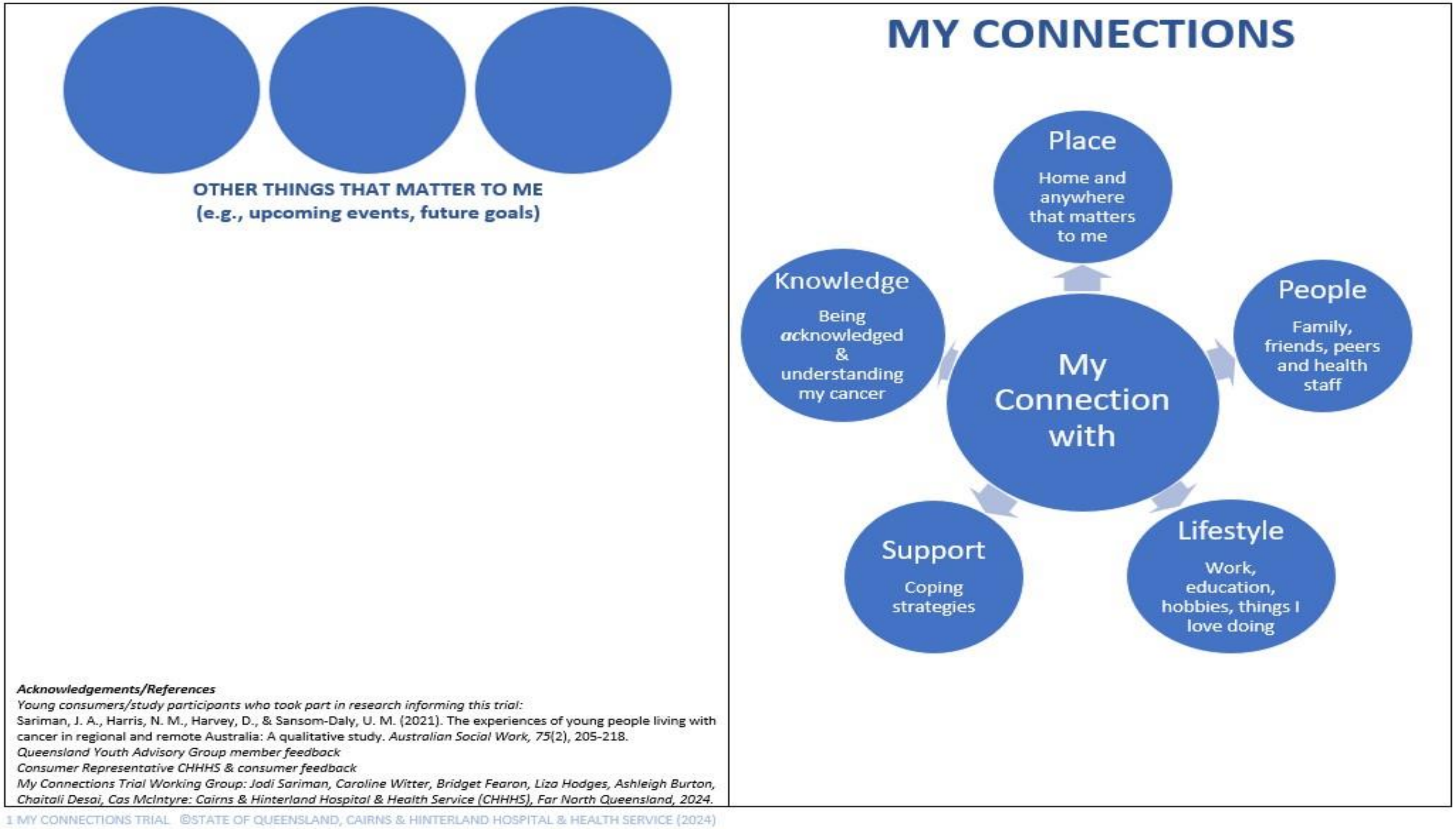
7. What was it like when your treatment finished or your returned home (or both)?	8. What was it like for them when they finished treatment or returned home (or both)?
Please think about what your life was like before you got cancer: 8. What changes do you think happened for you because of getting cancer?	*Please think about anything the young person/people shared with you about how getting cancer changed their life:* 9. What changes did they say happened to them because of getting cancer?
Please think about the whole experience from your cancer diagnosis to now: 9. As you look back on all that has happened for you with getting cancer and having treatment, how do you think being from (hometown) affected your experience?	*Please think about the whole experience of the young person/people from their cancer diagnosis to after treatment finished:* 10. As you reflect on their entire cancer journey, how do you think being from Far North, outer regional or remote Queensland affected their experience?
	Please reflect on your experience working with young people with cancer, what they have shared with you about what is important to them and what you have observed as being important to them.
10. What advice would you give another young person living in a regional, rural or remote are if they got cancer? 11. What advice would you given social workers or other health staff about helping young people from regional, rural or remote areas when they get cancer?	11. What advice would you give a young person living in Far North, outer regional or remote Queensland areas if they got cancer? 12. What advice would you give social workers or other health staff in Far North, outer regional or remote Queensland areas regarding how best to assist young people diagnosed with cancer from those areas? 13. What advice would you give social workers or other health staff in specialist major regional or metropolitan cancer care facilities regarding how to best assist young people diagnosed with cancer from Far North, outer regional and remote Queensland areas?
12. Do you have any further comments you would like to make?	14. Do you have any further comments you would like to make?

---

* Social Work participants were instructed as follows prior to commencement of the interview:
- please do not disclose names or any information that might identify a patient or their relatives/loved ones. In an effort to ensure this does not occur, please try to focus on common or broad issues you have observed in practice for young people from Far North, outer regional or remote areas, rather than individual patients.

Appendix G: “My Connections” Tool Trial Booklet

*note this booklet needs to be printed out, double-sided and folded over in middle for pages to appear in order



OTHER THINGS THAT MATTER TO ME
(e.g., upcoming events, future goals)

Acknowledgements/References
Young consumers/study participants who took part in research informing this trial:
Sariman, J. A., Harris, N. M., Harvey, D., & Sansom-Daly, U. M. (2021). The experiences of young people living with cancer in regional and remote Australia: A qualitative study. *Australian Social Work, 75*(2), 205-218.
Queensland Youth Advisory Group member feedback
Consumer Representative CHHHS & consumer feedback
My Connections Trial Working Group: Jodi Sariman, Caroline Witter, Bridget Fearon, Liza Hodges, Ashleigh Burton, Chaitali Desai, Cas McIntyre: Cairns & Hinterland Hospital & Health Service (CHHHS), Far North Queensland, 2024.

1 MY CONNECTIONS TRIAL ©STATE OF QUEENSLAND, CAIRNS & HINTERLAND HOSPITAL & HEALTH SERVICE (2024)

MY CONNECTIONS

My Connection with

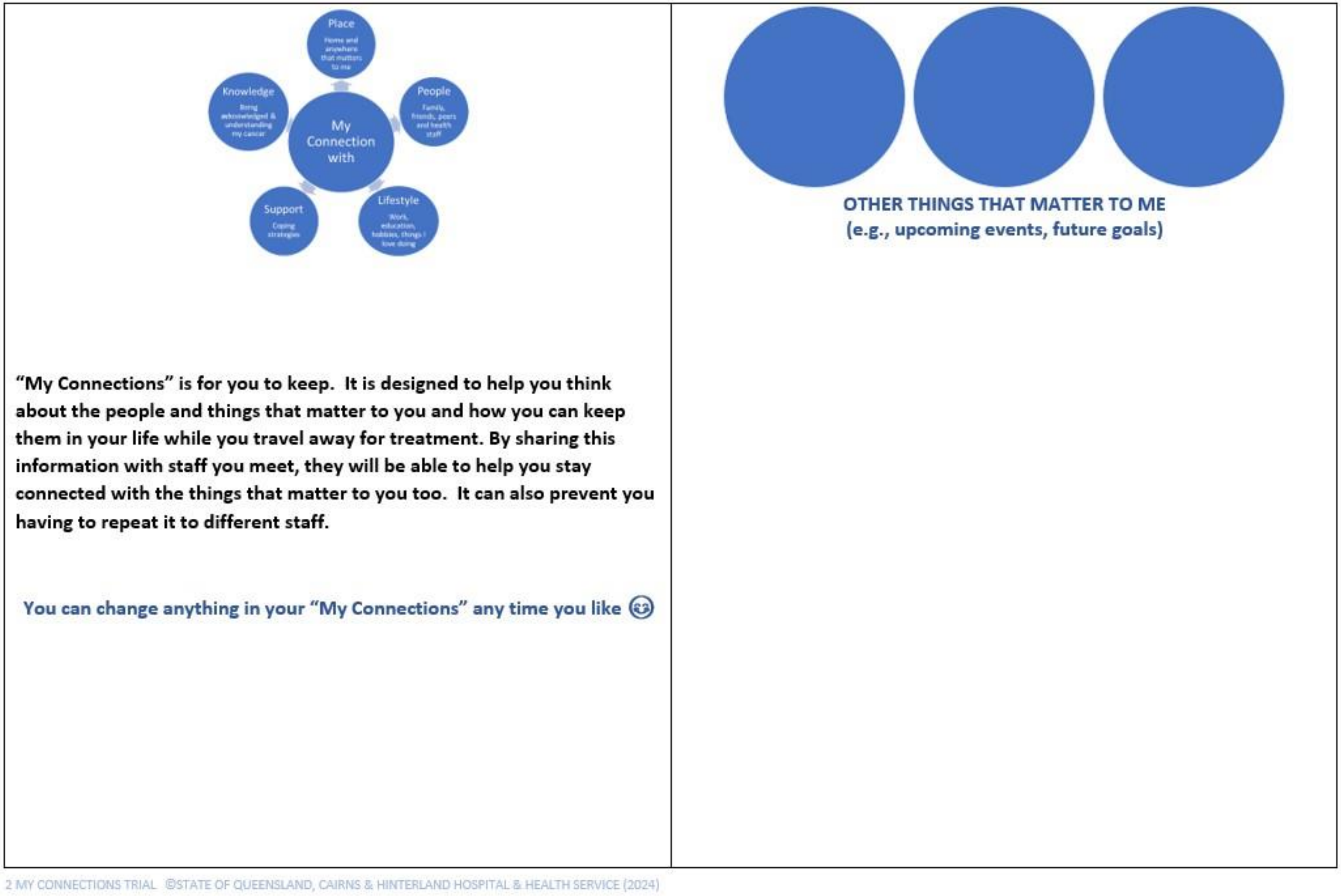
Place
Home and anywhere that matters to me

People
Family, friends, peers and health staff

Lifestyle
Work, education, hobbies, things I love doing

Support
Coping strategies

Knowledge
Being *a*cknowledged & understanding my cancer



"My Connections" is for you to keep. It is designed to help you think about the people and things that matter to you and how you can keep them in your life while you travel away for treatment. By sharing this information with staff you meet, they will be able to help you stay connected with the things that matter to you too. It can also prevent you having to repeat it to different staff.

You can change anything in your "My Connections" any time you like ☺

OTHER THINGS THAT MATTER TO ME
(e.g., upcoming events, future goals)

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OTHER THINGS THAT MATTER TO ME
(e.g., upcoming events, future goals)

Place

Home and anywhere that matters to me

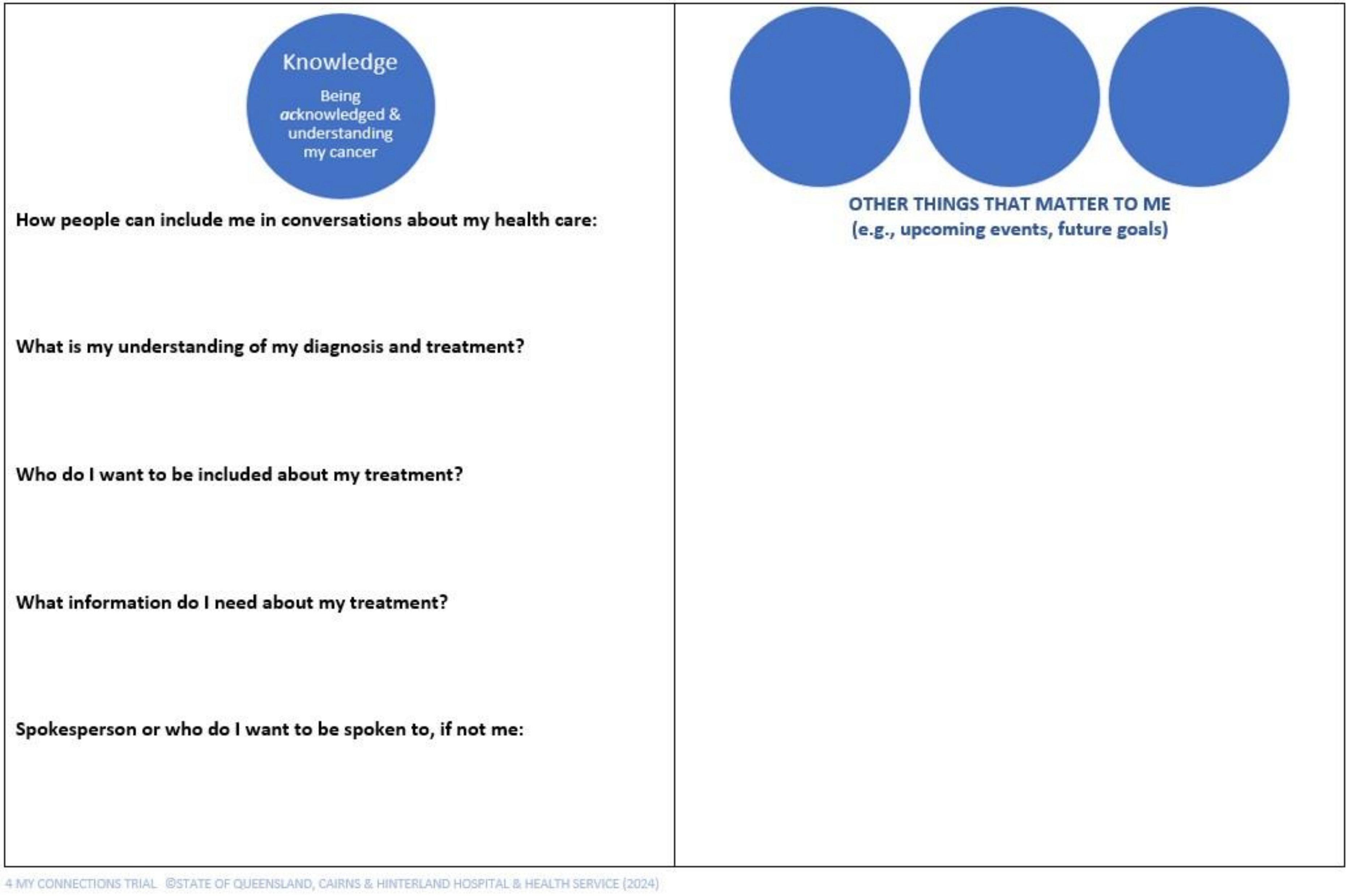
Where is my home?

What places are important to me?

What are my treatment location preferences? e.g., close to home

These things are important for my treatment space:

Who is welcome in my treatment space:



Knowledge

Being acknowledged & understanding my cancer

How people can include me in conversations about my health care:

What is my understanding of my diagnosis and treatment?

Who do I want to be included about my treatment?

What information do I need about my treatment?

Spokesperson or who do I want to be spoken to, if not me:

OTHER THINGS THAT MATTER TO ME
(e.g., upcoming events, future goals)

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OTHER THINGS THAT MATTER TO ME
(e.g., upcoming events, future goals)

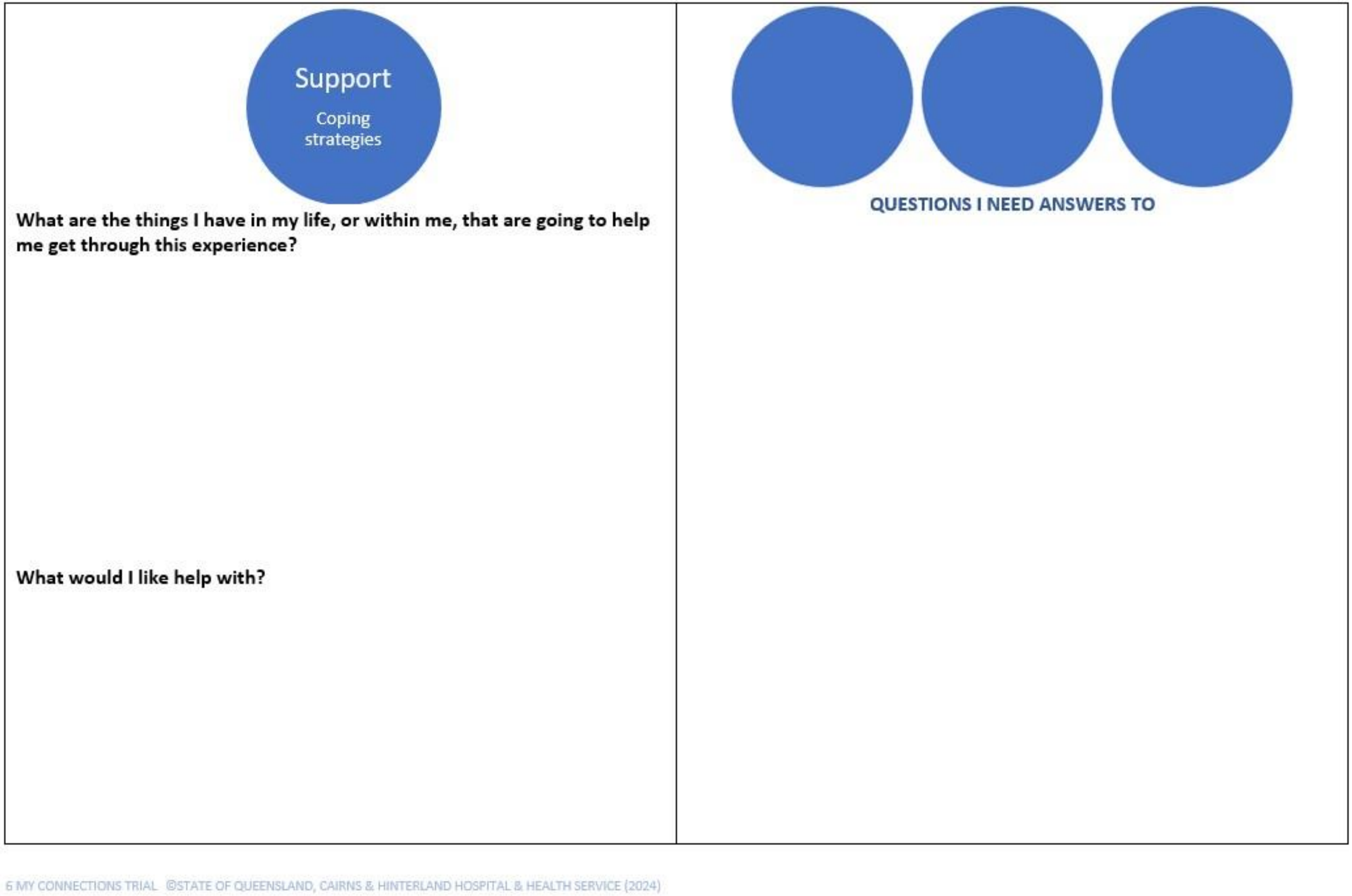
People

Family, friends, peers and health staff

Who are my people?

Who are important to me?

Key Health staff involved in my care:



Support

Coping strategies

What are the things I have in my life, or within me, that are going to help me get through this experience?

What would I like help with?

QUESTIONS I NEED ANSWERS TO

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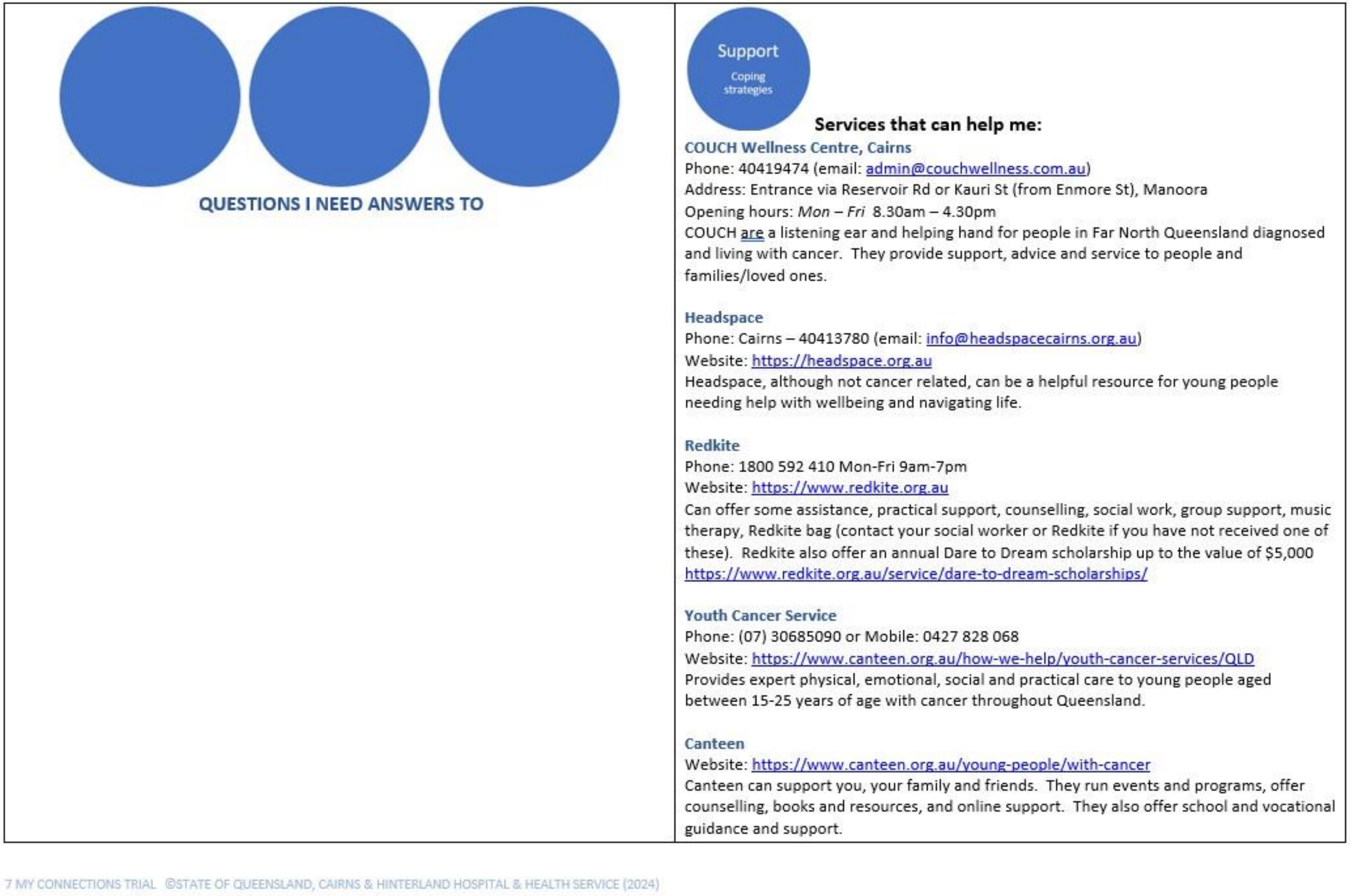

QUESTIONS I NEED ANSWERS TO

Support

Coping strategies

Services that can help me:

COUCH Wellness Centre, Cairns
Phone: 40419474 (email: admin@couchwellness.com.au)
Address: Entrance via Reservoir Rd or Kauri St (from Enmore St), Manoora
Opening hours: *Mon – Fri* 8.30am – 4.30pm

COUCH are a listening ear and helping hand for people in Far North Queensland diagnosed and living with cancer. They provide support, advice and service to people and families/loved ones.

Headspace
Phone: Cairns – 40413780 (email: info@headspacecairns.org.au)
Website: https://headspace.org.au

Headspace, although not cancer related, can be a helpful resource for young people needing help with wellbeing and navigating life.

Redkite
Phone: 1800 592 410 Mon-Fri 9am-7pm
Website: https://www.redkite.org.au

Can offer some assistance, practical support, counselling, social work, group support, music therapy, Redkite bag (contact your social worker or Redkite if you have not received one of these). Redkite also offer an annual Dare to Dream scholarship up to the value of $5,000 https://www.redkite.org.au/service/dare-to-dream-scholarships/

Youth Cancer Service
Phone: (07) 30685090 or Mobile: 0427 828 068
Website: https://www.canteen.org.au/how-we-help/youth-cancer-services/QLD

Provides expert physical, emotional, social and practical care to young people aged between 15-25 years of age with cancer throughout Queensland.

Canteen
Website: https://www.canteen.org.au/young-people/with-cancer

Canteen can support you, your family and friends. They run events and programs, offer counselling, books and resources, and online support. They also offer school and vocational guidance and support.

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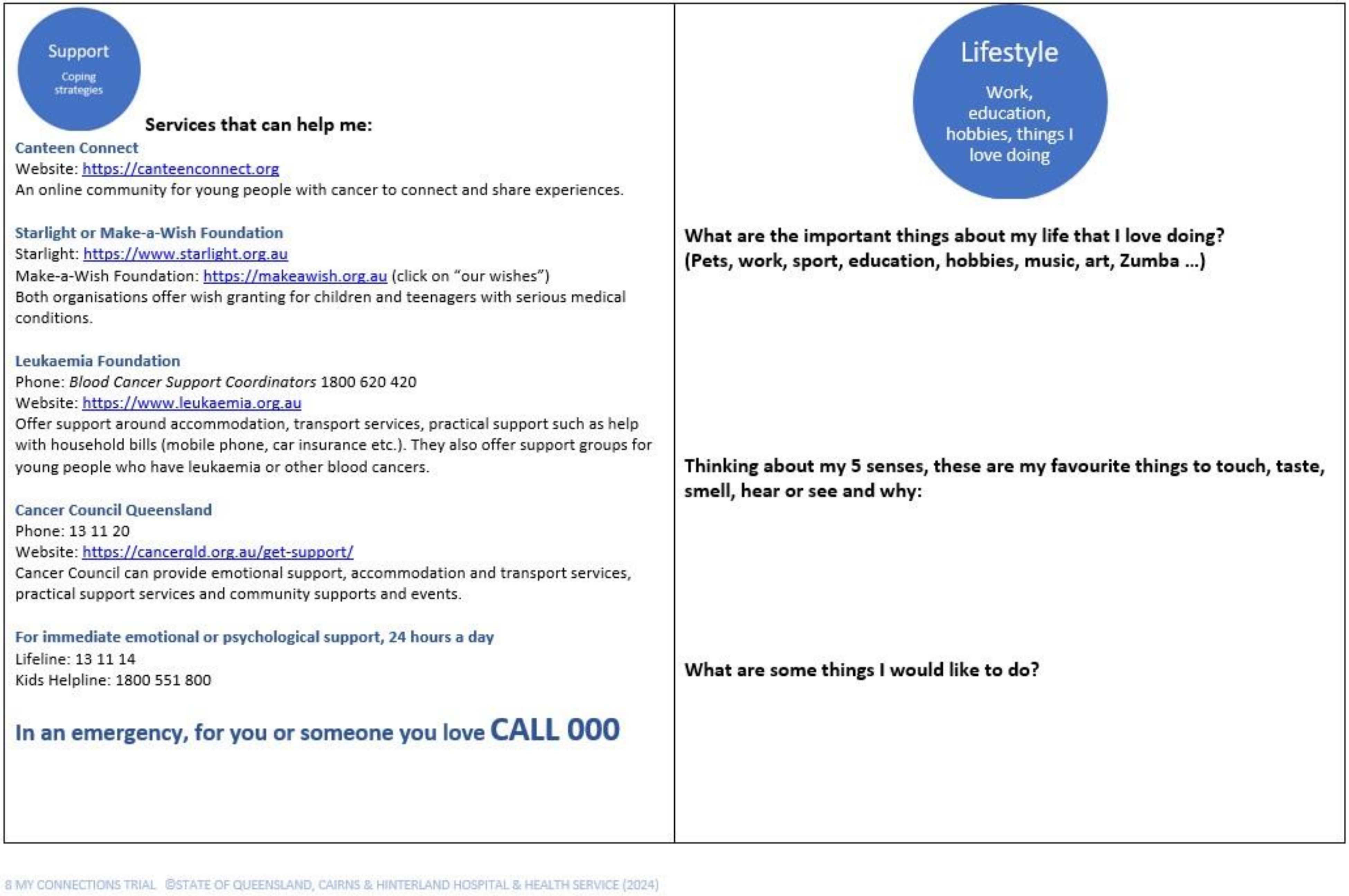


Support

Coping strategies

Services that can help me:

Canteen Connect
Website: https://canteenconnect.org
An online community for young people with cancer to connect and share experiences.

Starlight or Make-a-Wish Foundation
Starlight: https://www.starlight.org.au
Make-a-Wish Foundation: https://makeawish.org.au (click on "our wishes")
Both organisations offer wish granting for children and teenagers with serious medical conditions.

Leukaemia Foundation
Phone: *Blood Cancer Support Coordinators* 1800 620 420
Website: https://www.leukaemia.org.au
Offer support around accommodation, transport services, practical support such as help with household bills (mobile phone, car insurance etc.). They also offer support groups for young people who have leukaemia or other blood cancers.

Cancer Council Queensland
Phone: 13 11 20
Website: https://cancerqld.org.au/get-support/
Cancer Council can provide emotional support, accommodation and transport services, practical support services and community supports and events.

For immediate emotional or psychological support, 24 hours a day
Lifeline: 13 11 14
Kids Helpline: 1800 551 800

In an emergency, for you or someone you love CALL 000

Lifestyle

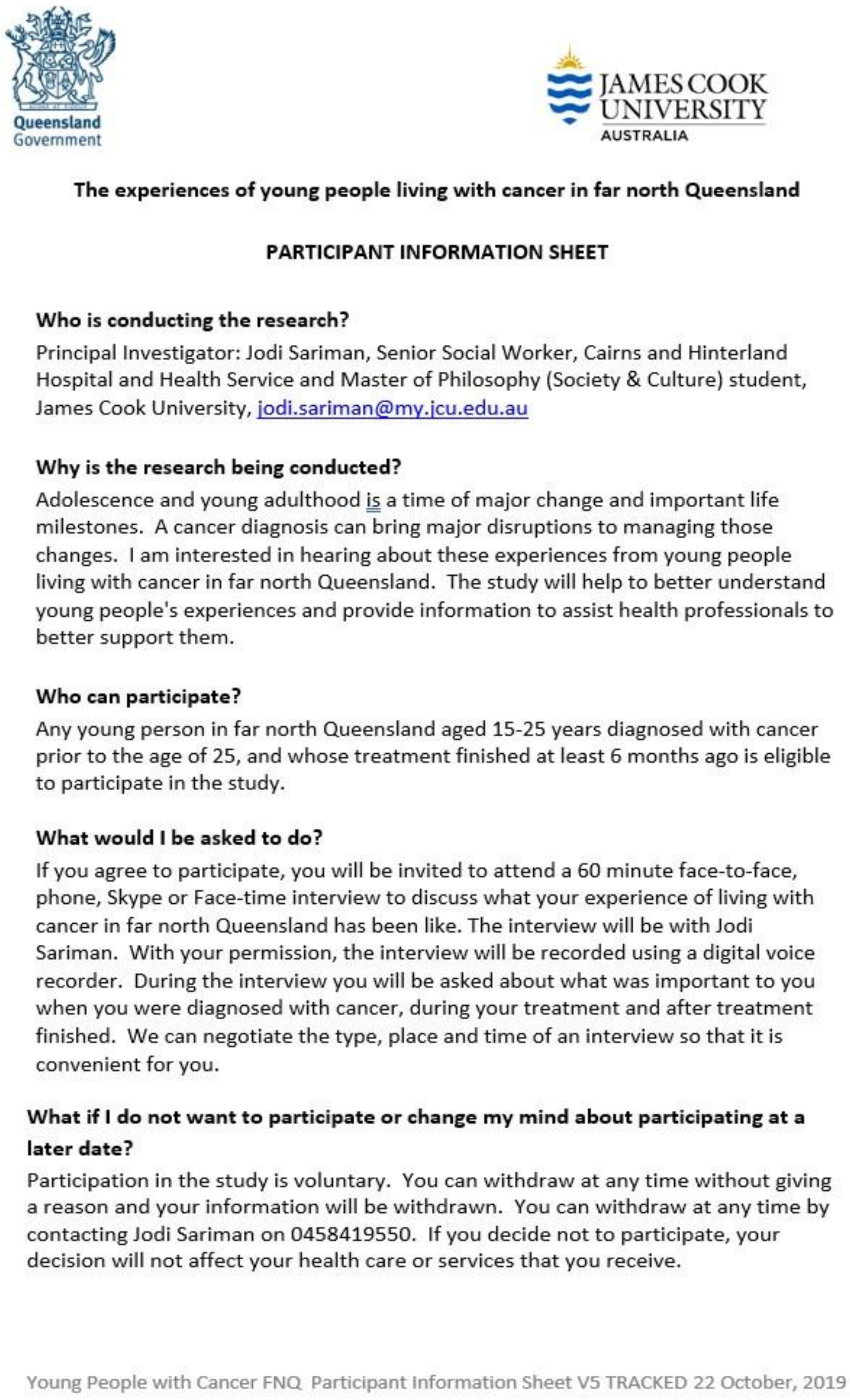
Work, education, hobbies, things I love doing

What are the important things about my life that I love doing?
(Pets, work, sport, education, hobbies, music, art, Zumba ...)

Thinking about my 5 senses, these are my favourite things to touch, taste, smell, hear or see and why:

What are some things I would like to do?

Appendix H: Participant Information Sheet Phase One



Queensland Government

JAMES COOK UNIVERSITY AUSTRALIA

The experiences of young people living with cancer in far north Queensland

PARTICIPANT INFORMATION SHEET

Who is conducting the research?

Principal Investigator: Jodi Sariman, Senior Social Worker, Cairns and Hinterland Hospital and Health Service and Master of Philosophy (Society & Culture) student, James Cook University, jodi.sariman@my.jcu.edu.au

Why is the research being conducted?

Adolescence and young adulthood is a time of major change and important life milestones. A cancer diagnosis can bring major disruptions to managing those changes. I am interested in hearing about these experiences from young people living with cancer in far north Queensland. The study will help to better understand young people's experiences and provide information to assist health professionals to better support them.

Who can participate?

Any young person in far north Queensland aged 15-25 years diagnosed with cancer prior to the age of 25, and whose treatment finished at least 6 months ago is eligible to participate in the study.

What would I be asked to do?

If you agree to participate, you will be invited to attend a 60 minute face-to-face, phone, Skype or Face-time interview to discuss what your experience of living with cancer in far north Queensland has been like. The interview will be with Jodi Sariman. With your permission, the interview will be recorded using a digital voice recorder. During the interview you will be asked about what was important to you when you were diagnosed with cancer, during your treatment and after treatment finished. We can negotiate the type, place and time of an interview so that it is convenient for you.

What if I do not want to participate or change my mind about participating at a later date?

Participation in the study is voluntary. You can withdraw at any time without giving a reason and your information will be withdrawn. You can withdraw at any time by contacting Jodi Sariman on 0458419550. If you decide not to participate, your decision will not affect your health care or services that you receive.

Young People with Cancer FNQ Participant Information Sheet V5 TRACKED 22 October, 2019

Appendix I: Participant Informed Consent Phase One

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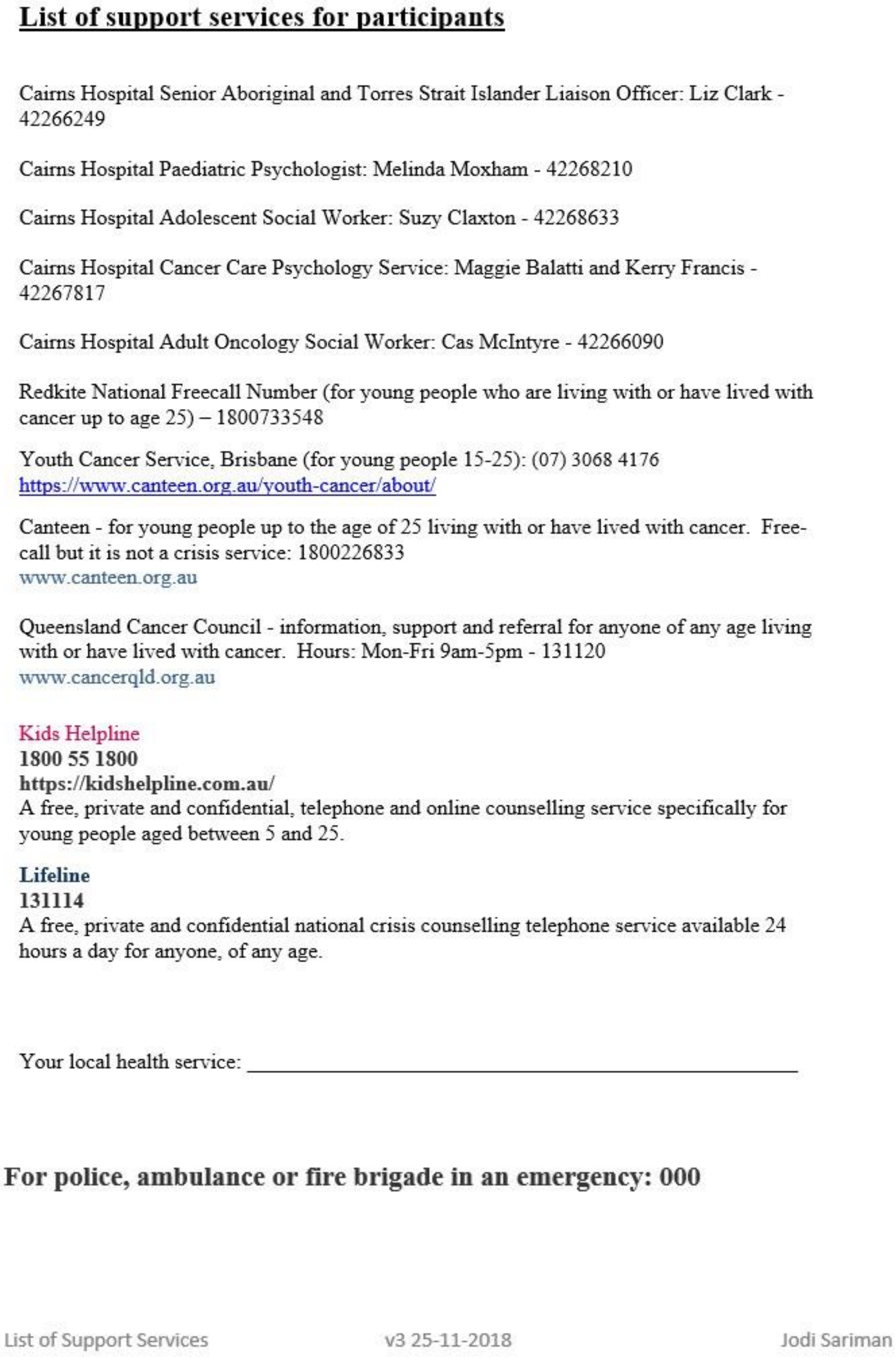
Appendix J: List of Support Services for Participants Phase One



List of support services for participants

Cairns Hospital Senior Aboriginal and Torres Strait Islander Liaison Officer: Liz Clark - 42266249

Cairns Hospital Paediatric Psychologist: Melinda Moxham - 42268210

Cairns Hospital Adolescent Social Worker: Suzy Claxton - 42268633

Cairns Hospital Cancer Care Psychology Service: Maggie Balatti and Kerry Francis - 42267817

Cairns Hospital Adult Oncology Social Worker: Cas McIntyre - 42266090

Redkite National Freecall Number (for young people who are living with or have lived with cancer up to age 25) – 1800733548

Youth Cancer Service, Brisbane (for young people 15-25): (07) 3068 4176
https://www.canteen.org.au/youth-cancer/about/

Canteen - for young people up to the age of 25 living with or have lived with cancer. Free-call but it is not a crisis service: 1800226833
www.canteen.org.au

Queensland Cancer Council - information, support and referral for anyone of any age living with or have lived with cancer. Hours: Mon-Fri 9am-5pm - 131120
www.cancerqld.org.au

Kids Helpline
1800 55 1800
https://kidshelpline.com.au/
A free, private and confidential, telephone and online counselling service specifically for young people aged between 5 and 25.

Lifeline
131114
A free, private and confidential national crisis counselling telephone service available 24 hours a day for anyone, of any age.

Your local health service: ____

For police, ambulance or fire brigade in an emergency: 000

List of Support Services v3 25-11-2018 Jodi Sariman

Appendix K: Written Interview Phase One

Interview Schedule

1. Please tell me a little about yourself.

Prompts:

- how would you describe yourself?
- what are your likes/dislikes (eg. music, movies), friends, school/work/college/TAFE/Uni, family, interests

I want you to think back to the beginning of this experience of having cancer.

2. What are your clearest memories, both positive and negative, about that time?

Prompts:

- how were you told you had cancer and who told you?
- who did you speak to about your diagnosis?
- what were people's reactions?
- what were your interactions with health/hospital staff like?
- what were you thinking or feeling?
- what did you want to do?

3. What was most important to you at that time?

Prompts:

- practical issues (finances, housing, school/college/TAFE/Uni)
- relationships with friends and family
- what was going to happen to you
- if life was going to change.

4. How do you think living in (home town) affected what happened after your diagnosis?

Prompts:

- travel
- financial costs
- work
- school/college/TAFE/Uni
- friends and family - did they come with you?
    - were you separated from them?

Now I'd like you to think about the period of time when you were having treatment.

5. What are your clearest memories about having treatment?

Prompts:

- where you had your treatment
- treatment itself (side effects, physical reactions, pain, discomfort etc.)
- the staff you had contact with
- the significant people in your life (eg. family or friends) and your relationship with them while you were having treatment
- physical separation from friends and family and home town
- work
- school/college/TAFE/university

6. How do you think being from (home town) made things different for you during treatment?

Prompts:

- what was different for you compared to young people who lived in the city where you had treatment?

Please think about when your treatment finished, or when you were able to return home (if you did).

7. What was it like when your treatment finished or you returned home (or both)?

Prompts:

- what happened when treatment finished, or when you returned home
- what you were thinking or feeling
- your relationships with other people - family and friends, hospital/health staff
- work
- school/college/TAFE/Uni
- what you did.

Please think about what your life was like before you got cancer.

8. What changes do you think happened for you because of getting cancer?

Prompts:

- changes in life in general
- changes in you and how you see the world now
- changes in friends and family (and your relationships with them)
- changes in work, school/college/TAFE/Uni

- changes in your own physical abilities.

Please think about the whole experience from your cancer diagnosis to now.
9. As you look back on all that has happened for you with getting cancer and having treatment, how do you think being from (home town) affected your experience?

Prompts:

- your access to treatment - how easy or not it was to get to treatment
- your relationships with your friends and family
- work
- school/college/TAFE/Uni
- financially.

10. What advice would you give another young person living in a regional, rural or remote area if they got cancer?

11. What advice would you give social workers or other health staff about helping young people from regional, rural or remote areas when they get cancer?

12. This brings us to the end of the interview. Do you have any further comments you would like to make?

Thank you very much for your time.

Appendix L: Letter of Support Director of Oncology & Haematology CHHHS

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Appendix M: Letter of Support Director of Paediatrics CHHHS

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Appendix N: Letter of Support Director of Social Work CHHHS

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Appendix O: Letter of Support Director of Social Work QCH

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Appendix P: Letter of Support QCH Site Contact Phase Two

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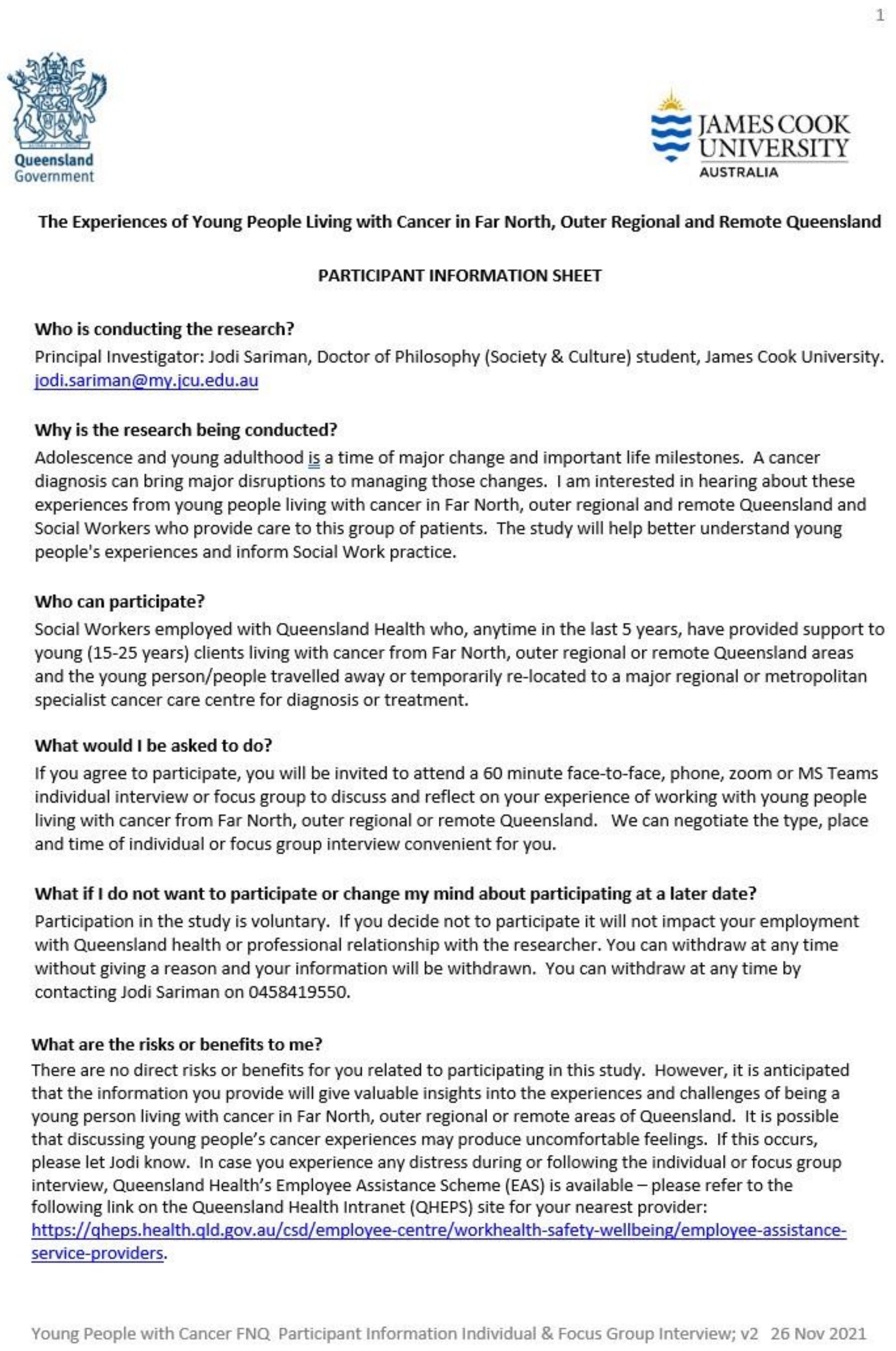
Appendix Q: Participant Information Sheet Phase Two



Queensland Government

JAMES COOK UNIVERSITY AUSTRALIA

The Experiences of Young People Living with Cancer in Far North, Outer Regional and Remote Queensland

PARTICIPANT INFORMATION SHEET

Who is conducting the research?

Principal Investigator: Jodi Sariman, Doctor of Philosophy (Society & Culture) student, James Cook University. jodi.sariman@my.jcu.edu.au

Why is the research being conducted?

Adolescence and young adulthood is a time of major change and important life milestones. A cancer diagnosis can bring major disruptions to managing those changes. I am interested in hearing about these experiences from young people living with cancer in Far North, outer regional and remote Queensland and Social Workers who provide care to this group of patients. The study will help better understand young people's experiences and inform Social Work practice.

Who can participate?

Social Workers employed with Queensland Health who, anytime in the last 5 years, have provided support to young (15-25 years) clients living with cancer from Far North, outer regional or remote Queensland areas and the young person/people travelled away or temporarily re-located to a major regional or metropolitan specialist cancer care centre for diagnosis or treatment.

What would I be asked to do?

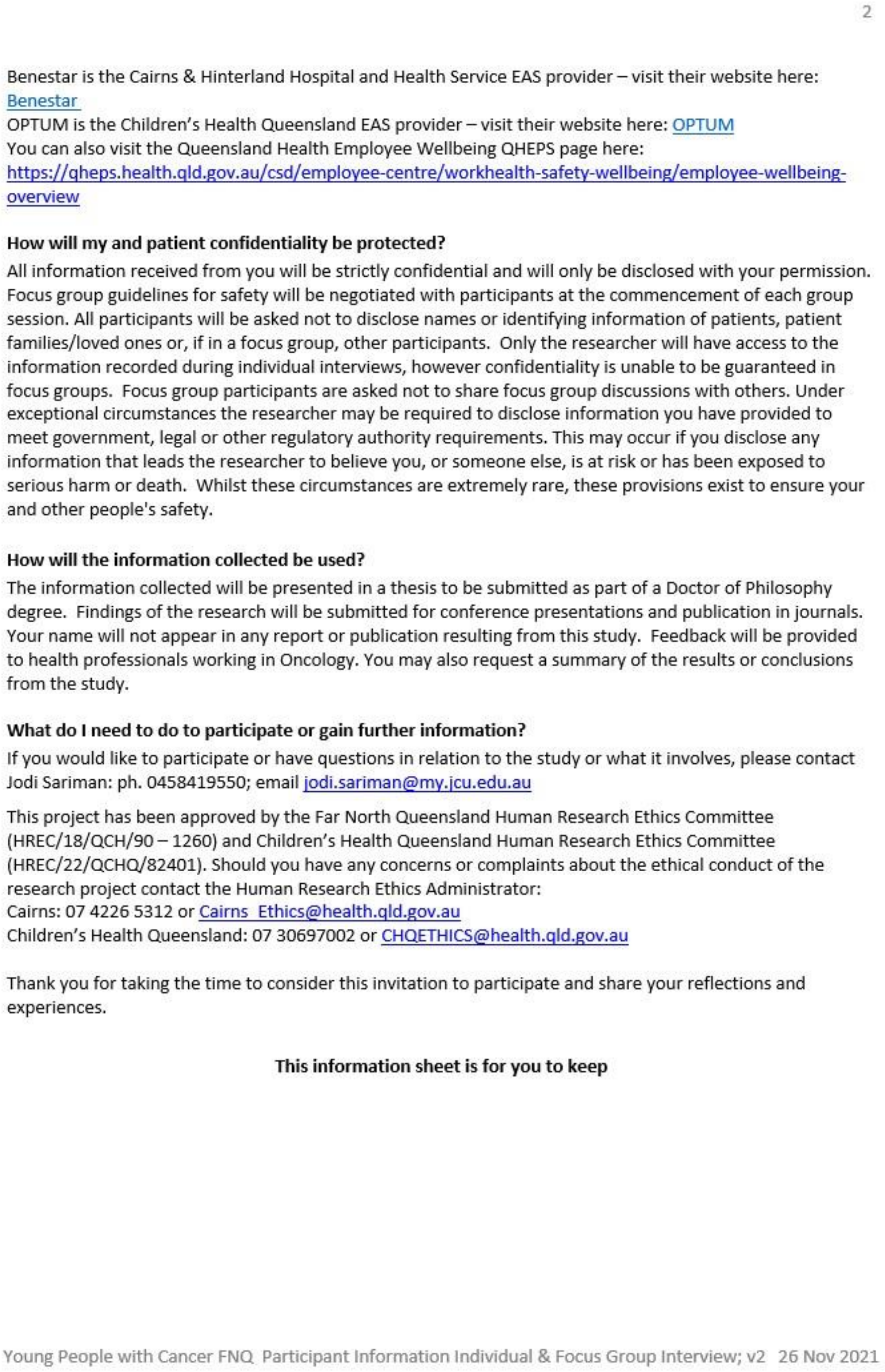
If you agree to participate, you will be invited to attend a 60 minute face-to-face, phone, zoom or MS Teams individual interview or focus group to discuss and reflect on your experience of working with young people living with cancer from Far North, outer regional or remote Queensland. We can negotiate the type, place and time of individual or focus group interview convenient for you.

What if I do not want to participate or change my mind about participating at a later date?

Participation in the study is voluntary. If you decide not to participate it will not impact your employment with Queensland health or professional relationship with the researcher. You can withdraw at any time without giving a reason and your information will be withdrawn. You can withdraw at any time by contacting Jodi Sariman on 0458419550.

What are the risks or benefits to me?

There are no direct risks or benefits for you related to participating in this study. However, it is anticipated that the information you provide will give valuable insights into the experiences and challenges of being a young person living with cancer in Far North, outer regional or remote areas of Queensland. It is possible that discussing young people's cancer experiences may produce uncomfortable feelings. If this occurs, please let Jodi know. In case you experience any distress during or following the individual or focus group interview, Queensland Health's Employee Assistance Scheme (EAS) is available – please refer to the following link on the Queensland Health Intranet (QHEPS) site for your nearest provider: https://qheps.health.qld.gov.au/csd/employee-centre/workhealth-safety-wellbeing/employee-assistance-service-providers.



Benestar is the Cairns & Hinterland Hospital and Health Service EAS provider – visit their website here: Benestar
OPTUM is the Children's Health Queensland EAS provider – visit their website here: OPTUM
You can also visit the Queensland Health Employee Wellbeing QHEPS page here:
https://qheps.health.qld.gov.au/csd/employee-centre/workhealth-safety-wellbeing/employee-wellbeing-overview

How will my and patient confidentiality be protected?

All information received from you will be strictly confidential and will only be disclosed with your permission. Focus group guidelines for safety will be negotiated with participants at the commencement of each group session. All participants will be asked not to disclose names or identifying information of patients, patient families/loved ones or, if in a focus group, other participants. Only the researcher will have access to the information recorded during individual interviews, however confidentiality is unable to be guaranteed in focus groups. Focus group participants are asked not to share focus group discussions with others. Under exceptional circumstances the researcher may be required to disclose information you have provided to meet government, legal or other regulatory authority requirements. This may occur if you disclose any information that leads the researcher to believe you, or someone else, is at risk or has been exposed to serious harm or death. Whilst these circumstances are extremely rare, these provisions exist to ensure your and other people's safety.

How will the information collected be used?

The information collected will be presented in a thesis to be submitted as part of a Doctor of Philosophy degree. Findings of the research will be submitted for conference presentations and publication in journals. Your name will not appear in any report or publication resulting from this study. Feedback will be provided to health professionals working in Oncology. You may also request a summary of the results or conclusions from the study.

What do I need to do to participate or gain further information?

If you would like to participate or have questions in relation to the study or what it involves, please contact Jodi Sariman: ph. 0458419550; email jodi.sariman@my.jcu.edu.au

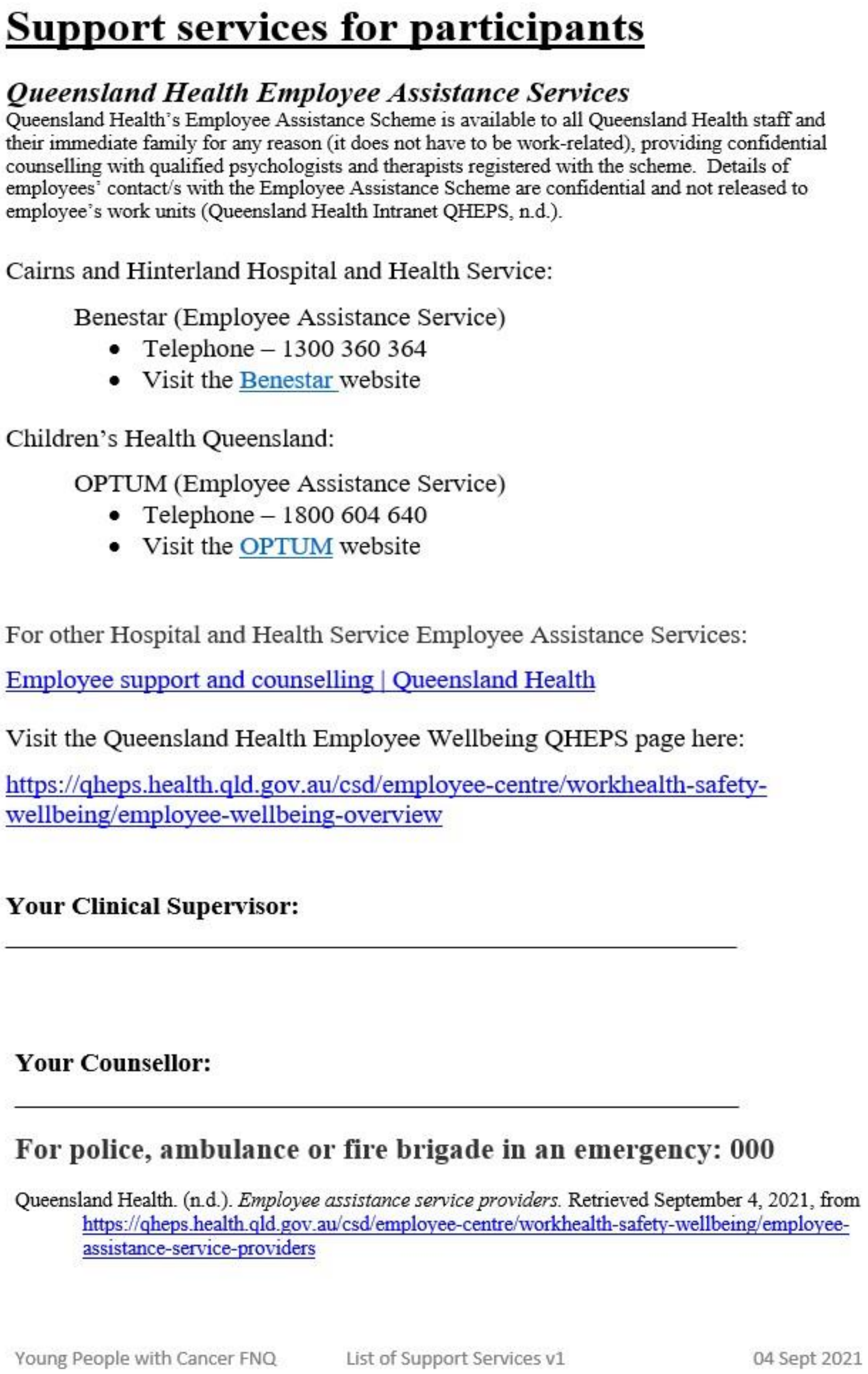
This project has been approved by the Far North Queensland Human Research Ethics Committee (HREC/18/QCH/90 – 1260) and Children's Health Queensland Human Research Ethics Committee (HREC/22/QCHQ/82401). Should you have any concerns or complaints about the ethical conduct of the research project contact the Human Research Ethics Administrator:
Cairns: 07 4226 5312 or Cairns_Ethics@health.qld.gov.au
Children's Health Queensland: 07 30697002 or CHQETHICS@health.qld.gov.au

Thank you for taking the time to consider this invitation to participate and share your reflections and experiences.

This information sheet is for you to keep

Appendix R: Participant Informed Consent Phase Two

Appendix S: List of Support Services for Participants Phase Two



Support services for participants

Queensland Health Employee Assistance Services

Queensland Health's Employee Assistance Scheme is available to all Queensland Health staff and their immediate family for any reason (it does not have to be work-related), providing confidential counselling with qualified psychologists and therapists registered with the scheme. Details of employees' contact/s with the Employee Assistance Scheme are confidential and not released to employee's work units (Queensland Health Intranet QHEPS, n.d.).

Cairns and Hinterland Hospital and Health Service:

Benestar (Employee Assistance Service)
- Telephone – 1300 360 364
- Visit the Benestar website

Children's Health Queensland:

OPTUM (Employee Assistance Service)
- Telephone – 1800 604 640
- Visit the OPTUM website

For other Hospital and Health Service Employee Assistance Services:

Employee support and counselling | Queensland Health

Visit the Queensland Health Employee Wellbeing QHEPS page here:

https://qheps.health.qld.gov.au/csd/employee-centre/workhealth-safety-wellbeing/employee-wellbeing-overview

Your Clinical Supervisor:

____

Your Counsellor:

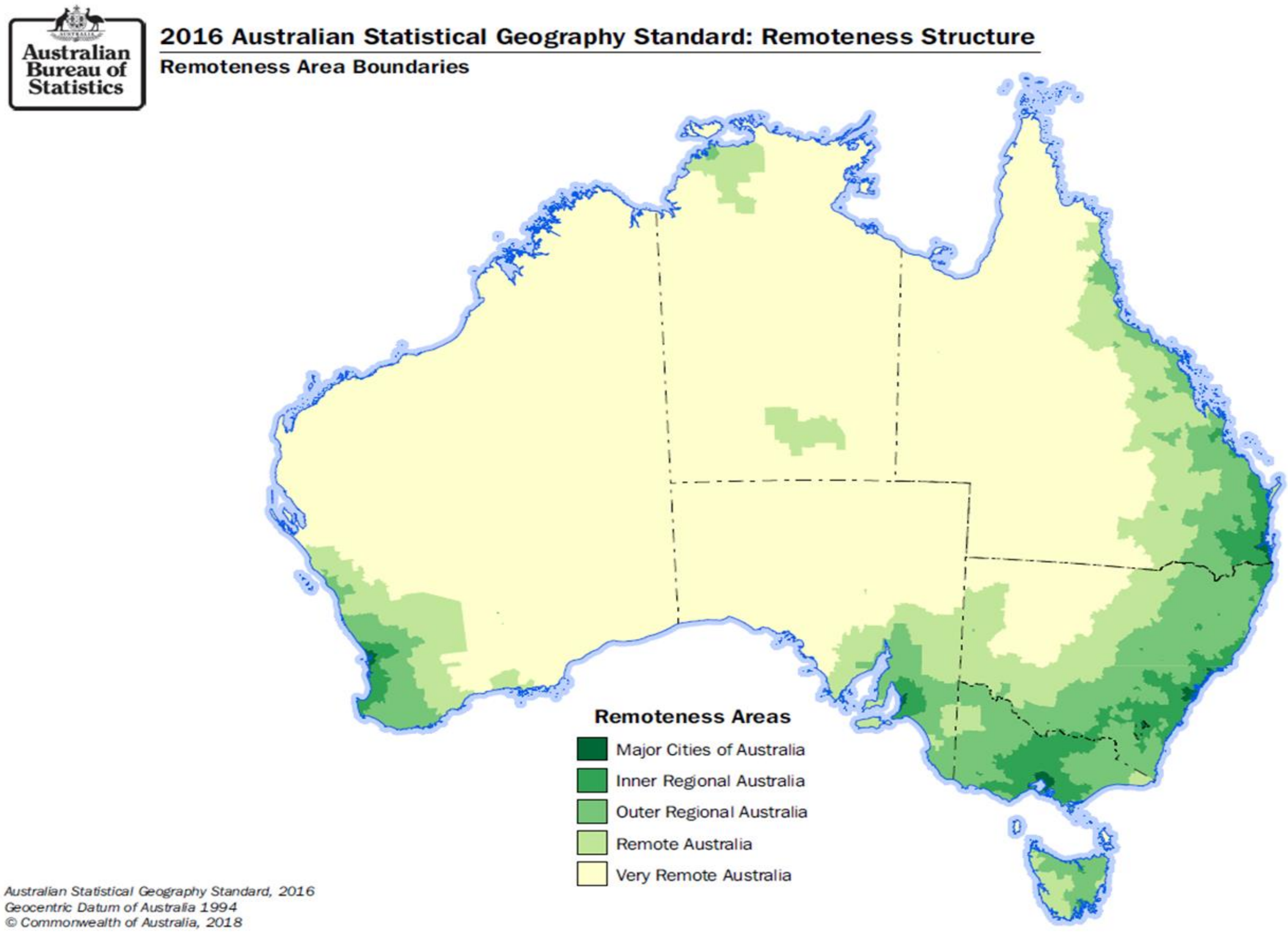
____

For police, ambulance or fire brigade in an emergency: 000

Queensland Health. (n.d.). *Employee assistance service providers.* Retrieved September 4, 2021, from https://qheps.health.qld.gov.au/csd/employee-centre/workhealth-safety-wellbeing/employee-assistance-service-providers

Young People with Cancer FNQ List of Support Services v1 04 Sept 2021

Appendix T: ASGS Remoteness Structure Australia Map (ABS, 2016)



Australian Statistical Geography Standard, 2016
Geocentric Datum of Australia 1994
© Commonwealth of Australia, 2018

Appendix U: My Connections Trial: QI Activity (Young People Living with Cancer in FNQ)

APPENDIX C: QI Registration and Completion Forms (Part A and Part B)

PART A: QI Registration (submit once approved)

A. Give a brief description of how the idea for the activity arose: (max 150 words)

Whilst working as the Paediatric/Paediatric Oncology Senior Social Worker, J Sariman identified the psycho-social difficulties children & young people living with cancer from Far North, Outer Regional and Remote areas, and their families, encounter having to re-locate to specialist cancer care centres in Major Regional and Metropolitan cities for their specialist cancer care. Caroline Witter, Paediatric NUM (now Paediatric Oncology Regional Case Manager) studied the vulnerability of the particular age-group of 15-25 year-olds living with cancer and identified service delivery gaps to this group in FNQ as part of studies undertaken in 2014 for a Graduate Certificate in Adolescent health and Well-being, majoring in Adolescent Oncology, with the University of Melbourne. This background led to research being undertaken by J Sariman exploring what the experience is like for young Far North Queenslanders living with cancer. The published research (Sariman et al., 2021), along with the ongoing practice experience of CHHHS Paediatric Oncology and Adult Oncology/Haematology nursing staff, has identified a gap in consistent supportive care for young people aged 15-25 years living with cancer in Far North Queensland accessing the CHHHS Paediatric Oncology and Adult/Haematology

B. Define the problem (problem statement): (max 150 words)

There is a current gap in consistent supportive care for young people aged 15-25 years living with cancer in Far North Queensland accessing the CHHHS Paediatric and Adult Oncology/Haematology (Liz Plummer Cancer Care Centre & Cairns Hospital Cancer Care Ward) services. A need is seen to develop a consistent approach across the two services. Current published research (Sariman et al., 2021) conducted in Far North Queensland with young people aged 15-25 living with cancer is available to guide initiatives to target supportive care to this group of patients.

C. Describe the proposed activity or intervention: (max 200 words)

Develop a consistent approach across CHHHS Paediatric Oncology and Adult Oncology/Haematology (Liz Plummer Cancer Care Centre & Cairns Hospital Cancer Care Ward) for young people aged 15-25 years living with cancer in Far North Queensland. An interventional resource will be developed and trialled for staff working with young people living with cancer in these services as a QI Activity.
The objective is to develop an evidence-based interventional resource, for use with young people from Far North Queensland aged 15-25 year living with cancer accessing the Paediatric Oncology and Adult Oncology/Haematology service to assist/support them through their cancer care experience.

D. How will this activity address the problem?

Young consumers aged 15-25 living with cancer in Far North Queensland will have consistent access to an evidence-based interventional resource to assist them through their cancer care experience regardless of whether accessing the Paediatric Oncology or Adult Oncology/Haematology services.

E. Is the activity likely to be transferable to other areas across the HHS?

☑ Yes ☐ No ☐ Maybe

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1 NB: This application may be completed and submitted online via the Riskman Quality Improvement Module

PLAN

Describe/title of the activity or intervention: (max 150 words)

Young People Living with Cancer in Far North Queensland "The In-Betweeners"

Location of the activity (be specific):

CHHHS, Cairns Hospital: Paediatric Oncology and Adult Oncology/Haematology Services

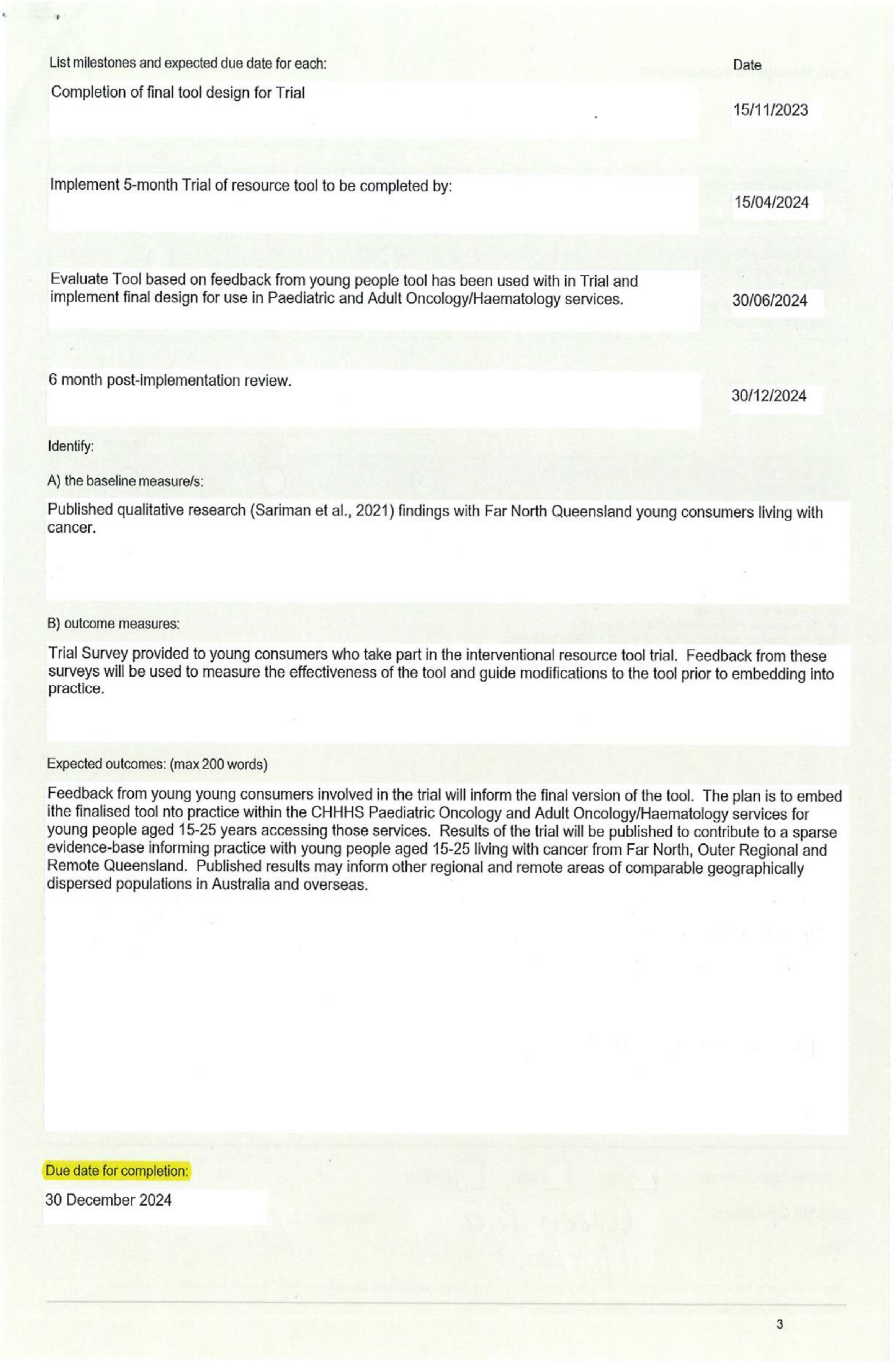
List the main tasks or steps required as part of the "doing" of the activity: (max 200 words)
This is not your "project plan" - it is an overview only

1. Using available evidence, including recent published research with young poeple living with cancer in Far North Queensland (Sariman et al., 2021) and resources in use with specialist cancer care support services working with young people like Canteen, Youth Cancer Service and Redkite, design an interventional tool for use with young people from Far North Queensland aged 15-25 years living with cancer accessing the Paediatric Oncology and Adult Oncology/Haematology services to assist/support them through their cancer care experience.
2. Design a feedback survey for young people involved in the trial to provide their feedback on the tool's effectiveness.
3. Trial the tool with young people accessing the Paediatric Oncology and Adult Oncology/Haematology services.
4. Analyse the feedback young people provide through the surveys on the effectiveness of the tool in assisting them through their cancer care experience.
5. Use analysed feedback to modify, as required, the tool and then embed into practice.

Identify the person/s responsible to undertake the task or steps within the activity: (max 150 words)

Please refer to Project Overview (Project on a Page) attached which provides a detailed breakdown of project goals, working group members and timeline for key project activities.

WORKING GROUP
Project Lead: J Sariman (Patient Safety Quality Officer)
Executive Sponsor: Tania Cavanagh (Executive Director of Allied Health)
Working Group: Caroline Witter (Regional Case Manager, Paediatric Oncology); Bridget Fearon (CN, Liz Plummer Cancer Care Centre); Ashleigh Burton (RN, Cairns Hospital Cancer Care Ward & Oncology Day Unit); Cas McIntyre (Senior Social Worker, Liz Plummer Cancer Care Centre); Jennifer Davis (Senior Psychologist, Liz Plummer Cancer Care Centre); Chaitali Dasai (Senior Social Worker, Paediatric Oncology); Liza Hodges (Aboriginal and Torres Strait Islander Senior Hospital Liaison Officer).



List milestones and expected due date for each:	Date
Completion of final tool design for Trial	15/11/2023
Implement 5-month Trial of resource tool to be completed by:	15/04/2024
Evaluate Tool based on feedback from young people tool has been used with in Trial and implement final design for use in Paediatric and Adult Oncology/Haematology services.	30/06/2024
6 month post-implementation review.	30/12/2024

Identify:

A) the baseline measure/s:

Published qualitative research (Sariman et al., 2021) findings with Far North Queensland young consumers living with cancer.

B) outcome measures:

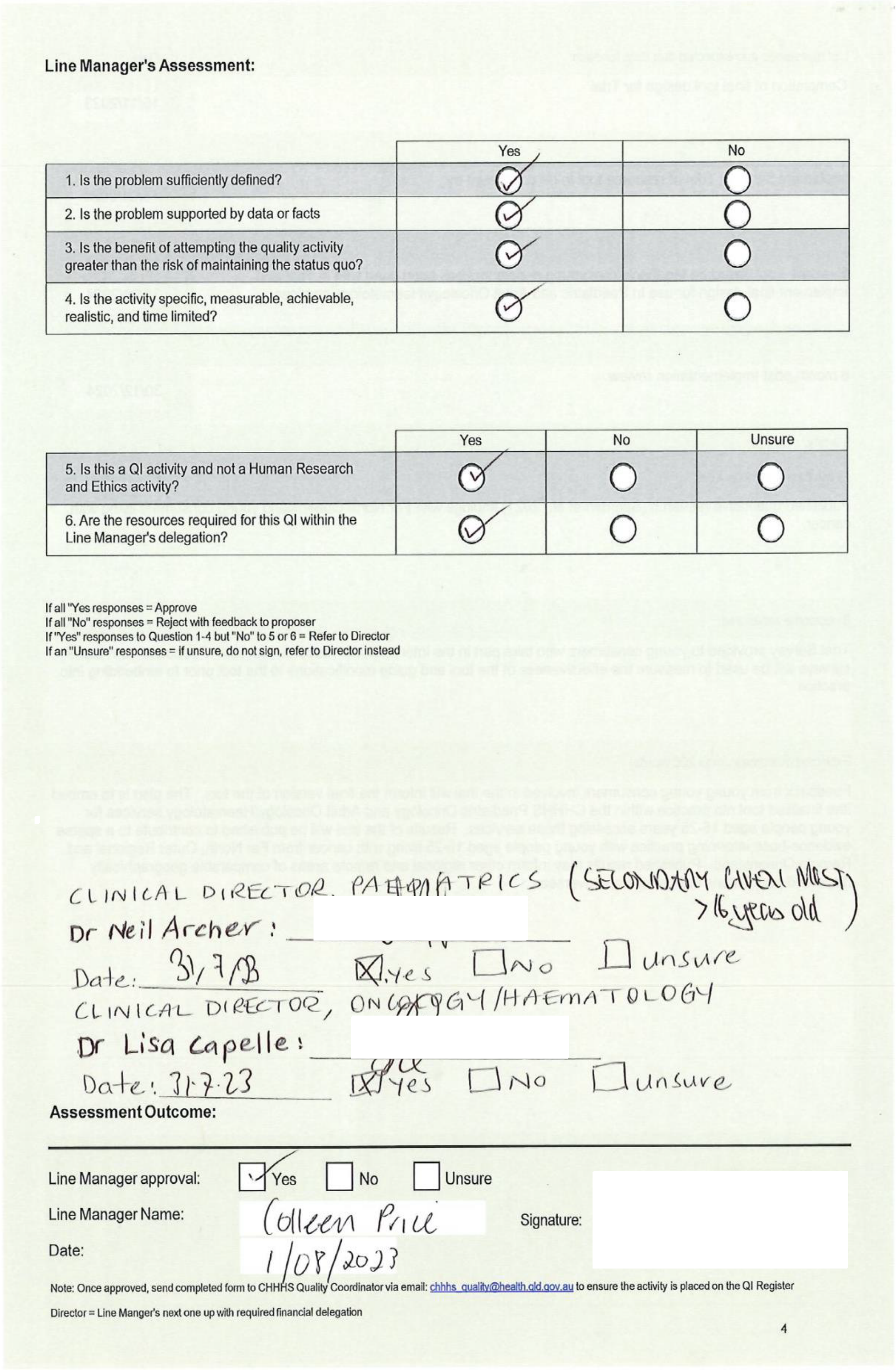
Trial Survey provided to young consumers who take part in the interventional resource tool trial. Feedback from these surveys will be used to measure the effectiveness of the tool and guide modifications to the tool prior to embedding into practice.

Expected outcomes: (max 200 words)

Feedback from young young consumers involved in the trial will inform the final version of the tool. The plan is to embed ithe finalised tool nto practice within the CHHHS Paediatric Oncology and Adult Oncology/Haematology services for young people aged 15-25 years accessing those services. Results of the trial will be published to contribute to a sparse evidence-base informing practice with young people aged 15-25 living with cancer from Far North, Outer Regional and Remote Queensland. Published results may inform other regional and remote areas of comparable geographically dispersed populations in Australia and overseas.

Due date for completion:

30 December 2024



Line Manager's Assessment:

	Yes	No
1. Is the problem sufficiently defined?	✓	○
2. Is the problem supported by data or facts	✓	○
3. Is the benefit of attempting the quality activity greater than the risk of maintaining the status quo?	✓	○
4. Is the activity specific, measurable, achievable, realistic, and time limited?	✓	○

	Yes	No	Unsure
5. Is this a QI activity and not a Human Research and Ethics activity?	✓	○	○
6. Are the resources required for this QI within the Line Manager's delegation?	✓	○	○

If all "Yes responses = Approve
If all "No" responses = Reject with feedback to proposer
If "Yes" responses to Question 1-4 but "No" to 5 or 6 = Refer to Director
If an "Unsure" responses = if unsure, do not sign, refer to Director instead

CLINICAL DIRECTOR. PAEDIATRICS (SECONDARY CAVEAT MOST >16 years old)
Dr Neil Archer: [redacted]
Date: 31/7/23 ☒ yes ☐ No ☐ unsure
CLINICAL DIRECTOR, ONCOLOGY/HAEMATOLOGY
Dr Lisa Capelle: [redacted]
Date: 31.7.23 ☒ yes ☐ No ☐ unsure

Assessment Outcome:

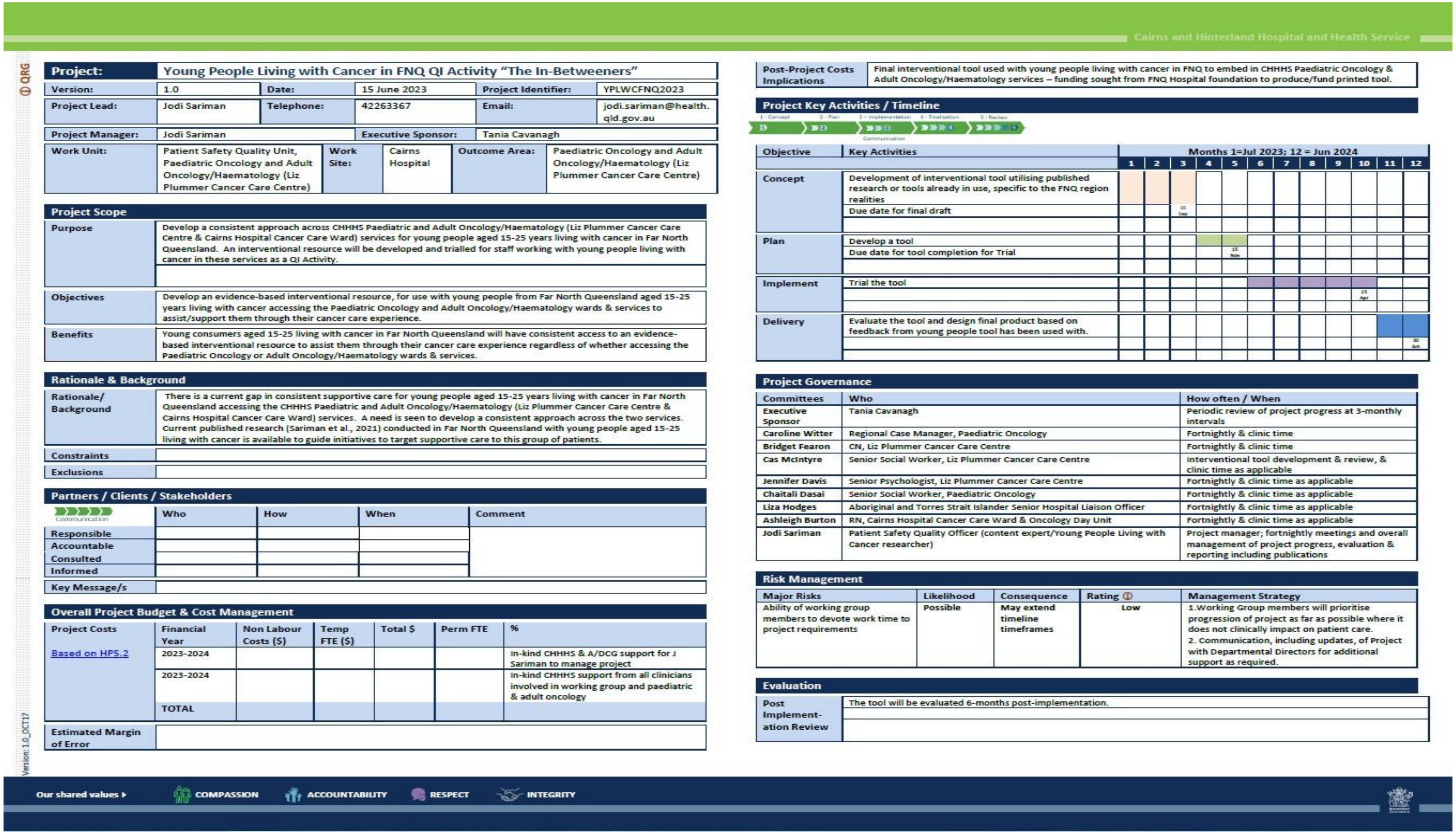
Line Manager approval: ☑ Yes ☐ No ☐ Unsure
Line Manager Name: Colleen Price
Signature: [redacted]
Date: 1/08/2023

Note: Once approved, send completed form to CHHHS Quality Coordinator via email: chhhs_quality@health.qld.gov.au to ensure the activity is placed on the QI Register

Director = Line Manger's next one up with required financial delegation

4

Appendix V: My Connections Trial: Project Plan “The In-Betweeners”



Cairns and Hinterland Hospital and Health Service

QRG

Project:	**Young People Living with Cancer in FNQ QI Activity “The In-Betweeners”**				
Version:	1.0	**Date:**	15 June 2023	**Project Identifier:**	YPLWCFNQ2023
Project Lead:	Jodi Sariman	**Telephone:**	42263367	**Email:**	jodi.sariman@health.qld.gov.au
Project Manager:	Jodi Sariman	**Executive Sponsor:**	Tania Cavanagh		

Work Unit:	Patient Safety Quality Unit, Paediatric Oncology and Adult Oncology/Haematology (Liz Plummer Cancer Care Centre)	**Work Site:**	Cairns Hospital	**Outcome Area:**	Paediatric Oncology and Adult Oncology/Haematology (Liz Plummer Cancer Care Centre)

Project Scope

Purpose	Develop a consistent approach across CHHHS Paediatric and Adult Oncology/Haematology (Liz Plummer Cancer Care Centre & Cairns Hospital Cancer Care Ward) services for young people aged 15-25 years living with cancer in Far North Queensland. An interventional resource will be developed and trialled for staff working with young people living with cancer in these services as a QI Activity.
Objectives	Develop an evidence-based interventional resource, for use with young people from Far North Queensland aged 15-25 years living with cancer accessing the Paediatric Oncology and Adult Oncology/Haematology wards & services to assist/support them through their cancer care experience.
Benefits	Young consumers aged 15-25 living with cancer in Far North Queensland will have consistent access to an evidence-based interventional resource to assist them through their cancer care experience regardless of whether accessing the Paediatric Oncology or Adult Oncology/Haematology wards & services.

Rationale & Background

Rationale/ Background	There is a current gap in consistent supportive care for young people aged 15-25 years living with cancer in Far North Queensland accessing the CHHHS Paediatric and Adult Oncology/Haematology (Liz Plummer Cancer Care Centre & Cairns Hospital Cancer Care Ward) services. A need is seen to develop a consistent approach across the two services. Current published research (Sariman et al., 2021) conducted in Far North Queensland with young people aged 15-25 living with cancer is available to guide initiatives to target supportive care to this group of patients.
Constraints	
Exclusions	

Partners / Clients / Stakeholders

Communication	**Who**	**How**	**When**	**Comment**
Responsible				
Accountable				
Consulted				
Informed				
Key Message/s				

Overall Project Budget & Cost Management

Project Costs	**Financial Year**	**Non Labour Costs ($)**	**Temp FTE ($)**	**Total $**	**Perm FTE**	**%**
Based on HP5.2	2023-2024					In-kind CHHHS & A/DCG support for J Sariman to manage project
	2023-2024					In-kind CHHHS support from all clinicians involved in working group and paediatric & adult oncology
	TOTAL					
Estimated Margin of Error						

Version:1.0_OCT17

Post-Project Costs Implications	Final interventional tool used with young people living with cancer in FNQ to embed in CHHHS Paediatric Oncology & Adult Oncology/Haematology services – funding sought from FNQ Hospital foundation to produce/fund printed tool.

Project Key Activities / Timeline

Objective	**Key Activities**	**Months 1=Jul 2023; 12 = Jun 2024**											
		1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
Concept	Development of interventional tool utilising published research or tools already in use, specific to the FNQ region realities	■	■	■									
	Due date for final draft			15 Sep									
Plan	Develop a tool				■	■							
	Due date for tool completion for Trial					15 Nov							
Implement	Trial the tool						■	■	■	■	■		
											15 Apr		
Delivery	Evaluate the tool and design final product based on feedback from young people tool has been used with.											■	■
													30 Jun

Project Governance

Committees	**Who**	**How often / When**
Executive Sponsor	Tania Cavanagh	Periodic review of project progress at 3-monthly intervals
Caroline Witter	Regional Case Manager, Paediatric Oncology	Fortnightly & clinic time
Bridget Fearon	CN, Liz Plummer Cancer Care Centre	Fortnightly & clinic time
Cas McIntyre	Senior Social Worker, Liz Plummer Cancer Care Centre	Interventional tool development & review, & clinic time as applicable
Jennifer Davis	Senior Psychologist, Liz Plummer Cancer Care Centre	Fortnightly & clinic time as applicable
Chaitali Dasai	Senior Social Worker, Paediatric Oncology	Fortnightly & clinic time as applicable
Liza Hodges	Aboriginal and Torres Strait Islander Senior Hospital Liaison Officer	Fortnightly & clinic time as applicable
Ashleigh Burton	RN, Cairns Hospital Cancer Care Ward & Oncology Day Unit	Fortnightly & clinic time as applicable
Jodi Sariman	Patient Safety Quality Officer (content expert/Young People Living with Cancer researcher)	Project manager; fortnightly meetings and overall management of project progress, evaluation & reporting including publications

Risk Management

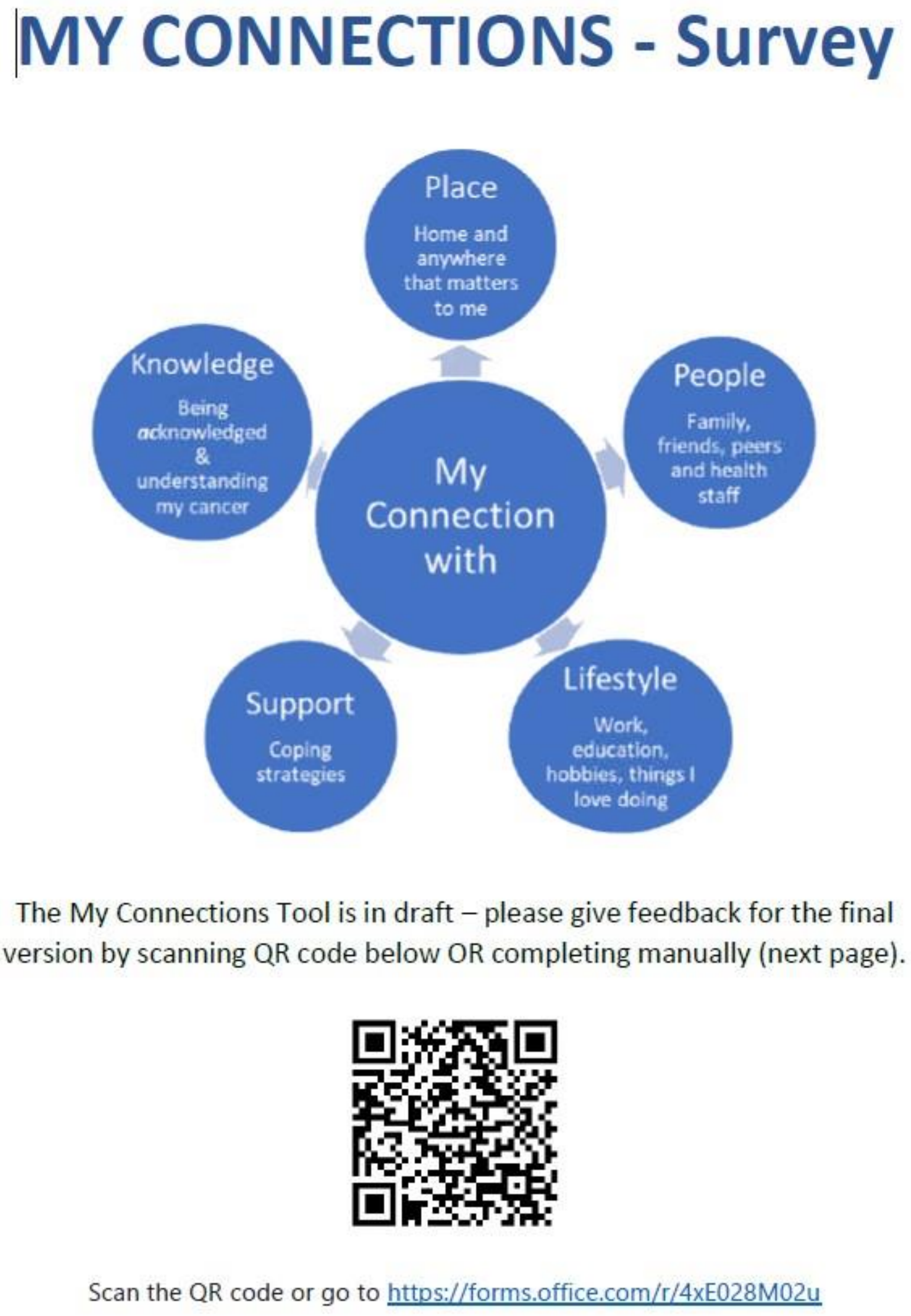
Major Risks	**Likelihood**	**Consequence**	**Rating**	**Management Strategy**
Ability of working group members to devote work time to project requirements	Possible	May extend timeline timeframes	Low	1.Working Group members will prioritise progression of project as far as possible where it does not clinically impact on patient care. 2. Communication, including updates, of Project with Departmental Directors for additional support as required.

Evaluation

Post Implement-ation Review	The tool will be evaluated 6-months post-implementation.

Our shared values ▸ COMPASSION ACCOUNTABILITY RESPECT INTEGRITY

Appendix W: My Connections Survey page 1

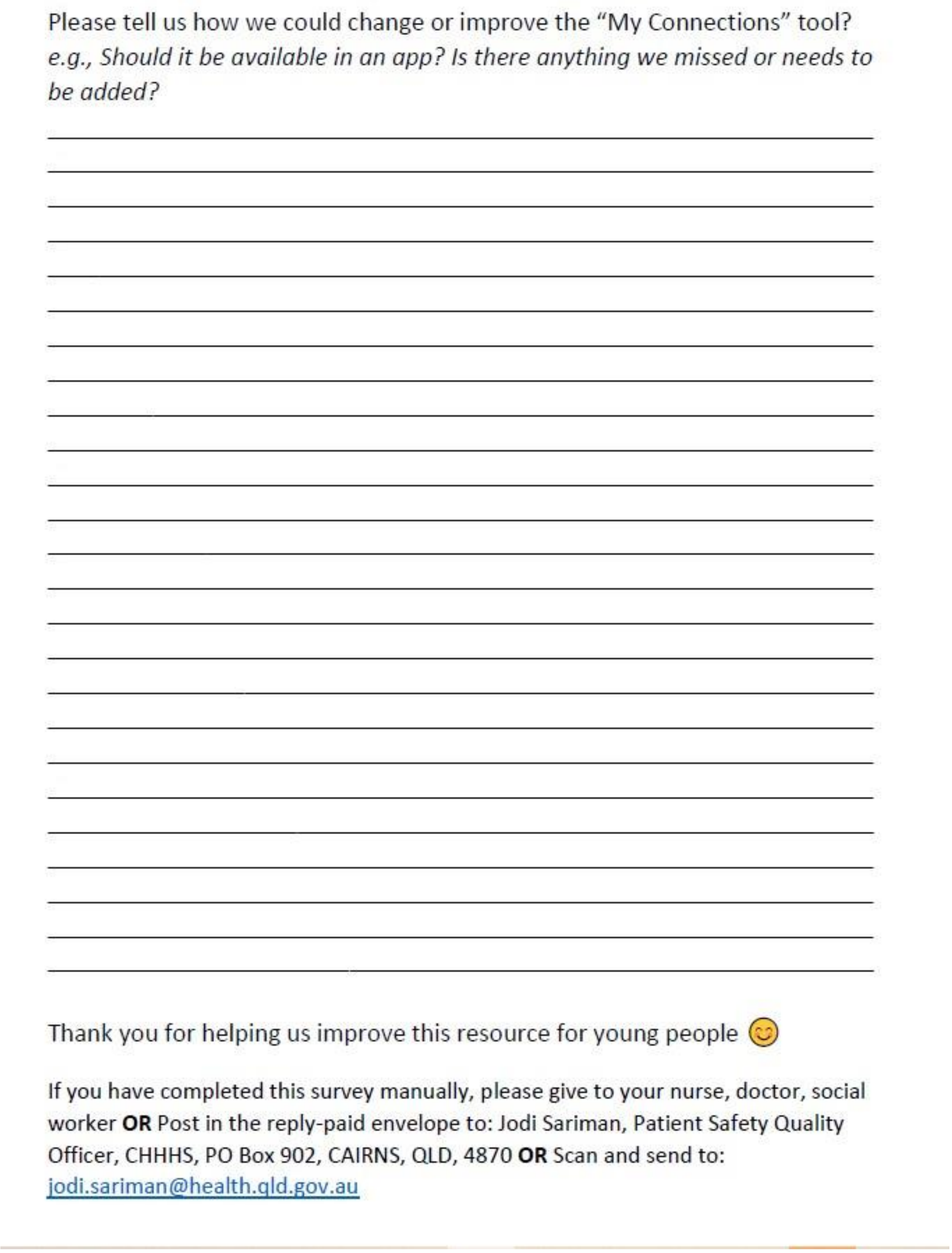


MY CONNECTIONS - Survey

The My Connections Tool is in draft – please give feedback for the final version by scanning QR code below OR completing manually (next page).

Scan the QR code or go to https://forms.office.com/r/4xE028M02u

My Connections Survey page 2



Please tell us how we could change or improve the “My Connections” tool? *e.g., Should it be available in an app? Is there anything we missed or needs to be added?*

Thank you for helping us improve this resource for young people 😊

If you have completed this survey manually, please give to your nurse, doctor, social worker **OR** Post in the reply-paid envelope to: Jodi Sariman, Patient Safety Quality Officer, CHHHS, PO Box 902, CAIRNS, QLD, 4870 **OR** Scan and send to: jodi.sariman@health.qld.gov.au