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Access to Australian community palliative care services: The influence of peri-urban location

Submitted by Shirley Papavasiliou

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Generative AI technology was not used in the preparation of any part of this thesis.

Statement of Originality

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university; and to the best of my knowledge and belief this thesis does not contain any material previously published or written by another person except where due reference is made in the text.

Abstract

Background

Evidence supports the benefits of palliative care provision for people diagnosed with a life-limiting illness and their family caregivers (Borbasi, 2017). Palliative care with a person-centred approach aims to optimise quality of life by prioritising the needs and values of individuals in every interaction with healthcare services. Ensuring that every person has access to the healthcare they need, when and where they need it, is recognised as a basic human right (World Health Organization [WHO], 2021). Inequities of access to healthcare services in rural and remote areas of Australia are well known (Australian Institute of Health and Welfare [AIHW], 2019). Peri-urban areas, in particular, offer a rural lifestyle in proximity to urban centres and have witnessed a surge in popularity and unprecedented population growth, impacting the provision of healthcare services. This research suggests that barriers to accessing community palliative care services in peri-urban locations are less understood and require exploration. This dissertation will argue that current classifications of location used to determine palliative care service policy, methods of delivery and allocation of resources, fail to consider the heterogeneity and complexities of peri-urban locations.

Methodology

An exploratory, inductive and interpretative approach to the research was adopted to develop and administer an online web-based Qualtrics survey for data collection. The aim was to understand the barriers to access from the perceptions of providers and consumers of community palliative care in peri-urban locations. Thematic analysis was adopted to find the participant meaning in the qualitative data, while descriptive statistical analysis tools were used to analyse the quantitative data to support the identified reality of participants. Participants included health practitioners (n = 50), family caregivers (n = 91) and patients (n = 30) patients.

Findings

This research identified a number of key issues influencing community palliative care provision in peri-urban locations. The barriers to access, known to exist in rural Australia, were also identified in peri-urban areas, with the home location viewed by both practitioners and caregivers as an obstacle to accessing required services. The distance and time involved in travel influenced decision-making and choice of location for care and place of death. Practitioners described the physical and emotional risks they suffered from their perception of an inability to provide appropriate care to clients. Caregivers voiced frustration and described increased carer stress that they attributed to unmet needs. Therefore, this research contributes to knowledge by identifying the need for service providers to consider some of these complexities of peri-urban locations in policy.

Research Limitations

The voluntary participation in the survey could represent respondent bias, potentially contaminating results; participants may have been motivated by a desire to voice grievances.

Significance

The risk for physical and emotional distress is real for those individuals seeking palliative care but facing accessibility barriers. The removal of personal choice and preferences in care, treatment and locations for care and death has the potential to impede quality of life, wellbeing, and the grieving process. The demand and need for community palliative care services is increasing and policy recommendations play a critical role in removing barriers due to geographic location.

Keywords

Palliative care, Community care, Peri-urban, End-of-Life, barriers to access

Glossary of Key Terms

Access: Levesque et al.'s (2013b) conceptualisation of access to healthcare was used to support this research. It recognises access as a complex framework with integrated barriers identified by 5 dimensions from both the provider (supply side) and the individual (demand side). The 5 dimensions of accessibility are influenced by the corresponding dimensions or determinants of abilities of the population to utilise healthcare services. Access is viewed as the possibility to identify healthcare needs; seek, obtain or use services; reach resources; and be offered appropriate health services to fulfil needs (Levesque et al., 2013b).

Anticipatory grief: This refers to the distress a person may feel prior to their own death or the death of a loved one. It's also called preparatory grief (Johns, 2015).

Anticipatory prescribing: These are measures and/or medication put in place by clinicians to meet predicted acute events during the palliative journey (Ding et al., 2019).

Bereavement: This broad term encompasses the entire experience of family members and friends in the anticipation and adjustment following the death of a loved one (Christ et al., 2003).

Choice: In healthcare, this refers to the concept that individuals can make informed decisions about their care and services. Choice is a cornerstone of person-centred care and is essential for promoting autonomy, satisfaction and quality-of-life by provision of care tailored to meet individual needs, wishes and preferences, including choice of provider and location for care (Kozikowski et al., 2022; Zolkefli, 2017)

Community palliative care: Community or home-based palliative care is care provided to individuals diagnosed with a life-limiting illness and their families, outside the hospital setting (Kamal et al., 2013). The alternative setting, or place of residence might include owned or rented personal residences, retirement villages and other communal living arrangements such as mobile homes, caravans, cars and other locations as appropriate for people who are experiencing homelessness. For the purpose of this research, residences which generally have access to clinical support 24/7 will be excluded, including residential aged care facilities, correctional facilities, remand centres and detention centres, group homes and, other specialist housing for people with a disability or those experiencing severe mental illness (PCA, 2018b).

Complex grief: This is a syndrome which is chronic and debilitating, and results in significant distress and impairment following the death of a loved one. Symptoms consist of a sense of disbelief regarding the death, persistent intense longing and separation distress, a sense of meaninglessness, trouble accepting the reality of the loss, and yearning for and preoccupation with the deceased (Holland & Neimeyer, 2010). It is also referred to as prolonged, pathological, complicated or traumatic grief.

Controlled medicine: This is also known as a controlled drug, drug of dependence, scheduled medicine, controlled poison or narcotic substance. It is a medication that is scheduled under the national classification system (Poisons Standard) according to the level of regulatory control over the availability of the medicine (Caring@home, 2020).

End-of-life care: Generally, this refers to the last few weeks of life in which a patient is rapidly approaching death. The needs of the patient and their caregivers are higher at this time (PCA, 2015).

Family: The concept of family encompasses the biological family, the family acquired by marriage/contract, and the family of choice (including pets) and friends. ‘Family caregivers’ refers to those identified as closest to the patient in knowledge, care and affection. The patient defines who will be involved in their care (Canadian Hospice Palliative Care Nursing Standards Committee, 2014).

Family/caregiver: A relative, friend or partner who has a significant personal relationship and provides assistance (physical, social and/or psychological) to a person with a life-threatening illness. They may or may not reside with the person receiving care and may be primary or secondary family caregivers (Becqué et al., 2021).

Greenfield areas: These are areas on the urban fringe that are zoned for future urban development. In these areas, infrastructure, policies and actions are identified that require resolution prior to planned residential development (Attorney-General's Department, 2021).

Healthcare professional: Aso referred to as a clinician, for the purpose of this research, the term healthcare professional covers a wide range of professions, including doctors, nurses, physiotherapists, pharmacists, occupational therapists, dietitians, volunteers, carers and more. Their involvement and level of expertise varies depending on the complexity of patients’ needs (KPMG, 2020). Some specialise in palliative care as a full-time role and others will have palliative care as a part of their daily work.

Health inequity: This is the disparities in health between population groups that are avoidable, unfair and unjust (Dahlgren & Whitehead, 2006).

Imprest stock: This refers to the emergency medication supplied to establish and maintain a stock of medications for use elsewhere (Caring@home, 2020)

Life-limiting illness: This is an overarching term that encompasses all conditions appropriate for hospice or palliative care, sometimes termed terminal illness. It refers to any illness that can reasonably be expected to result in death within a foreseeable future (Macauley, 2019). It includes both malignant and non-malignant illnesses.

Model of service delivery: This describes the mode or method in which healthcare is delivered - either face-to-face, remotely via digital health, or a combination of both. It is related to the model of care utilised (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2021c).

Model of care: This is a multifaceted concept which broadly defines the way health services are delivered to ensure best practice patient care (Agency for Clinical Innovation (ACI), 2013)

Multidisciplinary team (MDT): This refers to the team approach to palliative care. Individuals have clearly defined responsibilities within a team of professionals from multiple disciplines, who function independently with discipline-specific goals and treatment (Bowen, 2014).

Palliative approach: This is when the primary focus shifts from life-prolonging treatments towards symptom management and improving quality of life. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying (Royal Australian College of General Practitioners (RACGP), 2023).

Palliative care: This is the holistic care provided to a person diagnosed with a life-limiting illness and their family members and caregivers. It is also known as comfort care, as the aim is not to provide a cure but to optimise quality of life and reduce suffering of patients and their families (WHO, 2020a).

Peri-urban: For the purpose of this research, the term peri-urban will be used to describe the outer metropolitan fringe space between metropolitan and rural surrounds, which has experienced increased residential development.

Person-centred care: This refers to healthcare which actively includes the patient and the family in the decision-making process for care and treatment, recognising the right of patients to make decisions and choices. It is also known as patient-centred care and person and family centred care and respects individual preferences and diversity (ACSQHC, 2023b)

Place: This refers to the specific location or setting where treatment and care is provided, or death occurs. It reflects the personal wishes and physical needs of the person involved. The term is inclusive of hospital and hospice settings, owned or rented personal residences, retirement villages and other living arrangements such as mobile homes, caravans and care facilities (Gu & Wang, 2020).

Preterminal: This generally refers to the phase of relative stability or minor decline, prior to the rapid decline that ends with death (Cohen-Mansfield et al., 2017).

Primary care: This refers to the health services and staff that have a primary or 'first contact' relationship and may undertake an ongoing role in the support of patients (F. Gardiner et al., 2020). The term is inclusive of general practitioners, community nurses, and specialist services including oncologists, renal, cardiac or respiratory physicians and acute care staff.

Psychosocial care: This type of care is concerned with the psychological and emotional wellbeing of patient and family/caregivers, including issues of self-esteem, social functioning, insight into an adaption to illness and its consequences (Hudson et al., 2010).

Specialist palliative care service: In this research, the term refers to the specialist multidisciplinary practice of palliative care and the designated service system developed and funded to deliver that care which differs by organisation, state and territory (Michael et al., 2016).

Terminal phase: Often termed end-of-life, the terminal phase is generally the last few weeks of life in which a patient is rapidly approaching death. The terminal phase refers to the specific phase of the last days or hours when the patient is recognised as imminently dying. The needs of the patient and their carers are higher at this time, requiring increased support and services (PCA, 2015).

Urban: This is generally defined by population density and size, and accessibility to goods and services using statistical data. It may be referred to as metropolitan or suburban or as a town or city area (ABS, 2016b).

Rural: This refers to those areas which are not part of any urban area in the Australian Statistical Geography Standard (ASGS) (Australian Bureau of Statistics (ABS), 2016a). It often refers to areas of open land used for agricultural purposes, with low density housing and population (National Geographic, 2024).

Table of Contents

Table of Figures

Table of Tables

Chapter 1: Introduction and thesis overview

1.1 Aim of the study

The aim of the research is to understand if choice of home location in a peri-urban area influences access to community palliative care services. The inequities of access related to rural and remote Australia are well known, and often termed the urban–rural divide (Rainsford, 2019). What is less understood, however, is how rapid acceleration in population growth in areas on the fringes of urban and regional centres influences access to services. Often termed peri-urban areas, these locations are a popular choice for relocation, offering affordable housing in a rural environment but still within close proximity to urban centres (McFarland, 2015). Residential development planning includes the infrastructure and services needed to meet the needs of new communities; however, infrastructure and service growth in peri-urban locations has consistently lagged behind the housing construction (Kent et al., 2019; Newton et al., 2017).

Peri-urban health services, including local hospitals, are generally smaller facilities with less available infrastructure, a limited workforce, poor access to specialist care, and a reliance on generalist primary healthcare providers (Bradford et al., 2016; Wenham et al., 2020). Residential development changes the land use and occurs as land becomes available, subsequently blurring the lines between urban and rural when defining peri-urban locations (Meeus & Gulinck, 2008). Health service planning assumes that the close proximity to metropolitan centres is an advantage for peri-urban residents; it plans modes of service delivery with the expectation that patients will travel to receive these services. This expectation follows the need for planners to provide a fair distribution of limited resources to locations and services considered to be in most need; in Australia, that means, urban centres (Garrard, 1996). Peri-urban locations, however, remain partially rural and the inconsistencies with funding and allocation of resources to these locations and to palliative care invoke questions of fairness (Simon, 2008). Feedback sought by health services from clinicians and consumers regarding service delivery aids program development; however, it also has the potential for bias and does not necessarily reflect actual needs (Weng et al., 2022).

This research seeks to explore the perceptions and views of health professionals, family caregivers and patients on accessing effective, person-centred, community palliative care services. The complexities involved in palliative and end-of-life care provision invoke potentially differing priorities, needs and perspectives among all individuals and services involved. Health professionals are in the unique position of understanding access barriers from a systemic, workplace and patient viewpoint. Family caregivers are central to the care needs of a palliative patient throughout the journey and, to optimise quality of life, will need to interact with the healthcare system to access required resources (Appelin et al., 2005). However, what constitutes required resources differs for every patient, influenced by the presence or absence of personal support, knowledge of palliative care, needs, preferences and culture (Maxwell et al., 2022).

Regardless of the differences, every viewpoint is important for gaining an understanding of the barriers to accessing quality community palliative care in peri-urban locations. Understanding barriers may guide future peri-urban health policies which influence patient and family caregiver accessibility to in-home palliative services, choice of end-of-life care, place of death, quality of life and bereavement services (Saurman et al., 2022). This chapter will introduce the study and provide an overview of the following chapters.

1.2 Research questions

The objective of this research is to create recommendations that address any identified discrepancies in policies and practices to ensure that best practice in community palliative care services is maintained in peri-urban locations. Key research questions have been formulated to identify if a relationship exists between peri-urban locations and barriers to provision of person-centred in-home palliative care.

To reach the aim of the study, the following overall research question was developed:

How does counter-urbanisation influence community palliative care provision in peri-urban Australia?

To help address this overall research question, a set of additional research questions were formulated:

- How are peri-urban areas defined?
    - How is a peri-urban location defined in community health policies?
- What are the key influences of counter-urbanisation on community palliative care accessibility in peri-urban Australia?
- What role does digital technology play in peri-urban community palliative care delivery?
- Do patients’ and family members’ expectations of peri-urban community in-home palliative care differ to the care that health professionals provide?
- How does location influence accessibility to in-home palliative care services?

1.3 Background

In Australia in the mid-1990s, a trend of internal migration emerged, with people moving away from densely populated urban areas (Amirinejad et al., 2018; Nygaard & Parkinson, 2021; Ruiz-Martínez & Esparcia, 2020). This trend, termed 'counter-urbanisation', has seen people enticed to relocate for reduced housing prices and a lifestyle change (Davies, 2021; Guaralda et al., 2020). In recent times, this trend has been linked with COVID-19, as people fled the major cities following the implementation of infection control measures, including lockdowns, social isolation requirements and orders to work from home (Amirinejad et al., 2018; Attorney-General's Department, 2021; Davies, 2021; McManus, 2022). Financial year data from 2020–21 reflects the influence of COVID-19 in accelerating Australian internal migration, although it is unclear if the response will remain a temporary or a permanent transition as control measures have been gradually removed (ABS, 2022c; Davies, 2021; Guaralda et al., 2020; McManus, 2022).

Regardless of the reasons behind the trend, counter-urbanisation has resulted in accelerated growth outside of Australian major cities and a blurring of the lines between the previously distinct categories of urban and rural (Guaralda et al., 2020; Hugo, 2002; McManus, 2022). The resulting potential for uncontrolled urban sprawl has been restrained to some extent, by State and Territory government development plans and policies (Australian Digital Health Agency, 2021). New residential developments in peri-urban areas are co-located with major and local road network expansion to improve accessibility to urban centres (Brousselle et al., 2020; Department of the Treasury, 2021). The term 'peri-urban' is not clearly defined but it generally refers to those areas at the broad interface between metropolitan and rural surrounds, which encompass diverse locations, a range of land uses and a variety of communities (Liu & Robinson, 2016).

Peri-urbanisation generally refers to the transitional process whereby rural areas on the fringe of urban centres, change in physical, economic and social terms to become more urban in character (Simon, 2020; Webster & Muller, 2009). The prefix peri is derived from the Greek *peri,* meaning around, enclosing or near, so the term translates to mean urbanisation processes on the urban fringe (Follmann, 2022). These areas often remain categorised as rural due to the challenges associated with their distance from major cities, despite being deemed within the urban sprawl and accessible to services using improved road networks (Attorney-General's Department, 2021; Liu & Robinson, 2016).

Healthcare and resource allocation in Australia have historically followed the approach of service delivery for defined populations based on geographic statistical data provided by the

ABS (PCA, 2005; Senate Standing Committee on Community Affairs, 2007). This data classifies locations as urban and non-urban based on spatial units aggregated by population density and remoteness using a calculation of indexed accessibility to urban service centres (Senate Standing Committee on Community Affairs, 2007). The Australian Institute of Health and Welfare (AIHW) releases data at a range of geographical levels from States and Territories to smaller areas which improve understanding for clinicians and policymakers at a local level (AIHW, 2022b). Data used at a local level includes ABS statistical data, incorporating Estimated Resident Population (ERP), and localised data including Primary Health Network (PHN) areas, Local Health Network (LHN) areas and Local Government Areas (LGAs) (AIHW, 2022b). Peri-urban areas are not currently viewed as separate locations in geographic statistical data calculations; rather, they are considered a continuation of their surrounding urban or rural areas.

Areas of increased population growth and residential development can be identified using ABS data, which provides evidence of increased population growth and dwelling density (ABS, 2022a). Using current statistical data generated from current geographic classifications as a standalone measure to determine the character of an area and the needs of individual communities, however, can be misleading and result in difficulties for policymakers (Wood et al., 2023). Although statistical data may highlight an increased population in a rural area, the relative proximity of a location to metropolitan services can influence the model of health service delivery adopted by providers. Health providers may recognise the increased urban style growth in a rural area but continue to provide a rural mode of healthcare delivery under the belief that specialised healthcare is readily accessible via proximity to urban centres.

A failure to recognise the diversity of peri-urban locations ignores the complexities involved in service delivery for palliative clients and their families and is unlikely to result in effective, person-centred care. Accessibility, however, is not simply related to geographic distance – it includes availability and suitability of services to need, affordability and acceptability (Taylor et al., 2021b). A lack of accessibility to health services is one of the reasons why people living in rural areas experience poorer health status in comparison with their metropolitan counterparts (AIHW, 2019; Thomas et al., 2015). The term ‘urban–rural health divide’ is used to explain this inequity in healthcare provision. It includes a lack of local specialist expertise, limited allied health and in-home support, and a reliance on local General Practitioners (GPs) (RACGP, Rainsford, 2019; 2023). Inequities are also due in part to an older population with increased health needs and chronic medical conditions.

The COVID-19 pandemic had an unintentional consequence of removing some of the barriers of access by transforming the way Australians access healthcare services (Caffery et al., 2022). Research during the COVID-19 pandemic found that Australian medical clinics developed their digital technology to enable healthcare services to continue (Jackson, 2022; Petrie et al., 2021). Digital technologies has removed the barriers of time and location to accessing healthcare services and has been of particular benefit to people living outside of metropolitan centres (Cherry et al., 2018). Digital health promotes advocacy for people to participate in needs assessments, enables contact with specialists in tertiary centres and enhances the number of patient–physician encounters in the patient’s own home, improving wellbeing and quality of life (Erdiaw-Kwasie & Alam, 2016; Lally et al., 2021; Milch et al., 2021).

Whilst the change from a traditional face-to-face model of service delivery to digital health improved accessibility in the short term, it is important to refrain from viewing digital health as the panacea to removing the inequities of heath service access in all situations in the long term. Palliative care practitioners have voiced concerns about the difficulties in conveying empathy and communicating sensitive information, responding to body language and facial cues during telephone consults, and a lack of physical contact when touch is often used to support someone in distress (Collier et al., 2016; Milch et al., 2021). The uptake of digital health has been limited to the willingness of healthcare services to change their healthcare delivery and the quality and accessibility of existing digital infrastructure (Ruiz-Martínez & Esparcia, 2020). The urban–rural digital divide extends to internet use and accessibility, despite the pandemic resulting in an acceleration of a national program of development and implementation of digital technology to enhance the Australian health system (Davies, 2021; Rainsford, 2019). The known challenges associated with the urban–rural health divide are factors that have the potential to influence the accessibility and quality of healthcare service delivery for peri-urban residents (Schulte et al., 2022).

Care for a person diagnosed with a life-limiting illness, including end-of-life care, is termed palliative care. This type of care responds to the needs, values, and preferences of people receiving care and their families (Saurman et al., 2022). In-home or community palliative care and a home death have been associated with a higher quality of life and are often used as markers of a ‘good death’ (Boamah et al., 2021; Gerber et al., 2019). Patients diagnosed with a life-limiting illness commence a palliative approach to care to provide physical, psychological, social, and spiritual comfort (Callisto et al., 2021). Palliative care is provided in many locations by many health professionals and multidisciplinary teams (MDTs) and includes end-of-life care and the choice of a home death (Agllias, 2018). Specialist palliative care is available to those persons with complex care needs to support the care given by the primary care provider in home settings, but the extent of the support provided depends upon available resources (Pask et al., 2018).

Palliative care differs to other health services because it responds to individual needs at any time in the palliative journey, which can span weeks to years, depending on the disease trajectory. Healthcare services required by this group include tertiary centres for both inpatient and outpatient care and local specialist and allied health care providers, both in-clinic and in-home. Consumers in peri-urban areas may well have access to local hospitals, but these facilities often lack access to the specialised services required by this group (Pesut et al., 2014). Ensuring care is responsive to patient preferences may be difficult in a community context due to environmental and personal or behavioural barriers (Kwame & Petrucka, 2021).

There is a known benefit for persons who live outside of metropolitan areas to remain in their own homes for as long as possible. Findings from a Royal Commission into Aged Care found that many Australians verbalise a preference for end-of-life care in their home, regardless of location (Commonwealth of Australia, 2021; Gerber et al., 2019; Kenny et al., 2021; KPMG, 2020). Forced relocation for treatment, rehabilitation, or aged care services can result in disconnection from community, friends and family (Taylor et al., 2021b). Unfortunately, for older Australians and those with a life-limiting illness, there are significant waiting lists for supports provided through a federally-funded Home Care Package which aims to assist people to remain in their own home (Commonwealth of Australia, 2021).

Rationale for the study

Peri-urban areas are heterogeneous, being rural areas transitioning to urban land uses, unique in diversity of location, structure, culture, community and geographical area (Buxton & Butt, 2020). Development has not been constrained to planned greenfield development sites, with ad-hoc residential development occurring as land becomes available (Newton, 2010). Residential growth has often outpaced the ability of governments and private entities to plan and develop appropriate infrastructure and provide the services required to meet the needs of local communities (Infrastructure Australia, 2018).

Ensuring that every person has access to the health care and medication they need, when, and where they need it, is recognised as a basic human right. The rights of patients receiving healthcare in Australia can be found in the Australian Charter of Healthcare Rights, legislation and common law (ACSQHC, 2020; Attorney-General's Department, n.d.). Health care services include palliative care, which is a person-centred approach, aimed at improving the quality of life for people diagnosed with a life-limiting illness, with little to no prospect of a cure (Palliative Care Victoria, 2017). It is widely accepted that provision of good quality palliative care in the patient’s choice of location, improves overall wellbeing for patients and their family members, enables choice of place for end-of-life care and death, and facilitates the grieving process for family and friends. The WHO recognises palliative care as an ethical responsibility of health systems globally (WHO, 2021). As an ethical responsibility, the provision of quality, person-centred palliative care in the location of choice becomes critical in maintaining quality of life of individuals and communities.

Barriers to access result in unmet needs for patients and family caregivers, increasing potential for relocation, distress, suffering, and complex grief (Driessen et al., 2023). Healthcare professionals face feelings of frustration, stress and burnout due to an inability to provide the holistic community palliative care they believe is appropriate (Baqeas et al., 2021). These are core reasons for understanding the influence of a peri-urban location to accessing community palliative care service delivery. The ethical responsibility for Australia to ensure equitable access to person-centred palliative care services in the location of patient choice further supports the need to conduct this research.

A mix of specialist and generalist providers from public and private sectors provide palliative care, depending on the needs and wishes of the individual and the availability of services (AIHW, 2022d; Wenham et al., 2020). Palliative care services are delivered in multiple settings to provide care throughout the palliative journey; however, these services lack uniformity as each differs in team structure, location of care, and available services (Hui & Bruera, 2020). Community palliative care service delivery is influenced by funding arrangements, variations in organisational structures and patterns of service delivery, with geographic location a particular influence on service availability and models of care outside of urban areas (Eagar et al., 2006; Groeneveld et al., 2017).

Current structure, availability, and allocation of resources for service delivery in fringe areas experiencing urban-style growth, is based on a rural mode of service delivery with an expectation that proximity to urban centres ensures equitable access to services (Rural Health Standing Committee, 2018). However, this view appears to fail to consider that community palliative care service delivery is person-centred, tailored to the individuals' needs and preferences for services and support, which differs for every person. The structure, availability and allocation of services and resources in each peri-urban location need to be explored and evaluated for efficacy so that improvements can be made to existing services to meet the needs and expectations of an increasing number of peri-urban residents. The surge in popularity of peri-urban living necessitates an understanding of the basis for health service policy development in these areas which have a history of known health service challenges. If community health service delivery is based on a mode of delivery that assumes peri-urban areas are homogenous with their surrounding rural or urban areas, then it is unlikely to result in effective, person-centred care.

Research demonstrates that Australians living in rural areas experience poorer access to, and use of health services, in comparison with metropolitan counterparts, with access issues increasing with remoteness (AIHW, 2019; End of Life Directions for Aged Care (ELDAC), 2024; Thomas et al., 2015). One area of research which seems to have been overlooked, however, is the influence of peri-urban locations on community palliative care provision. Population growth in these outer fringe areas has potential to not only increase the number of people impacted by the urban-rural inequities but also the demands on existing primary services. In 2019, 14.8% of all registered deaths in Australia, or 24,970 deaths, were registered at a person's home or place of residence (not including aged care facilities) with an unknown number of family members and caregivers impacted (AIHW, 2021a).

1.4 Significance of the study

Death and dying are inevitable parts of life that no one can avoid. The subject remains taboo for many, but the way we care for dying people can be viewed as a measure of our individual values and of our society. The quality and accessibility of palliative and end-of-life care will affect all of us in some manner and must be a priority to providers, policy makers and governments. In the words of Dame Cicely Saunders, founder of the modern hospice movement;

> how people die remains in the memory of those who live on so we should strive to make a good death the expectation rather than the exception in all settings. (cited in Deloitte, 2014, p. 1)

All people have the right to expect equitable access to person-centred, quality healthcare at any point in their life journey, including at the end-of-life (ACSQHC, 2023a; Wenham et al., 2020). Evidence has shown that this basic right is challenged by inequities of access due to geographical location (Bakitas et al., 2015; Matsumoto et al., 2013). The choice to relocate from an urban centre should not influence access to quality, person-centred palliative care services. Barriers to access influence preferred end-of-life care and place of death, impact patient quality of life, remove patient choice, increase likelihood of emergency and acute presentations and impede the grieving process of family and friends (KPMG, 2020; Saurman et al., 2022).

The experience of caring for a loved one at home will linger in memories long after the person has died, with potential for long-term psychosocial and physical impacts on family caregivers. Healthcare providers have an ethical and moral right to ensure the wellbeing of the community they serve. Any perception that the care provided has failed to meet the needs of patients and families can also be frustrating and distressing for all clinicians involved, increasing the likelihood of increased compassion fatigue, stress and burnout (Chan et al., 2021; Terry et al., 2015).

The physical, social, financial, and emotional implications for the increasing number of Australians choosing to relocate to peri-urban locations is why it is important to understand the challenges to palliative care service delivery in these fringe areas, now and in the future. We need to understand the specific needs of peri-urban locations to allocate resources appropriate to the diverse communities involved. Current policies and procedures rely on generic urban or rural modes of service delivery as a one-size-fits-all approach.

1.5 Structure of the thesis

The thesis comprises 9 chapters:

- Chapter 1 has provided the context for the thesis and presented the aims, research questions and thesis structure.

- Chapter 2 provides the background of the problem space with an overview of palliative care and difficulties associated with community service delivery related to peri-urban locations. Known barriers to care in rural and remote Australia are outlined, as are the methods of geographical classification of location used in definitions of urban, rural and remote. The chapter summarises changes imposed on healthcare provision that influence community palliative care in peri-urban areas.

- Chapter 3 presents the impact on the physical and psychosocial health and wellbeing of those affected by death and dying and the influence of inequities of access. Perspectives of patients, family caregivers, clinicians and the health system will be discussed, along with the influence of the COVID-19 pandemic.

- Chapter 4 outlines the research process and the corresponding methods applied to each stage. The research process employed an exploratory, inductive and interpretative approach which aimed to respond to the problem space. The chapter will outline the research design and discuss the use of a literature review and pilot study to help identify the problem space and develop the research questions and aim. This chapter will outline how a survey to collect data and validate results was developed, considering the risk of emotional distress to participants due to the research subject. The next stage outlines the qualitative and quantitative data analyses tools, in particular the use of a thematic analysis.

- Chapter 5 provides a summary of the pilot study which adopted an ethnographic approach, conducted to ascertain the feasibility of the research method being developed. Observation and informal discussions were undertaken with a small number of health professionals providing community palliative care in a peri-urban region of South Australia prior to survey development. Identified key issues will be discussed, including home location and barriers to accessing resources, and the risks experienced by both practitioners and family givers.

- Chapter 6 explores the views of health practitioners by thematic analysis of free-text survey responses and a descriptive statistical analysis of quantitative data. The relationship between barriers to accessing required resources, including anticipatory and end-of-life medication, trained staff, and after-hours support, due to home location distance is discussed. An emphasis was placed on a lack of system-led policies and organisational characteristics, including poor support from leadership by research participants. Practitioners highlighted the emotional toll associated with a perceived inability to provide appropriate care to palliative patients and family caregivers due to a home location being situated in a peri-urban area.

- Chapter 7 explores the views and perceptions provided by family caregivers related to barriers to accessing appropriate care in their home locations. Family caregivers highlight the difficulties accessing services in their peri-urban home location and the relationship between person-centred care access and distance. Descriptive responses highlight the consequences of unmet needs and expectations associated with access barriers, including the need to relocate; or transfer for end-of-life care, and the disappointment at the inability to reassure their loved ones that their wishes would be met. The research participants' preference for face-to-face encounters was highlighted, rather than a reliance on digital health service delivery.

- Chapter 8 explores the perceptions of patients. Patients are those who have been diagnosed with a life-limiting illness and who are accessing care in their home location. The similarities and differences between the responses of patients and family caregivers is discussed; the level of appreciation of available services voiced by patients was noticeably higher. The loss of choice of treatment, care and place of care was discussed, with time and distance to home location influencing access.

- Chapter 9 provides a summary of the issues relating to community palliative care provision in peri-urban areas which have become evident in this research. The focus will be on implications and future recommendations for service providers in the form of a paper directed to the Chief Executive of the Department of Health and Wellbeing, SA Health, Dr Robyn Lawrence.

Chapter 2: Background

2.1 Introduction

In chapter 2, the exploration of the problem space will consider the complexities involved in planning and delivering effective palliative care, with an emphasis on the significance of the context of community service delivery in peri-urban locations. The chapter begins by presenting a comprehensive background on the fundamental elements that have shaped the landscape of palliative care, and how it has evolved into a holistic approach. The focus extends to the challenges involved in delivering palliative care services in peri-urban areas, to establish a foundational understanding of the influence of counter-urbanisation on community palliative care provision in peri-urban locations.

By addressing the difficulties associated with community service delivery, the chapter aims to provide understanding of the unique circumstances prevalent in these semi-rural regions. This includes an examination of the barriers that often impede the seamless provision of palliative care, offering insight into the distinctive challenges faced in peri-urban locales. The narrative proceeds to illuminate the divide between urban and rural and remote Australia, outlining the limitations and barriers related to geographical location.

To distinguish between urban, rural, and remote locations, the chapter provides a comprehensive summary of the known methods employed for geographical classification. This detailed exploration provides background to the research questions by helping us to understand the diverse landscapes in which palliative care services are delivered and highlights the lack of clarity on defining peri-urban locations. The chapter also provides a thorough summary of the changes that have been imposed on healthcare provision that directly impact the delivery of community palliative care in peri-urban regions.

By examining these shifts, the chapter aims to contextualise the evolving nature of healthcare practices and their implications for palliative care services. Through this analysis, the chapter sets the stage for understanding the dynamic interplay between healthcare policies, geographic classifications, and the challenges encountered in delivering effective palliative care within the unique context of peri-urban areas.

2.2 Palliative care

2.2.1 Definition and history of palliative care

Palliative care originated in the modern hospice movement in England in the late 1950s and early 1960s with a focus on care for the dying (Loscalzo, 2008). Dame Cicely Saunders opened St Christopher's Hospice in London in 1967 and challenged the view at that time, that lack of a cure constituted a failure on the part of the physician, and introduced a multidisciplinary approach to end-of-life care (Alcalde & Zimmermann, 2022; Saunders, 2001). This approach has been adopted throughout this research. Inspired by this philosophy, Dr Balfour Mount, founded a hospice-style inpatient unit in Montreal, Canada in 1973 (Duffin, 2014). To remove the negative stigma associated with the word 'hospice', he introduced the term 'palliative care', based on the Lain *palliare* meaning 'to cloak' (Duffin, 2014).

Australia was relatively slow to transition from provision of terminal care in an acute setting to programs providing palliative care services in the home (Malden et al., 1984). Over the past 40 years, the impetus for the transition from hospice to palliative care services has come from oncology services that recognised that patients' needs were being unmet (Currow & Phillips, 2013). The report 'Palliative care for cancer patients' commissioned in 1983, is viewed as a defining moment in the early evolution of palliative care in Australia, rejecting the concept at that time of admission to acute care for terminally ill patients (PCA, 2023; Webster, 1985). Since that time, palliative care services in Australia have transitioned to a strong network of providers focused on delivering quality care in many settings, including in-home and community care. The definition of palliative care used in this research is as follows:

> …the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers. (IAHPC, 2024)

Community or community-based palliative care is defined as palliative care delivered outside of hospital and outpatient clinics, with the aim of providing home-based individualised multidisciplinary support to patients and family members (Chan et al., 2021; Olvera et al., 2023). There are many benefits for people who choose to remain living in their own homes for as long as possible, including improved overall wellbeing, the ability to maintain healthy lifestyles and maintain relationships with family and community (Taylor et al., 2021b; Thornton et al., 2022). Provision of palliative care services in the community recognises that the term ‘own home’ could include personal residences, retirement villages, communal living arrangements, residential aged care facilities or mobile homes. Community palliative care services often extend into Residential Aged Care Facilities (RACF); however, this research will not include this care service because these facilities are already well-equipped to provide prompt and effective palliative care (Sandsdalen et al., 2016). RACFs generally have access to a GP and staff who are adequately skilled in palliative care on site over a 24 hour period, which can reduce the need for transfer to an acute setting and provide necessary support for family members.

2.2.2 Palliative approach to care

Palliative care is an approach which aims to optimise quality of life and the dying experience for people diagnosed with life-limiting illnesses, including cancer, dementia, and non-malignant degenerative diseases (AIHW, 2022d; PCA, 2018b). Unfortunately, palliative care patients generally have multiple and complex psychological, social and symptom concerns (Pask et al., 2018), which makes the care process complicated and dynamic. Patients and family members go through changing and escalating physical, spiritual and emotional care that influences their quality of life and wellbeing during the palliative journey (Chan et al., 2021). Palliative care involves treating each person as an individual with support tailored to meet the person’s unique needs and situation (PCA, 2018a).

A palliative approach to care recognises that death is inevitable and transfers the focus from a cure to holistic care to support the needs and values of the patient, caregivers, and family members (Agllias, 2018; Saurman et al., 2022). The goal of a palliative approach is to improve comfort and function by addressing physical, psychological, social, emotional, cultural and spiritual needs (PalliAged, 2022). The following provides a taxonomy of the palliative care objective(s):

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if required
- will enhance quality of life, and may also positively influence the course of illness

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (PCA, 2015)

The World Health Assembly recognises that:

> …palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received. (WHO, 2013)

2.2.3 Person-centred approach

Patient or person-centred care is defined as, 'providing care that is respectful of and responsive to individual preferences, needs and values and ensuring that patient values guide all clinical decisions' (ACSQHC, 2024).

A patient or person-centred approach to healthcare means recognising that every person is a human being and not simply a medical condition or disease to be treated (Coulter & Oldham, 2016). Person-centred care involves effective communication, dignity, trust and respectful relationships, to seek and understand the needs, wishes, preferences of patients, family members and caregivers (ACSQHC, 2023b). A person-centred approach is fundamental to effective and quality palliative care, to ensure access is available to appropriate information, support, and care, when and where it is needed by the person(s) involved. Eight dimensions have been identified as important for providing person-centred care:

- respect for patients' values, preferences and needs
- provision of information and education
- access to care
- emotional support
- involvement of family, friends and caregivers
- continuity and seamless transition between health care settings
- physical comfort
- coordination of care. (Galekop et al., 2019)

The importance of safety and quality healthcare when using a person-centred approach is embedded throughout all Australian Healthcare Standards developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC) (2023b). This includes the National Safety and Quality Health Service Standards and the Primary and Community Healthcare Standards (ACSQHC, 2021b, 2021c). The approach involves the patient, their families and support people at the centre of all decision-making about care, as shown in Figure 1. The primary focus is on symptom management and quality of life rather than life-prolonging treatments.

Figure 1 Placing the person at the centre of care (Department of Health and Aged Care (DoHAC), 2019)

Person-centred care is a core value in palliative care, ensuring dignity and respect for individuals and family needs, cultural and religious preferences. A person-centred approach is central to holistic care which supports the needs and values of the patient, caregivers, and family members in service delivery (Agllias, 2018; Saurman et al., 2022). The holistic scope of palliative care is highlighted in Figure 2.

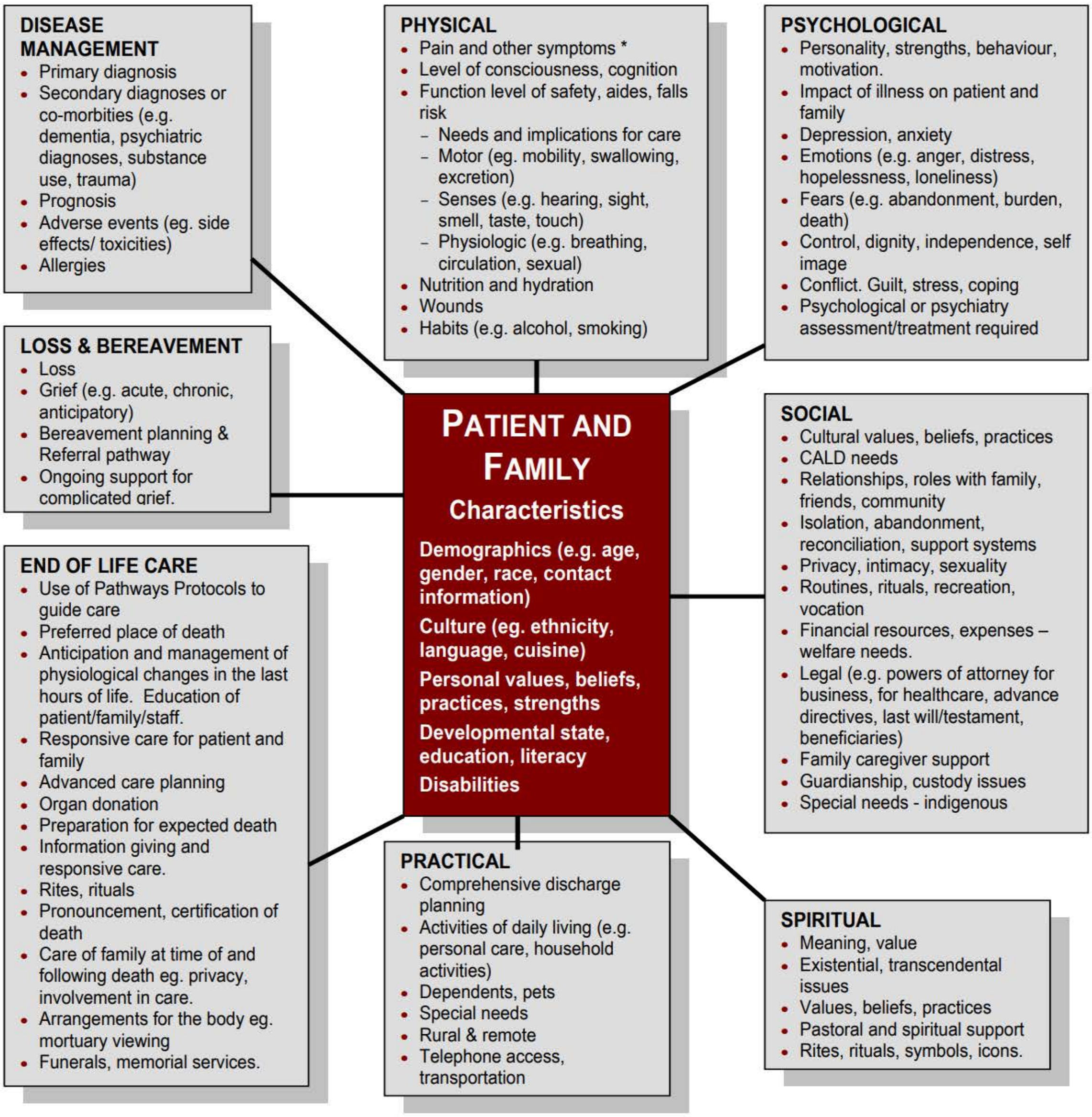


Figure 2 Domains of palliative care (Department of Health Western Australia (WADOH), 2008)

Palliative care differs from other health services in that patients must access care based on their individual needs at any time during the palliative journey, from diagnosis to end-of-life. This can span weeks to years, depending on the disease trajectory (RACGP, 2023). Figure 3 provides a visual representation of individual needs and service involvement across the palliative journey. Healthcare services required by this group include tertiary centres for both inpatient and outpatient care and local specialist and allied healthcare providers, both in-clinic and in-home. Integration of palliative care early in the disease process is effective at improving quality of life and reducing unnecessary hospitalisations and the associated costs (Namasivayam et al., 2022; Seow et al., 2021).

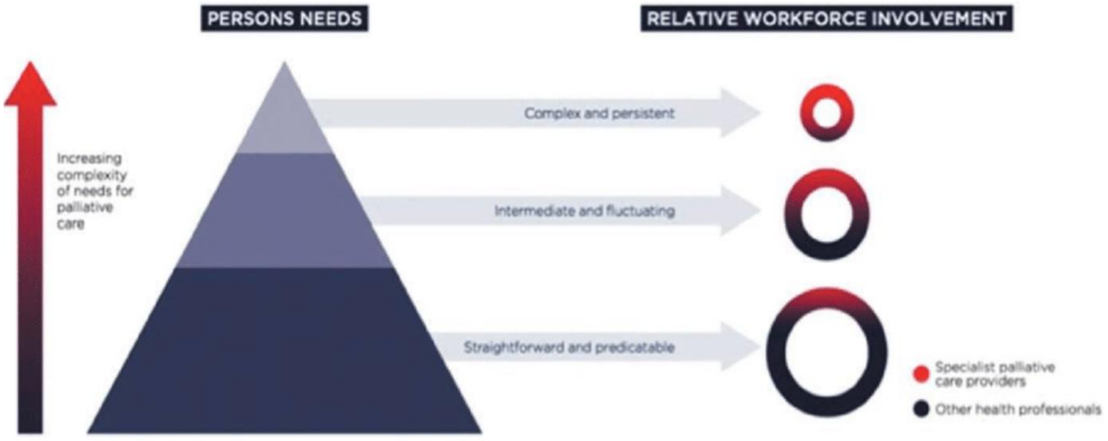


Figure 3 Indication of service provision based on needs (PCA, 2018b)

Palliative care is provided in many settings with person-centred care supporting choice of location for care, including end-of-life care and the choice of a home death (Agllias, 2018). It is widely accepted that provision of good quality palliative care in the patient's choice of location improves overall wellbeing for patients and their family members and facilitates the grieving process for family and friends. The palliative journey differs for each individual and is not linear in nature, with the needs and choices of the person at the centre of care constantly changing in an effort to optimise their health (Gorod et al., 2021).

Several factors influence the decisions or choices made by every individual. These factors, include past experience and memories, social and cultural rules and expectations, cognitive biases, age and individual differences, belief in personal relevance, and a perception of value (Dietrich, 2010; Latif, 2020). Individuals have the right to appoint a medical decision-maker if they are too unwell to voice their choice of medical treatment, care provider or location of care, including hospital, hospice or home (Zolkefli, 2017). Supporting patient choice for community-based palliative care not only aids the patient and family, but it also fosters seamless transitions between the settings required and reduces use of hospital resources (Kamal et al., 2013), as demonstrated in Figure 4.

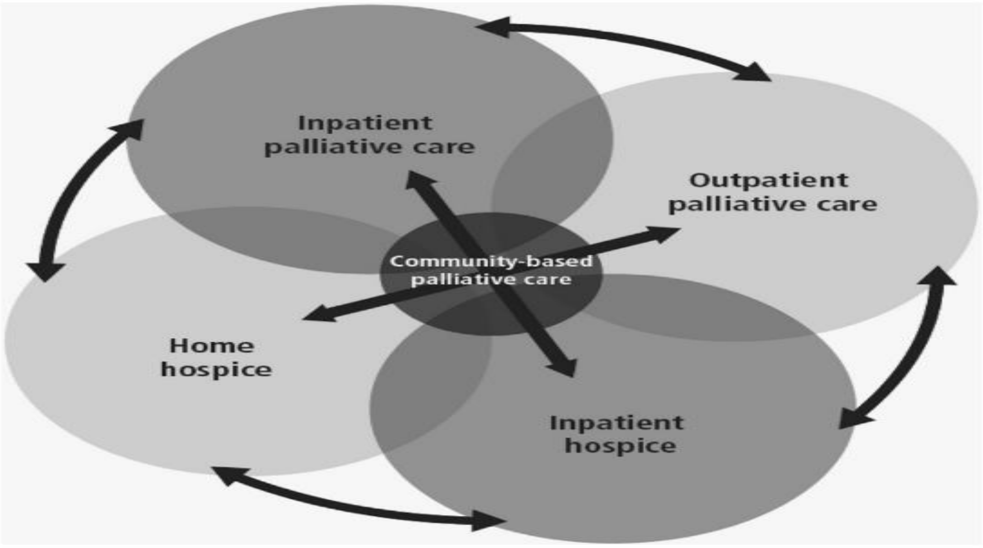


Figure 4 Community-based palliative care transitions (Kamal et al., 2013)

Many Australians have verbalised a preference to remain in their own home for as long as possible, with 60–70% expressing a wish for end-of-life care and a home death (Commonwealth of Australia, 2021; Gerber et al., 2019; Kenny et al., 2021; KPMG, 2020). This view is supported by the findings of the Royal Commission into Aged Care which found that many Australians verbalise a preference for end-of-life care in their home, regardless of location (Commonwealth of Australia, 2021; Gerber et al., 2019; Kenny et al., 2021; KPMG, 2020). In-home or community-based specialist palliative care and a home death have been associated with reduced hospital costs and a higher quality of life and are often indicators of a good death (Boamah et al., 2021; Gerber et al., 2019; Spilsbury & Rosenwax, 2017).

There are, however, no common measures of a good death, with preferred location only one of many core themes identified in the literature. Other themes include; pain-free status, life completion, dignity and quality of life (Meier et al., 2016). In 2019, however, only 14.8% of all registered deaths in Australia, or 24,970 deaths, were registered at a person's home or place of residence (not including aged care facilities) (AIHW, 2021a; Swerissen & Duckett, 2015). The proportion of institutionalised deaths has increased, with 51% or 86,276 of deaths in 2019 occurring in hospitals or medical centres and 29.5% or 49,896 in residential care facilities (AIHW, 2021a).

Statistics, however, fail to acknowledge all factors associated with the specific setting or place of end-of-life care and death (Gu & Wang, 2020). A home death is more likely to occur when the person involved has expressed this wish, and not every person expresses a home death as their preferred option. A preference for hospital care may be verbalised due to concerns regarding quality of care available in the home, the appropriateness of family members attending to personal care, ambivalence towards professional carers in the home or not wanting to be a burden on family (Munday et al., 2007). Despite the common wish for end-of-life care at home, many people in the terminal stage are transferred to acute settings because their deteriorating condition and unstable symptoms can no longer be adequately managed in the home. Other reasons for being transferred to another location include a decision by the patient or family, lack of caregiver ability to manage 24-hour care or a lack of services to support the family (Champion et al., 2015).

2.2.4 Models of care

Evidence suggests that the complex and multidimensional needs of palliative patients are best met through an MDT approach, particularly due to the importance of continuity of care (Fernando & Hughes, 2019; Hudson et al., 2019). A team approach enables expert clinicians, including doctors, psychologists, pharmacists and nurses to share the responsibility, and to work together to communicate and coordinate the delivery of care (Bowen, 2014). Promoting one person who has the accumulated knowledge of the team as the point of contact encourages a respectful and trusting relationship, which can enhance care provision, reduce hospital admissions and support choice of end-of-life care (Hudson et al., 2019). Relational continuity of care goes beyond information and care provision. It seeks to promote feelings of satisfaction from patients and family members, and helps build and maintain an emotional bond and mutual understanding which ultimately optimises quality of life and care provision (Aghaei et al., 2020). Access to the MDT services and support required by people during the palliative journey, including at end-of-life is influenced by multiple factors which may not reflect the changing needs of communities. The health system structure, a combination of public and private providers, funding arrangements, and models of service delivery all have a direct effect on the quality of care and the eventual outcomes (Davidson et al., 2006).

A model of care is a multifaceted concept which broadly outlines the way in which health services are organised to deliver best practice patient outcomes (Luckett et al., 2014). Models provide a framework for implementing and evaluating care and services through core components which describe who delivers what interventions, when, where, how and to whom (PalliAged, 2017; Siouta et al., 2016). Regardless of the setting in which palliative care is delivered, models provide benefits to patients and carers (Brereton et al., 2017). There is no preferred organisational model of care, with various models available to meet the specific needs of particular groups that are associated with their illness or condition, setting, specialities, or services available (Davies et al., 2011; Rumbold & Aoun, 2021).

The curative model of care does not fit for medical conditions that may eventually lead to death and is not appropriate for palliative care service delivery (Neuberger, 2003).

Communities in rural Australia have typically relied on a traditional primary care model, with an emphasis on diagnosis and management by an individual practitioner and referrals where necessary (Woods, 2001). Integrated models of palliative care focus on the potential role of primary care and PHNs as hubs to facilitate integration of specialist palliative care and community services, with GPs an integral part of care provision (Rumbold & Aoun, 2021). Research has demonstrated an improvement in quality of life, symptom burden and psychological symptoms and an increased likelihood for a home death from an integrated model of care (Agency for Clinical Innovation (ACI), 2022a). GP-led clinical integrated models of care may benefit patients who have an established and trusting relationship with their GP, thereby promoting a relational continuity of care with their provider (Hudson et al., 2019). Challenges arise, however, if the GP lacks specialist palliative skills or is unable to prioritise the perspectives of the patient or family (Brown et al., 2018; Gilbert, 2020).

Subacute models of palliative care aim to optimise quality of life for the patient with an active and advanced life-limiting illness with care delivery under the management of a clinician with specialist palliative care expertise and evidenced by an individualised multidisciplinary management plan (Independent Health and Aged Care Pricing Authority (IHACPA), 2024). Subacute care needs and treatments differ from those of acute care as the goal is not driven by the diagnosis; rather, the goal is to maximise the functional status and quality of life of the patient (Pearse et al., 2011). Limitations occur with this type of model due to a lack of clarity on the term ‘specialised expertise’, resulting in varying responses to perceived goals of care, service delivery and care implementation (ACI, 2017). What is considered an appropriate composition of medical, nursing and allied health clinicians in local MDTs has the potential to limit the patient’s ability to meet their goals (ACI, 2017). Limitations to subacute models of care are exacerbated by the barriers to accessing specialist clinicians and expertise in peri-urban, rural and remote areas (Pearse et al., 2011)

The team approach is indispensable within models of palliative care service delivery and necessary to address the complex needs of the patient from diagnosis to the point of bereavement for loved ones (WHO, 2020a). Communication, information, and practical issues can be as overwhelming as physical symptoms such as fatigue, pain, reduced mobility, and loss of appetite (Bone et al., 2016). Allied health professionals can support medical practitioners in managing physical symptoms, advising on nutritional status or muscle strength, and offering support with finance, legalities, or psychosocial issues (Chan et al., 2021). The team structure and interactions between members varies depending on the model of teamwork adopted; however, evidence strongly suggests that palliative care is best delivered though an MDT-based model of care (Fernando & Hughes, 2019; Gilbert, 2020).

Commonly used terminology to describe palliative care teams include multidisciplinary, interdisciplinary, and transdisciplinary. A purely MDT has clearly defined responsibilities for each individual within the team of professionals from multiple disciplines, who function independently with goals and treatments that are discipline-specific (Martin et al., 2022). In an interdisciplinary team, members work interdependently to augment patient care and a transdisciplinary approach involves overlapping responsibilities between members (Fernando & Hughes, 2019).

Home and community-based models aim to provide appropriate and timely palliative care in-home, with community-based models of care promoting seamless transitions between palliative care settings (ACI, 2022a; Kamal et al., 2013). Studies have shown the benefits of palliative care outside of the inpatient care setting, with or without input from a specialist palliative care team, in terms of patient satisfaction, quality of life, reduced number of hospitalisations, length of hospital stays and symptom severity (Brereton et al., 2017; Cohn et al., 2017; Mathew et al., 2020). Person-centred models include ‘Respecting Choices’, an advance care planning model which aims to assist individuals to consider, choose and communicate their preferences for care and treatment (Agency for Clinical Innovation (ACI), 2022b). Another person-centred model is the 6S model which has Self-image as the central concept, with the patient and their own experience of the situation as the starting point. The other concepts – Self-determination, Symptom relief, Social relationships, Synthesis and Strategies – are all interrelated to Self-image (Österlind & Henoch, 2021).

Despite the significance of an effective model of care to support patient needs, a universally agreed model of care for palliative care does not exist (Siouta et al., 2016). It is essential for quality care provision that models developed and used by palliative care providers are dynamic and responsive to community and population changes and are underpinned by the diseconomies of scale resulting from distance and small dispersed populations (Wakerman et al., 2008). Organisations develop and adopt models of care tailored to local needs, resources, strategic plans and initiatives, and the costing, funding and revenue opportunities provided (ACI, 2013). The model adopted by an organisation is reflected in the type and structure of management and the organisation’s characteristics and philosophy which influences priorities of care and allocation of resources (Parreira et al., 2021). Providers need to consider feedback related to patient preferences, experiences, and needs, rather than rely on benchmarks and formal indicators of ideal location of death or perceived quality of life (Siouta et al., 2016). Barriers to accessing community palliative care in rural locations within peri-urban areas will be inherent in models of care that emphasise revenue opportunities or that fail to prioritise and adapt methods that cater to individual needs and preferences.

2.3 Known barriers to accessing palliative care

Despite evidence that palliative care services can improve quality of life and be provided alongside treatment options, multiple barriers remain to accessing care. The challenges faced by someone who is diagnosed with a life-limiting illness are already substantial and potentially overwhelming for the person and the family involved, without the added complexity of accessing services. Availability of palliative care services is influenced by geographical location, provider funding arrangements, variations in organisational structures and patterns of service delivery (Eagar et al., 2006; Wenham et al., 2020). Common barriers are provided in Figure 5.

CONSUMER-SIDE

- Lack of comfort discussing death and dying
- Lack of understanding/awareness of palliative care
- Fear and mistrust (e.g. of Western medicine, health care services, perceived authority)
- History of trauma
- Social/family breakdown, isolation
- Delayed diagnosis/presentation to healthcare services

SERVICE-SIDE

- Lack of relevant cultural awareness/competency within available services
- Lack of health worker skills/experience (in palliative care and/or working with people from under-served population groups)
- Lack of available services and support to facilitate dying in setting of choice
- Referral issues (lack of/late referral to specialist services)

Language and communication barriers

Mismatching cultural understandings and preferences

CONSUMER-SIDE	SERVICE-SIDE
Fear/perception of stigma/discrimination/racism	Actual stigma/discrimination/racism
Financial constraints	Insufficient funding/ funding model issues

Figure 5 Common barriers to quality palliative care (Australian Healthcare Associates (AHA), 2019)

In addition to common barriers, the following 9 populations of interest have been identified as having co-existing vulnerabilities and/or complex needs in relation to accessing quality palliative care and community services (AHA, 2019):

- Aboriginal and Torres Strait Islander peoples

- care leavers and people affected by forced adoption
- people from culturally and linguistically diverse (CALD) backgrounds
- people with disabilities
- people experiencing homelessness
- people who are incarcerated
- people who identify as lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual (LGBTIQA+)
- refugees
- veterans (AHA, 2019)

Understanding barriers to accessing palliative care in Australia is multifaceted, however concerns related to accessibility are primarily related to the vast geographical area of the country (Shukla et al., 2020). Geographic locations are a known barrier to accessing quality and person-centred palliative care for Australians living outside of high-density urban centres, influencing available services, choice and location of care (Schulte et al., 2022; Taylor et al., 2021b; Thomas et al., 2015). This is why it is important to explore the shifting trends in the distribution of the Australian population.

2.4 Population shift

2.4.1 Urbanisation

History has shown that the first European settlers gravitated to the colonial settlements on the Australian coastline, with these settlements later becoming the current major cities (Dodson, 2016). This trend of Australians settling in urban areas continued throughout the nineteenth century, as people sought to live close to employment opportunities (Amirinejad et al., 2018; Nygaard & Parkinson, 2021; Ruiz-Martínez & Esparcia, 2020). Despite the popularity of living in major cities, issues such as overcrowding, a lack of consistent infrastructure, housing shortages and high housing costs emerged as the population increased (Dodson, 2016; Slavko et al., 2020). The amount of land available for urban planning, however, was finite, with population growth in cities accommodated by either an increase in density or expansion into surrounding rural areas (Gurran et al., 2021; McFarland, 2015). Increased housing pressures resulted in an expansion of city boundaries, with a pattern of suburban development intensifying from the late 1940s to the early 1960s (Berry, 1999; Dodson, 2016; Macintyre, 2018).

Uncontrolled urban sprawl was initially made possible by access to rail transport, which allowed residents to commute from new residential developments to the city centre (Berry, 1999). Suburban developments expanded with more affordable housing than metropolitan centres, and the dominant aspiration of many people was to live in an owner-occupied, single family, fully detached home (Berry, 1999; Macintyre, 2018). The Australian suburban model was intensified by the removal of wartime petrol rationing in 1951 which then enabled the expansion of motor vehicle manufacturing, development of freeway schemes and local road access to augment existing rail transport (Davison & Yelland, 2004; Dodson, 2016).

The Commonwealth established a national housing program in 1945 to ensure that land was available to maintain the ever-increasing suburban development. This was a coordinated approach that also included State and Local Government Areas (LGAs) (Dodson, 2016). The government recognised the importance of home ownership to Australians – their desire for the 'great Australian dream' of a suburban quarter acre block and the growing trend of car ownership (Macintyre, 2018; Walters, 2021). Census data demonstrates that in 2016 over 70% of the Australian population lived in major cities, with the remainder living in regional and remote areas (Thomson et al., 2019). Subsequently, LGAs were encouraged to rezone greenfield areas to allow for increased suburban development and infrastructure including transport, sewerage, mains water, electricity and telephone lines (Macintyre, 2018). The term 'greenfield' refers to those areas on the urban fringe that are zoned for future urban development. It identifies that infrastructure, policies and actions will need to be resolved prior to planned residential development in these areas (Attorney-General's Department, 2021).

2.4.2 Counter-urbanisation

The urban trend of living in the densely populated cities and suburban areas of Australia began to change in the mid-1990s, with internal migration emerging (Amirinejad et al., 2018; Nygaard & Parkinson, 2021; Ruiz-Martínez & Esparcia, 2020). Relocating from major metropolitan areas and settling in outer metropolitan, regional or rural areas has been termed counter-urbanisation (Guaralda et al., 2020; McManus, 2022). Resettlement was considered a viable alternative to city living, influenced by the desire of some for an improved quality of life and better environmental conditions and escaping densely populated and polluted areas (Jończy et al., 2021). The reasons for internal migration, however, are multi-faceted and not necessarily due to a failure in urban design or an inability of urban areas to accommodate increased populations (Han et al., 2017; McManus, 2022).

There are links between household mobility and the housing pathway of downsizing (Jończy et al., 2021). Reasons for downsizing include wanting to carry out less maintenance and decrease floorspace due to physical inability, or a desire for a lifestyle change, often due to a life event such as retirement, divorce, illness, death of a partner or becoming an empty-nester (Han et al., 2017). Housing mobility has been linked to a financial strategy to release home equity, or the inability or unwillingness of residents to bear the cost of urban living expenses, including house prices and mortgage stress (Davies, 2021; Guaralda et al., 2020). Evidence supports the significance of relocating within proximity of family members, for financial, emotional and physical care and support, both young families and retirees (Argent & Plummer, 2022).

Downsizing and lifestyle changes, often termed tree or sea changes, are no longer deemed the domain of retirees (Ghin & Ainsworth, 2022). This is due in part to State Government planning and policy, locating new residential developments in conjunction with major and local road network expansion (Australian Government, 2021; Department of Planning Transport and Infrastructure (DPTI), 2017). Improved commute times have contributed to accelerated population growth to areas that were sought after for natural amenities but not previously considered viable for relocation due to their distance from metropolitan cities (Amirinejad et al., 2018). Improved accessibility, housing affordability, an increasing population and economic restructuring has resulted in accelerated growth in peri-urban locations on the urban fringes and a blurring of the lines between cities and rural regions.

2.5 Peri-urban

2.5.1 Definition of peri-urban

There is no universally accepted definition of urban or rural areas, nor criteria for differentiating the terms peri-urban or peri-urbanisation (Follmann, 2022; McBride & Moucheraud, 2022). A level of ambiguity exists in defining the space between urban and rural surrounds due to the number of terms in use that, often depend on the classification system being used. Terms are used interchangeably and include urban fringe, semi-urban, rural living zone, country living zone, exurban, peri-urban, metropolitan fringe or rural, which add to the lack of clarity in research (Buxton & Butt, 2020). The term peri-urban is increasingly used to describe those areas on the urban periphery, with an informal boundary defined by a significant economic relationship with the nearby urban centre due to commuting trends and often related to population density (Buxton & Butt, 2020; Gottero et al., 2021; Simone, 2022). For the purpose of this research, the term peri-urban will be used to describe the outer metropolitan fringe space between metropolitan and rural surrounds, which has seen increased residential development.

2.5.2 Residential development

Peri-urban areas at the broad interface between metropolitan areas and their rural surrounds encompass diverse locations and a variety of communities and land uses, and are generally within 150 km of urban centres (Liu & Robinson, 2016; Webster & Muller, 2009). The encroaching urban sprawl into peri-urban areas is helping to meet Australians' need for affordable housing; however, development has outpaced projections and this places pressure on water catchments, native vegetation, agricultural land and infrastructure (Buxton & Butt, 2020; Harman et al., 2015; Infrastructure Australia, 2018). Planning for sustainable growth and residential development in peri-urban areas to ensure future liveability and community wellbeing has been identified as a challenge for State and LGAs (Buxton & Butt, 2020; Gurran et al., 2021). Population increases, changes in the forms of land use, environmental concerns, and misconceptions about how peri-urban areas are identified all contribute to challenges in developing policies and planning and available infrastructure (Buxton & Butt, 2020). The lack of distinction between rural and urban classifications also increases difficulties for real estate developers seeking space for urban development and agricultural industries trying to retain land (Taylor et al., 2017).

Developing large tracts of available land tends to result in a development market dominated by large corporations which are able to consult with planning authorities (Walters, 2021). These corporations often consolidate the land into small, more affordable allotments, rather than the existing larger, lifestyle allotments, which alters the characteristics of the area and transforms it into an urban environment in a rural area (Walters, 2021). Thus, because expansion in peri-urban areas occurs as land becomes available, they are often irregular and do not fit within the Greater Capital City Statistical Areas (GCCSAs) or greenfield boundaries (Low Choy et al., 2008; McFarland, 2015).

The type and level of growth and changes in these outer fringe areas is influenced by two contrasting perspectives on how the spatial relationships between urban centres and the surrounding rural areas are viewed (Buxton & Butt, 2020). An urban perspective views the land surrounding metropolitan centres as a means of providing required land and resources for residential development and allowing urban centres to constantly expand (Buxton & Butt, 2020). However, population growth and the increasing length of commute times raise issues about the expansion of urban areas in relation to social, economic and environmental sustainability (Beer, 2014; Kent et al., 2019). A rural perspective recognises that although residential development may generate challenges, this internal migration may stimulate rural areas through new business ventures, new income streams, and skills and knowledge sharing (Buxton & Butt, 2020).

2.6 Impact on service delivery in peri-urban areas

Peri-urban areas have historically been viewed as a viable option for sustainable urban growth, due to their proximity to urban amenities (Argent & Plummer, 2022; Attorney-General's Department, 2021; Infrastructure Victoria, 2021; Wolff et al., 2021; Wynne et al., 2020). Land uses include a changing mix of established township, low density residential development, large rural living or lifestyle allotments that often involve some level of rural activity, and agricultural land (Attorney-General's Department, 2021; State Planning Commission, 2020).

New residential developments in greenfield and urban fringe areas are intentionally co-located with major and local road network expansions (Brousselle et al., 2020; Department of the Treasury, 2021). Improved infrastructure and new roadways have improved accessibility to services in urban centres, although improving commute times does not negate accessibility issues for those residents who are frail, elderly, unwell or rely on public transport (Schulte et al., 2022). A lack of public transport and a reliance on private transport have been identified as sustainability issues for future development in peri-urban areas due to time, financial costs and loss of productivity associated with increased travel (Newton et al., 2017; North Western Melbourne Primary Health Network (NWMPHN), 2021; Shao et al., 2019).

Outer fringe areas often receive a rural model of service delivery due to geographical location, meaning that it is more difficult to access the same goods, services and social interactions as metropolitan centres (Attorney-General's Department, 2021; Liu & Robinson, 2016). Populations in rural areas have historically relied heavily on the services delivered by primary health providers, including GPs, community-based health services and specialist community clinics (Halcomb et al., 2021). Primary health care services vary but include acute presentations, health screening and prevention and management of chronic conditions (Halcomb et al., 2021).

Modelling suggests that there is a problem with health service access in peri-urban areas, and this problem is comparable to the already acknowledged issues present in rural and remote areas of Australia (Olson et al., 2019). The concern is that modelling has indicated that these peri-urban areas share similarities with rural and remote regions, regarding inequities in health service access. This implies that, despite proximity and assumed access to urban centres and services, peri-urban areas face challenges in ensuring equitable access to health services. The problem is multifaceted, involving issues such as inadequate healthcare infrastructure, limited availability of healthcare professionals, and socioeconomic factors (Mortel et al., 2017; Schulte et al., 2022). Regardless of the location, allotment size or commute distance, the increased population growth in peri-urban locations corresponding to housing development has increased the number of people potentially impacted by the urban–rural inequity (Schulte et al., 2022). Understanding and addressing these challenges are crucial for ensuring that residents in peri-urban areas have fair and timely access to essential health services.

2.7 Urban–rural divide

The term ‘urban–rural divide’ refers to the unique challenges that people who live in rural and remote locations face due to geographical location. In Australia, around 7 million people, or approximately 28% of the population, live in rural and remote areas (AIHW, 2022f). The term, however, is often used in the context of multifaceted problems associated with location, including poorer access to goods and services (such as health and education) and employment opportunities, and poor-quality housing and digital infrastructure (Smith et al., 2008). People living outside of major cities in 2022 were less likely to have completed Year 12 or a non-school qualification, less likely to be employed than their counterparts in metropolitan areas, and in 2019–2020 had 15% less household income per week and paid higher prices for goods and services (ABS, 2022b; 2023d). A visual representation of the distribution of population is shown in Figure 6.

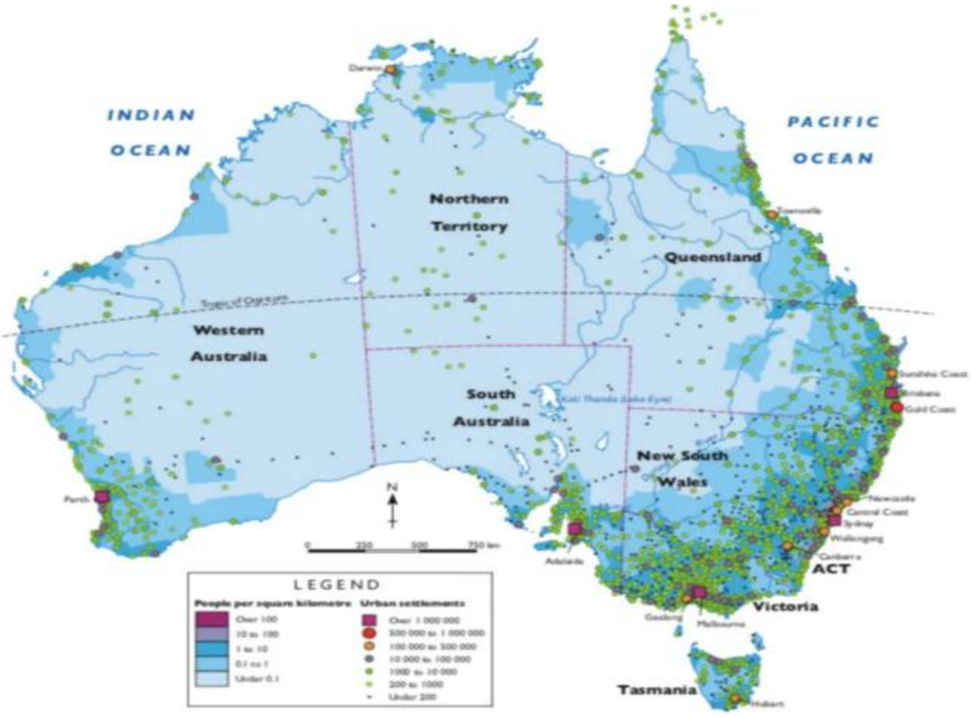


Figure 6 Map of Australia showing where people live (MapPorn, 2019)

2.7.1 Health divide: The result of the urban–rural divide

People living in rural areas experience poorer health in comparison with their metropolitan counterparts (Bradford et al., 2016; Smith et al., 2008). Research shows that people living outside of major cities have higher rates of hospitalisations, deaths and injury, have poorer access to primary healthcare services and are more likely to engage in risky behaviours such as smoking, than their metropolitan counterparts (AIHW, 2022f). The move towards digital health has the potential to remove the barrier of distance, however, rural residents are more likely to face reduced access to digital infrastructure and have limited capacity to use available technology (Warr et al., 2021). Areas outside of the metropolitan areas have historically had an older population who are frail and have increased health needs, chronic medical conditions, decreased mobility and lower socioeconomic status (AIHW, 2021d; Smith et al., 2008; Weng et al., 2021).

These issues are exacerbated by inequitable access due to a lack of public transport and geographic accessibility to the primary health services they require to maintain quality and timely healthcare (Taylor et al., 2021b). The result is a reduction in quality of life, increased likelihood of unnecessary and preventable hospitalisations and presentation to emergency departments, and unmet healthcare needs (Khanassov et al., 2016; Kurpas et al., 2014). Rural residents may be forced to relocate to urban centres due to difficulties associated with accessing treatment, rehabilitation, care and support services or residential aged care (Taylor et al., 2021b).

People living outside of major cities face difficulties in both access and capacity to use the modern and up-to-date digital technologies that urban residents generally access, use and expect in order to participate in society (Department of Infrastructure, 2020; Thomas et al., 2020). Despite ongoing infrastructure policies, these inequities, also referred to as the digital divide or digital exclusion, remain in rural areas of Australia (Davies, 2021; Erdiaw-Kwasie & Alam, 2016; Park, 2017). Digital divides can be divided into two orders. First order divides are associated with inequities of access to required infrastructure and second order divides contribute to circumstances which limit the capacity to use and benefit from available technology (Warr et al., 2021). The Australian Digital Inclusion Index (ADII) measures : key dimensions of digital inclusion: access, affordability and digital ability (Thomas et al., 2020). Although the overall digital inclusion score increased in 2020, the gaps between the digitally included and excluded widened, with the latter group having lower levels of education, employment and income (Thomas et al., 2020).

People living in rural and remote areas are more likely to be overlooked for telecommunication upgrades, resulting in limited or no access to high-speed internet infrastructure or reliable mobile phone coverage which increases disconnection to specialist health services (Guenther et al., 2020; Marshall et al., 2021). While digital exclusion often refers to limited internet access and infrastructure, it is a multilayered concept which recognises the way in which people engage with Information and Communications Technology (ICT) due to motivation, skills and opportunities to benefit (Park, 2017).

Ensuring that care is accessible to all Australians is one of the 6 principles viewed as fundamental to good palliative care, reflected with initiatives to remove accessibility barriers, throughout the National Strategy (DoHAC, 2019). The known challenges associated with the urban–rural health divide are factors that have the potential to influence the accessibility and quality of healthcare service delivery for peri-urban residents (Schulte et al., 2022).

2.8 Resource allocation

2.8.1 Australian healthcare system overview

Australia is a geographically large and sparsely populated country with an excellent health system and highly trained medical workforce. To achieve equal access to health services for all and maintain the balance between supply and demand, it is essential that finite resources, including an appropriate mix of medical specialities, are well distributed geographically (Khashoggi & Murad, 2020). The Australian healthcare system is complex, governed by a number of agreements developed by the Council of Australian Governments (COAG) (Senate Standing Committee on Community Affairs, 2012). The system operates under a mixed model of private and public health and hospital services, which is shown in Figure 7. The Federal, State and Territory, and local governments broadly share responsibility for funding, operating, managing, and regulating the health system (AIHW, 2022c). The private for-profit and not-for-profit sectors and voluntary organisations also play a role in operating and funding some health services (AIHW, 2022c). Approximately 55%, or 14.42 million Australians, now have private health cover, which is encouraged by a tax rebate on premiums (Private Healthcare Australia, 2023).

The 3 levels of government are collectively responsible for providing universal health care. The main responsibilities of each are as follows:

- Federal Government: Develops national health policy, administers the Medicare Benefits Schedule (MBS), provides funds to States and Territories for public hospital services, oversees PHNs, funds medicines through the Pharmaceutical Benefits Scheme (PBS), regulates private health insurance, funds community-controlled Indigenous primary healthcare, organises health services for veterans and funds health and medical research.

- State and Territory Governments: fund and manage public hospitals, regulate and license private hospitals, oversee LHNs, deliver public community-based and primary health services, and deliver preventive, ambulance and health complaints services.

- Local Governments: provide environmental health-related services such as waste disposal and water fluoridation, provide community and home-based health and support services, and deliver health promotion activities.

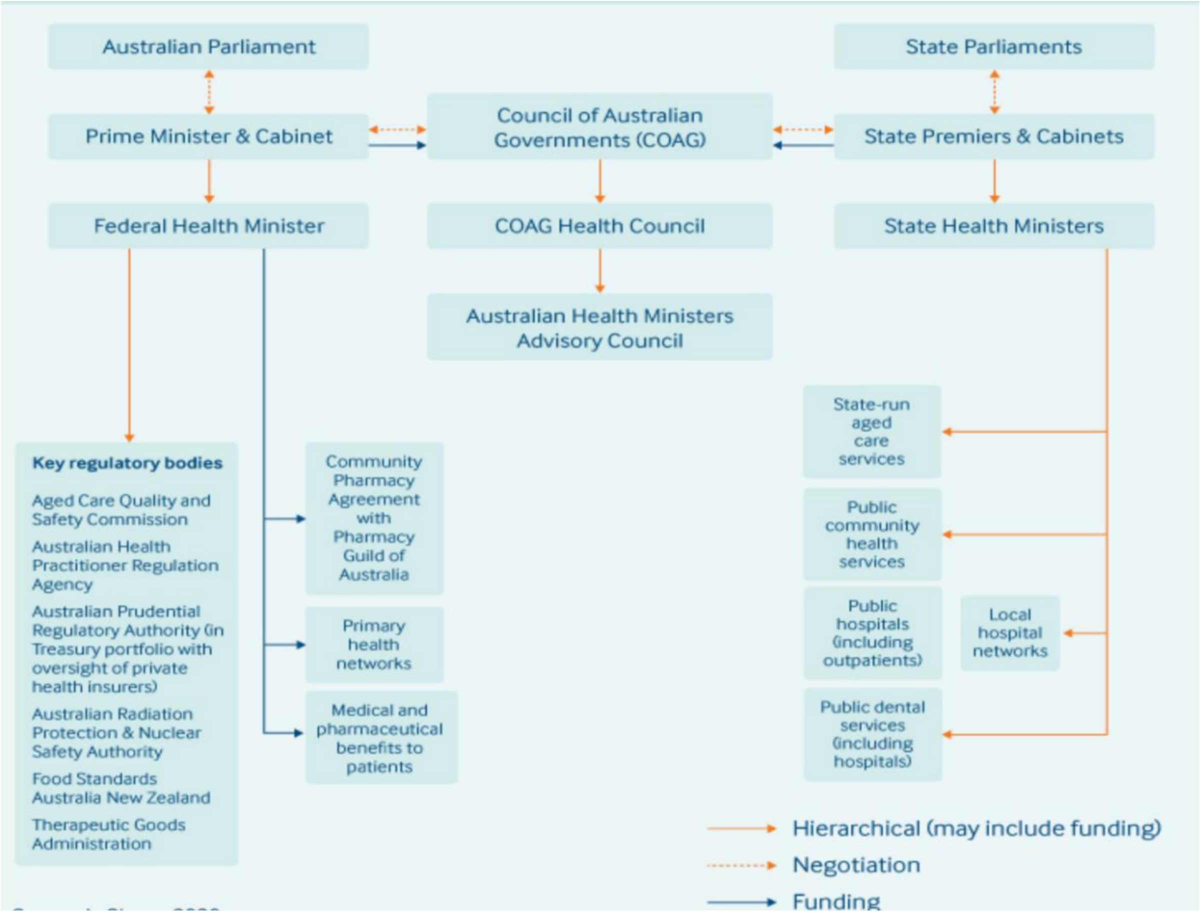


Figure 7 Organisation of the health care system in Australia (Glover, 2020)

2.9 Palliative care funding

As noted above, responsibility for providing and funding healthcare services is shared between the Federal and State and Territory Governments. The Federal Government does not directly fund palliative and hospice care services, but financial assistance is provided to State and Territory Governments to operate palliative services within health and community service provision responsibilities (Senate Standing Committee on Community Affairs, 2012). The Federal Government provides funding for national palliative care projects to assist universities, health services and palliative care organisations with research, education, and training and skills. State and Territory Governments provide grants to non-government organisations to promote access to these services.

The Federal Government pays approved aged care providers a subsidy for each person receiving government subsidised aged care (DoHAC, 2023a). Additional funding is given to aged care providers to look after those who have been assessed as needing palliative care, using the Aged Care Funding Instrument (ACFI) (AIHW, 2022d). In 2020–21 there were 90,700 admissions to hospital where palliative care was provided during all or part of the episode of care, with the average length of stay almost double the average for all overnight hospitalisations (AIHW, 2022d). Of these, 50,000 were for palliative care and 40,700 for other end-of-life care. One in two hospitalisations (53%) ended with the patient dying in hospital.

These figures demonstrate a 23% increase in the number of palliative care-related hospitalisations between 2015–16 and 2020–21 (AIHW, 2022d). In 2020–21, 14,500 people received 69,100 MBS-subsidised palliative medicine attendance and case conference services provided by palliative medicine physicians/specialists (AIHW, 2022d). Data does not identify avoidable hospitalisations; however the term ‘potentially preventable hospitalisation’ is an umbrella term used by researchers to describe hospital stays which could have been avoided with access to appropriate primary healthcare and which result in an increased burden on the health system (Glenister & Archbold, 2022).

Public and private hospitals both receive funding from the Federal, State and Territory Governments, private health insurance funds and individual out-of-pocket payments by individuals. However, the relative contributions made by these sources of funds vary across the sectors, reflecting the types of patients they treat, the services they provide, and the administrative arrangements in which they operate (AIHW, 2021c).

2.10 Geographical statistical data

The ABS collects and releases survey data which can then be used to support important decision-making (ABS, 2023g). This data is used by health service providers when developing, designing and planning policies for health service delivery within Australia (ABS, 2023g). The Census of Population and Housing (referred to as the Census) captures a large amount of the statistical data every 5 years which reflects the characteristics of Australian people. The ABS has developed a geographical classification system, which is hierarchical in structure, to provide accurate data on specific locations in Australia (ABS, 2021). The structure enables small areas to be grouped together to provide data about larger areas and enable comparison between old and new areas, reflecting any changes. Spatial categorisation systems include State and Territory boundaries, suburbs, LGAs, electoral divisions and postcodes. Each system has a specific purpose. Limiting data for planning and service delivery based on pre-defined area units, fails to consider the complexities of access, the fit between supply and demand, and the contextual variables associated with the location (McGrail et al., 2017; Wang, 2020).

Table 1 lists the main methods of classifying the locations used in health data analysis, research, resource allocation and service provision in Australia. The list is not exhaustive, and data obtained from the ABS is limited to Census data. Table 1 also provides a brief overview of the geographic or spatial classification used in healthcare, the method of classification and the measurements used to assist with comparison.

Table 1 Methods of statistical classification used in health

Model	**General Use**	**Classifications**	**Measurement**
The ASGS which replaced the Australian Standard Geographical Classification (ASGC) in use 1984–2011	Commonly used by AIHW in reports on smaller areas. Health services use ABS data in analysis and research Data may be used standalone or in conjunction with other statistical and/or social data	Classifies locations in hierarchical structure. Main structure has 7 levels from State/Territory (S/T), Statistical Areas Level 4 (SA4s), Statistical Areas Level 3 (SA3s), Statistical Areas Level 2 (SA2s), Statistical Areas Level 1 (SA1s), Mesh Blocks (MBs) The GCCSAs and Urban Centres and Localities (UCLs) and Section of State (SOS) are separate structures	Classifies areas as urban or rural based on aggregates of units of population size, dwelling density and urban character Data provided by ABS
Australian Statistical Geography Standard-Remoteness Area (ASGS-RA) developed from Australian Standard Geography Classification – Remoteness Area (ASGC-RA)	Purpose of releasing and analysing statistics to tailor services to meet the needs of regional and remote Australia	Classifies Australia into 5 classes of remoteness by accessibility to services Remoteness Areas (Ras) are aggregates of SA1s that are grouped together based on their average ARIA+ score	Classifies areas as remote using measurement of physical distance to an urban centre and the ARIA+ index of accessibility calculation to goods, services and opportunities for social interaction.
Indigenous Regions (IREG)	Health data directed at Indigenous health, particularly primary health care	Part of the ABS Indigenous structure enabling statistical analysis of data related to Indigenous communities and regions	Based on Indigenous population size in a hierarchical structure
Accessibility/ Remoteness Index of Australia Plus (ARIA+) developed in 2003 from Accessibility/Remoteness Index of Australia (ARIA)	Enable services to be tailored to meet the needs of regional and remote Australia	Continuous index of remoteness classifying locations into 5 areas of remoteness and 5 classes of accessibility	Defines remoteness in an index which calculates accessibility by levels per road distance to service centres Australia is divided into 1 km grids for ARIA and ARIA+ indexes which differs to SA1s used in ASGS-RA and ASGC-RA
Rural Remote and Metropolitan Area (RRMA), developed in 1994 and replaced with the ARIA	Used for general purpose policy and procedures related to rural and remote areas and workforce allocation	Classifies Australia into 3 zones (metropolitan, rural and remote areas) and 7 classes within the zones	Measures location by population size using Census data to classify locations
Modified Monash Model (MMM) introduced in 2015, developed from the Monash Model (MM)	Used in targeted programs to attract health professionals to more remote communities and to determine access to healthcare	Classifies locations as cities, rural, remote or very remote on an MM scale with 7 categories from major city to very remote.	Measures remoteness and population size of the area. Remoteness is determined by ASGS-RA.
PHN replaced Medicare Locals in 2015	Commonly used by AIHW in reports of smaller areas to meet local area needs	31 PHN areas which are classed as metropolitan or country Provides care for population in local area	Views locations as metropolitan or country, based on subsets of populations using data from ASGS-RA

LHN or Local Health District (LHD)	Provides public hospital services and may contain one or more public hospitals	Every public hospital is included in an LHN with boundaries defined by State/Territory governments.	LHNs are classified by S/T governments as metropolitan or country including at least one public hospital
Population Health Area (PHA)	Research and policy development requiring geographical statistical data for analysis and comparison in health datasets	Comprises a number of whole SA2s and aggregates of smaller SA2s	Classified per the SA2s which comprise the PHA to enable comparison of regions within the whole of Australia
Postcode and Postal Areas (POAs)	Postcodes assist with processing/delivery of mail POAs are an ABS postcode approximation POAs are used for a range of statistical data e.g. dashboards	Postcodes are defined geographic areas which are subject to change POAs are an ABS approximation of postcodes using one or more SA1s	Measures data in small spatial units of postcode areas or SA1s and aggregates
Local Government Area (LGA)	Datasets – e.g. life expectancy, mortality rates, rural and remote health outcomes	Comprises administrative areas of S/T which local governing bodies are responsible for	LGAs comprise a diverse range of communities with boundaries defined by S/T governments
ERP	Used by policymakers in planning	Links people to a usual place of residence and provides estimate by S/T and lower hierarchical levels	ABS official estimate of population by updating Census base by components of population change
Cities, Towns & Villages (CTV)	Used to analyse services	Extends statistical geography to consistently include joint population and service centres of any population size	Spatial distribution based on 2 characteristics – population centre and service centre –containing at least one identified service
Small towns	Used to gain insights into the makeup of small towns and implications for future policy and service delivery within regions	Locations with urban features grouped by population size	No explicit definition of towns, but urban centres and localities grouped by populations over 200

Table 1 demonstrates the complexities involved in the process of geographical classifications and measurements of accessibility and remoteness, which add to the service provision issues evident in peri-urban areas.

2.10.1 Classification of location

ABS data determines major classifications used to define areas in Australia as urban, rural, regional, or remote. The most commonly used classifications are as follows:

- RRMA classification (Senate Standing Committee on Community Affairs, 2007)
- ASGC 1984–2011 defines areas as urban/rural based on population density (ABS, 2006a, 2016b, 2022a)
- ASGC-RA determined 7 levels of remoteness between 1984–2011, based on distance by road to service centres (AIHW, 2004)
- ASGS 2011 to current (Edition 3) defines areas as urban/rural based on population density (ABS, 2006a, 2016b, 2022a)
- ASGS-RA which replaced the ASGC-RA in 2011, determines 5 levels of remoteness based on distance by road to service centres
- RAs and the ASGC-RA, based on ARIA or ARIA+ index values, classify remote areas
- ARIA or ARIA+, based on index values, classify remote areas based on the level of accessibility to goods, services and opportunity for social interaction (ABS, 2001b)

Ensuring that care is accessible to all Australians is one of the 6 principles viewed as fundamental to good palliative care, reflected in initiatives to remove accessibility barriers throughout the National Palliative Care Strategy (DoHAC, 2019). Health service policy decisions and the allocation of limited resources for service delivery are based on the degree of ‘urbanness or ruralness’ as defined by the ABS (AIHW, 2022b; 2009).

The ASGS collects and disseminates ABS geographical statistical data to classify locations in Australia based on hierarchical aggregates by population size, dwelling density and urban character to define areas as urban or non-urban (rural) (ABS, 2020). The smallest units of information provide the most accurate data and enable identification of smaller townships and communities which assists with effective resource allocation (ABS, 2022a). The boundaries range from small geographical areas to larger areas, but small areas are designed to ensure a size large enough to provide privacy and confidentiality to residents (ABS, 2020). Practitioners are already familiar with the challenges of maintaining privacy and confidentiality in small communities, including small rural pockets in peri-urban locations (Roufeil & Battye, 2008).

The importance of maintaining privacy has the unintended result of providing a larger spatial unit which provides a generalisation of the area as urban or non-urban. However, peri-urban locations are not homogenous; they have differing characteristics and often no discernible growth pattern (Buxton & Butt, 2020; McFarland, 2015). The smallest spatial unit used by health services is an SA2 with a population of 3,000 to 25,000 people. Small towns using Sections of State Ranges (SOSR) to compare small, medium and large towns with major cities (ABS, 2018a). Challenges become obvious in peri-urban areas due to the diversity of population and housing density that may be evident within each SA2. Definitions of Other Urban and Bounded Locality as urban or rural are too simplistic for use in peri-urban areas and fail to capture the needs of the community without additional local input.

The ASGC-RA classifies areas into 5 classes of remoteness via an index of accessibility, which has limitations when used in peri-urban areas due to a failure to consider consumer expectations of choice, quality and cost of available services (The Senate Community Affairs Committee Secretariat, 2012). ARIA and ARIA+ define remoteness in terms of relative access to a particular service. This definition uses the average distance of a location from a service centre and assumes that the greater the distance, the more remote the area and the less opportunities for social interaction and supply of goods and services.

Defining remoteness based on a simplistic measure of access alone does not consider the complexities involved, including location of the individual, distance to the service, the particular service involved and its affordability and appropriateness in the situation. Accessibility also becomes questionable when the requirement for a service centre does not include a requirement for specialist health services. Defining accessibility more broadly would lead to considering the dimensions of affordability, availability, accommodation, acceptability, and appropriateness.

The MMM is used by health providers to define a location as metropolitan, rural, remote or very remote, based on the ASGS-RA framework of geographical remoteness and town size (DoHAC, 2021). An MM category from 1 to 7 is used to determine eligibility for health workforce programs, including rural bulk billing and attracting health professionals to work in more remote and smaller communities; it is not relevant for peri-urban areas due to their proximity to major urban centres.

The ABS is not the sole provider of information used in health policy and research (Rural Health Standing Committee, 2018). Data provided by LGAs provide a smaller spatial unit than State or Territory, although the area has the potential to cover a diverse range of communities. It can be difficult to define peri-urban areas within LGA boundaries using LGA geography due to the variety of land uses that may exist. Classifying LGAs as peri-urban or metropolitan fringe due to their general proximity to urban centres has the potential to oversimplify challenges to accessing community health services that may exist for some residents within the LGA (ABS, 2020).

CTV geography was developed to assist with analysing the spatial distribution of services and access in regional areas of Australia. The Bureau of Infrastructure, Transport and Regional Economics (BITRE) (2019) uses ABS data to provide information on the spatial distribution of the Australian population by clustering people into locations where they both live and where services are located and can be accessed. Defining locations as CTVs extends statistical geography by identifying only those population centres which are also service centres and includes locations with populations of fewer than 200 persons (BITRE, 2019).

2.11 Summary

This chapter has addressed the research questions relating to how peri-urban areas are defined and how peri-urban locations are defined in community health policies. Rural locations challenge palliative care providers because they rely on primary healthcare providers and there are increased travel times for both patients and health workers which impact effective use and availability of resources and provision of quality care (Cinnamon et al., 2008). Healthcare resource allocation is influenced by funding arrangements, organisational structures and policies, and are based on geographical statistical data which uses population density and distance from services to ascertain accessibility. Distance is calculated using road distance between home location and the boundary of the closest urban centre. This simplistic calculation disregards the local geography, road surface, transport options and weather conditions, which all influence the actual time it takes to travel to an urban centre and the cost and accessibility of doing so. Healthcare providers calculate the distance to the closest hospital to ensure equitable access but that hospital may or may not have the capability to meet the complex healthcare needs of the patient (Barbieri & Jorm, 2019).

The surge in popularity of peri-urban living indicates the need for a better understanding of the basis for health service policy development in these areas which have a history of known health service challenges. It would appear unlikely that community health service delivery based on a model of delivery that assumes peri-urban populations are homogenous with their surrounding rural or urban areas will result in effective, person-centred care. Geographical classifications are provided in more detail in Appendix A.

Chapter 3: Social impact

3.1 Introduction

The term palliative care can have negative connotations for many people, because it can conjure visions of hospices and impending death (Collins et al., 2020). However, evidence suggests that early palliative care reduces physical and emotional distress and optimises quality of life for individuals, their caregivers, family members and friends (Aoun et al., 2020; Hui & Bruera, 2020; Seow et al., 2020). As the journey continues and death approaches, palliative support intensifies to relieve the patient's physical, spiritual and psychosocial suffering by controlling pain and other symptoms and avoiding prolonging the dying process (Mitchell, 2021; Rome et al., 2011). The focus of palliative care then shifts to bereavement and supporting the family following the patient's death.

Evidence has shown, however, that inequities of access to health and community services exist for those living outside metropolitan areas (Bakitas et al., 2015). Australians living in rural areas are known to experience poorer health and are far less likely to receive the palliative and end-of-life care needed, in comparison with their metropolitan counterparts (AIHW, 2022f; Bradford et al., 2016; Smith et al., 2008; Thomas et al., 2015). It is the similarities to rural locations which suggest that the urban–rural health divide will influence access to community palliative care service provision in peri-urban areas, thereby increasing the potential for physical and emotional distress, decreasing quality of life, and removing personal choice.

This chapter will address the overall research question by exploring some of the challenges of the urban–rural health divide in peri-urban locations and highlighting the implications of barriers to access for the patient, family caregiver and healthcare system. Attention will be given to the clinical challenges of care provision, the importance of psychosocial support, models of service delivery and the impact of the COVID-19 pandemic.

3.2 Clinical challenges

A diagnosis of a life-limiting illness presents substantial and overwhelming challenges for the person involved. Challenges include depression, feelings of hopelessness, loss of independence, fear of pain and other symptoms, loss of dignity and control, and fear of dying (Woo et al., 2006). The key components of community palliative care support include symptom assessment and management, support and coordination of services subject to needs and psychosocial care (Chan et al., 2021). Palliative care is holistic, person- and family-centred care; therefore, it is important to remember that the patient is not the only person impacted by an impending death. Families and loved ones are significantly affected by the diagnosis. There is an expectation that family members will manage the physical care and practical difficulties associated with daily living activities, cope with changed familial roles and responsibilities, and manage the associated financial and legal implications while handling their own home and work roles, emotional distress and concerns about future needs (Kristjanson & Aoun, 2004). Barriers to accessing in-home services can result in unplanned hospitalisation admission, presentation to emergency departments, reduced quality of life, strained and broken relationships and increased financial costs (Namasivayam et al., 2022; Pesut et al., 2014; Virdun et al., 2020).

Buxton and Butt (2020) noted that there are significant similarities and differences between areas classified as rural and those viewed as peri-urban. Peri-urban health services, including local hospitals, are generally smaller facilities with less available infrastructure, a limited workforce, and poor access to specialist care. They also rely on generalist primary healthcare providers to provide specialist palliative care (Bradford et al., 2016; Wenham et al., 2020). Although rural GPs play an essential role in providing palliative care, they may have limited knowledge and skills in managing end-of-life symptoms and inadequate training in facilitating difficult conversations, instead emphasising the pathophysiology of the disease (Brown et al., 2018; Ding et al., 2019; Erdiaw-Kwasie & Alam, 2016; Glare & Virik, 2001; Johnson et al., 2020). Any perception that the care provided has failed to meet the needs of patients and family members can be frustrating and distressing for all clinicians involved, increasing the likelihood of increased compassion fatigue, stress and burnout (Chan et al., 2021; Terry et al., 2015).

Challenges to accessing quality care can result in poor symptom management, increased anxiety, and poor coping strategies for patients. Pain and the fear of pain often drive patient behaviour and are common at the end-of-life, particularly cancer-related pain (Heinrich et al., 2022; Rome et al., 2011). Unrelieved pain can exacerbate other symptoms such as fatigue and anxiety, and increase psychological distress for patients and families, influencing decisions regarding the ability to cope and care location (Heinrich et al., 2022). Psychological distress for people facing an uncertain and impending death can result in depression, evidenced by feelings of hopelessness, helplessness, guilt, worthlessness, loss of perspectives, self-harm and suicidal ideation (Block, 2000).

Research has found that patients with cancer, especially those with a diagnosed psychiatric disorder, have a higher risk of dying by suicide (Cheung et al., 2017). There is an increased risk of suicide in the first year following diagnosis, especially in the first 3 months, which may arise through a desire for self-autonomy and control, with or without an associated diagnosis of depression (Cheung et al., 2017). The relatively higher risk of suicide has also been found to depend on the cancer type, generalised to those with a poor prognosis and high symptom burden in the first two years following diagnosis, and cancer types associated with long-term quality of life impairments (Hu et al., 2023). Figure 8 demonstrates the most frequent psychosocial risk factors for death by suicide in 2022. The factor ‘limitation of activities due to disability’, includes all types of disabilities and health conditions which affect an individual’s abilities and/or a perceived limitation of ability due to a newly diagnosed illness.

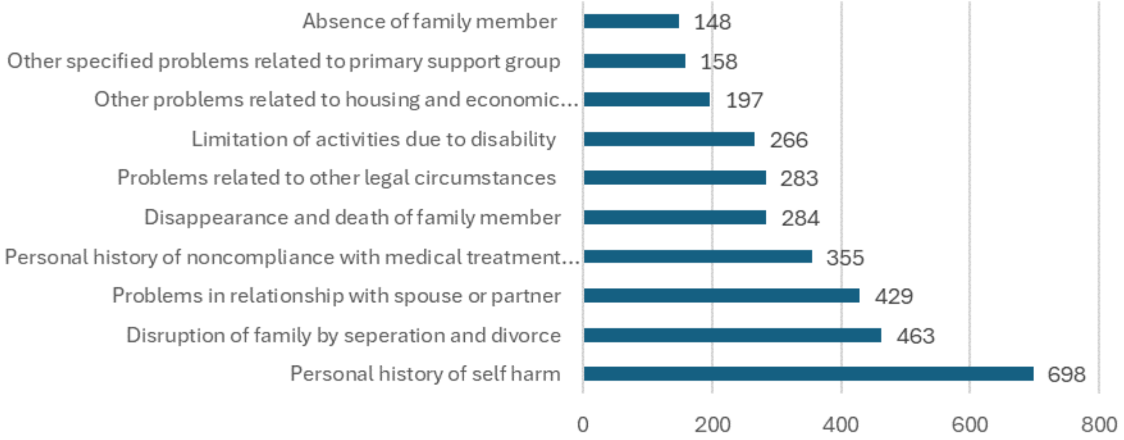


Figure 8 Number of suicide deaths, by psychosocial risk factors in 2022 (AIHW, 2023c)

Although suicidal thoughts may be fleeting in many people facing end-of-life, 3,249 deaths by suicide were recorded in Australia in 2022 – an average of 9 deaths per day (AIHW, 2023a). Data reveals that 1 in 5, or 20%, of suicides in New South Wales in 2019 were people with a terminal condition or those who had experienced a significant decline in physical health and functional ability (Go Gentle Australia, 2022). The perception of loss of independence, quality of life, value, dignity, pleasure in life, and sense of usefulness and purpose is associated with increased risk of suicidal ideation (Cheung et al., 2017).

Some people with a terminal illness will resort to tragic methods to end their lives, believing that they have no other option to end their suffering. Palliative care aims to optimise quality of life and remove distress through symptom management. For example, palliative sedation helps relieve the refractory distress of a dying patient but does not hasten death (Mroz et al., 2017). This is not physician assisted suicide (PAS), euthanasia or voluntary assisted dying (VAD). Euthanasia refers to a health practitioner intentionally ending the life of a patient through medical means following the explicit request of the patient, and PAS involves the health practitioner providing or prescribing drugs for a patient to end their own life (Mroz et al., 2017). VAD laws and legislation in relevant States and Territories provide an option for terminally ill people to die peacefully at a time and place of their choosing, either by self-administration or by a physician stepping in to assist (White et al., 2021). Further discussion about VAD, euthanasia, or PAS are outside the scope of this research.

It is important to remember that every number in the total of lives lost to suicide is a person, and a life which was valued and will be missed. The impact from the loss of this person on family, friends and the community cannot be underestimated, with an unnatural death such as suicide likely to result in traumatic grief (Swarte et al., 2003). Tragic deaths also impact the personal and professional lives of the health practitioners and support staff involved, resulting in consequences for staff wellbeing, recruitment, retention and patient care (Croft et al., 2023). Although palliative staff are frequently exposed to death, the emotional effects following a death by suicide have been described as strong feelings of guilt, sadness, grief, responsibility and shock, in addition to fear of post-death investigation and concern about blame from employers or professional bodies (Croft et al., 2023; Fairman et al., 2014). Long-term repercussions from a terminal patient taking their own life may result in loss of confidence, hypervigilance regarding suicide risk in patients, aversion to caring for terminal patients, career change or early retirement (Croft et al., 2023; Fairman et al., 2014).

The place where people with life-limiting illness receive care and die, and the option of how death occurs, depends heavily on accessibility to quality healthcare services. The choice may be a consequence of limited resources and a lack of available alternatives, rather than preference (Gomes & Higginson, 2006). Peri-urban locations offer limited options for treatment and care and limited choice of location for end-of-life care, often resulting in relocation or foregoing preferences for care, treatment and place of death (KPMG, 2020; Saurman et al., 2022). Patient preferences for a specific dying process, in-home or community palliative care, or a home death have been associated with a higher quality of life and are often used as a marker of a good death (Boamah et al., 2021; Gerber et al., 2019).

Factors which influence patient accessibility to a choice of in-home services and preferred place for end-of-life care and death, not only influences quality of life and wellbeing but also impedes the grieving process for family and friends (KPMG, 2020; Saurman et al., 2022). Families in rural environments feel unsupported if they're unable to fulfil the final wishes of a loved one to die at home due to a lack of support from service providers (Spelten et al., 2019). Generalist primary health care services and specialist services delivering community palliative care in rural locations have limited capacity and resources to support palliative patients, families, and communities, resulting in challenges to meet both demand and expectations for quality care (Namasivayam et al., 2022; Weng et al., 2022).

3.3 Psychosocial support

Grief is the normal emotional reaction to loss. Providing grief and bereavement support for people dealing with impending death and their family members coping with loss are core components of palliative care that have a significant, positive impact on the people involved (Hudson et al., 2012; PCA, 2020). In many instances, however, this support may be suboptimal or even non-existent in areas outside of urban centres, with emotionally-burdened family members hindering patients' care and adjustment to their illness (Hall et al., 2012). Following a death, most individuals will utilise their own strategies and support networks to deal with the grief reactions, but the consequences of bereavement vary for each individual (Hall et al., 2012; Hudson et al., 2018; Thompson, 2017).

Grief is a broad term which incorporates the losses that an individual may experience over a lifetime and is evidenced by a series of psychological, physical, behavioural and emotional responses (Murray, 2023). Anticipatory or preparatory grief refers to the distress a person may feel prior to their own death or the death of a loved one. Distress, in this context, includes the concept of social death, which refers to the ways in which someone is treated as if they were dead or non-existent although they remain physiologically alive (Borgstrom, 2017). Social death involves a loss of personhood, loss of social identity, a loss of social connectedness, and losses associated with physical deterioration (Králová, 2015). Social relevance refers to the manner in which clinicians interact and perceive a person who is dying which subsequently diminishes their self-identify (Borgstrom, 2017).

Bereaved family caregivers may experience a different form of social death, resulting from isolation caused by caring for a dying person, and a loss of identity and role (Schneider, 2006). The term bereavement pertains specifically to the state of having lost a loved one to death and the time period after, although the terms grief and bereavement are often used interchangeably (Johns, 2015). The emotional and physical pain experienced following the death of a loved one or by someone experiencing anticipatory grief or social death, is different for everyone (Johns, 2015; PCA, 2020). Factors such as personality, available support symptoms, relationships and disease progression all contribute to coping ability (Grief Australia, 2022).

Known as complicated or prolonged grief disorder, family caregivers experiencing intense feelings of grief for extended periods can face severe mental and physical health problems (Boelen & Prigerson, 2007; Prigerson et al., 1996). A lack of preparedness for death, unmet needs or an unnatural death have been associated with more intense and persistent symptoms of distress in an estimated 10% to 20% of family caregivers coping with bereavement (Hall et al., 2012). All individuals experience grief in the context of their whole being; however, traumatic grief can manifest as insomnia, substance misuse, depression, depressed immune function, hypertension, cardiac problems, cancer, and work and social impairment (Hall et al., 2012; Thompson, 2017). Prolonged or complicated grief increases the likelihood of frequent hospitalisation and higher use of medical services (Hall et al., 2012). When bereavement is the result of suicide, those left behind are at increased risk of ongoing mental health concerns and are two to five times more likely to die by suicide themselves (National Suicide Prevention Project Reference Group, 2020).

There is an expectation that all palliative care providers have the capacity to assess and provide referrals for family members and caregivers needing bereavement support (PCA, 2018c). Access to grief and bereavement support for individuals living outside of metropolitan areas, however, is often poor due to a lack of professionals experienced and educated in grief and loss, despite evidence suggesting the effectiveness of intervention (Currier et al., 2008; Johns, 2015). Palliative teams in peri-urban locations are often insufficiently resourced and may have limited access to generalist services let alone specialist bereavement support (PCA, 2020; Thompson, 2017). Furthermore, there has been a shortage of evidence-based strategies or accepted bereavement standards to help health professionals provide psychosocial and bereavement support (Hudson et al., 2018).

Bereavement support then falls to GPs or nursing staff with an interest in this area or generalist social workers who may be unwilling to accept a referral due to a lack of experience and skills in grief and loss (Bryce et al., 2021). Skilled psychiatry support via telehealth is available to support people in the community; however, even telehealth availability is limited by a lack of skilled clinicians (Nelson et al., 2023; Scheil-Adlung, 2015). A lack of bereavement support has the potential to significantly impact the wellbeing, physical and mental health and financial security of people unable to cope with the death of a loved one (Johns, 2015; PCA, 2020). The standard of quality care and access to skilled and competent staff should not depend on geographical location.

3.4 Ageing population

Another critical challenge is the current and projected increased rate of our ageing population. Australians are expected to live longer than ever, with the population projected to reach 40.5 million in 2062–63 (Department of the Treasury, 2023). Australia's population was 26,473,055 on 31 March 2023, indicating an annual growth of 2.2% or 563,200 people (ABS, 2023e). Australia's population will continue to age over the next 40 years, with the number of people aged 65 and over more than doubling, and those aged 85 and over expected to more than triple; the number of centenarians is expected to increase six-fold (Department of the Treasury, 2023). Figure 9 shows the distribution of age structures and the change between

1982–83, 2022–3 and projected age distribution in 2062-63. The reference to ‘older Australians’ used throughout this chapter, will refer to people aged 65 years or older.

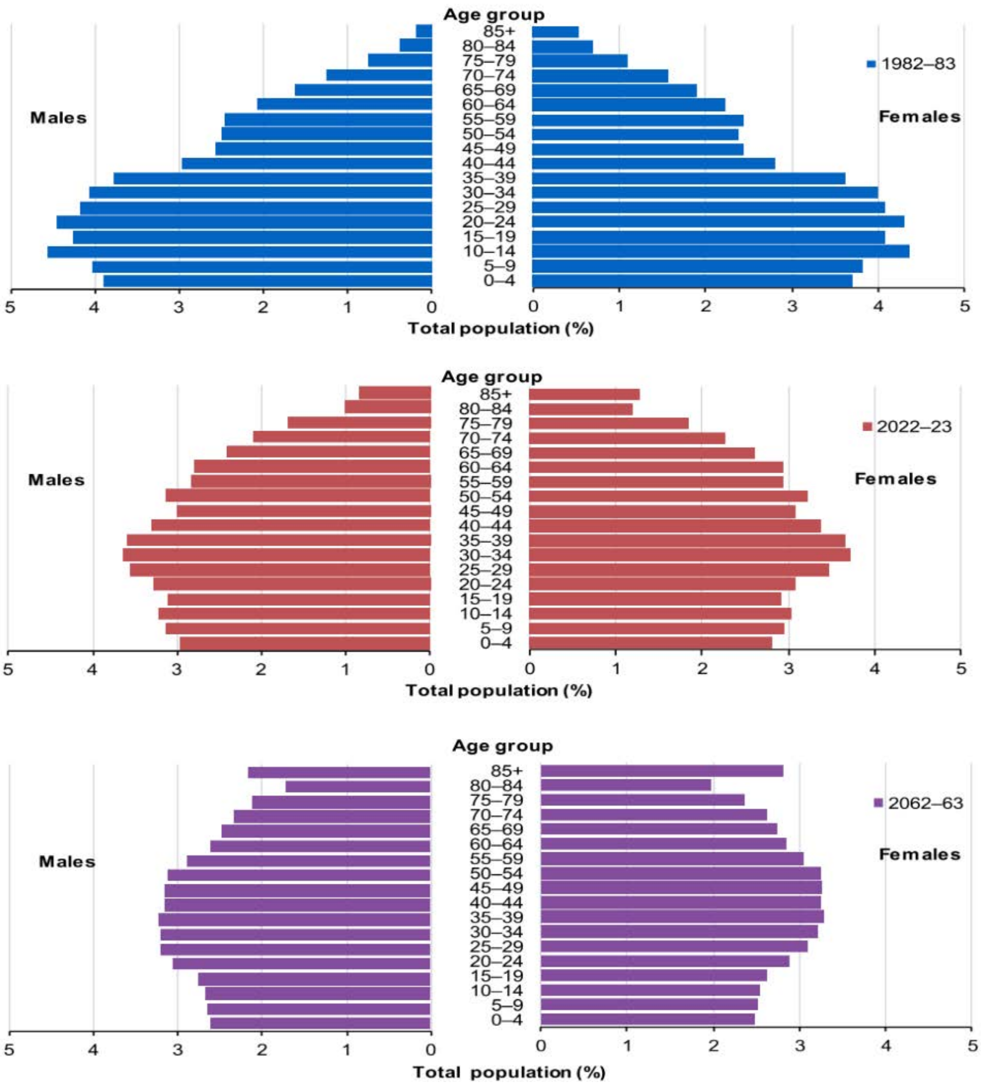


Figure 9 Comparison of age distribution, 1982–83, 2022–23 and 2062–63 (AIHW, 2023b)

Many older Australians report a desire to age in place, but the relationship between this desire and the reality of housing and financial circumstances will ultimately influence decision-making (AIHW, 2013; Urban Development Institute of Australia (UDIA), 2023). Research has estimated that 440,000 older, low-income households in Australia will be unable to find or afford suitable housing by 2031, due to home ownership rates falling, reduced access to public housing and more people carrying a mortgage debt into retirement (Faulkner et al., 2023). The need for homeowners and those seeking rental accommodation to find affordable housing is predicted to significantly increase population growth in peri-urban, rural and regional locations (Faulkner et al., 2023). In addition, lifestyle and downsizing are important factors for older Australians when considering whether to relocate, with peri-urban population growth driven by proximity to major cities, lower cost of living and retirement amenities (Centre for Population, 2019).

Future trends in population growth are difficult to project, but in the 12 months to June 2021, the combined population of Australian capital cities declined, while regional areas gained 49,000 people – an increase from 30,000 in 2019–20 (Centre for Population, 2022b). One of the challenges of predicting future growth in peri-urban locations is the lack of uniform distribution of growth, as development occurs at differing rates (Foster et al., 2013). Past trends, lifestyle factors, proximity to amenities and financial factors all indicate population growth of older Australians in peri-urban locations which will correspond with increased demand for community palliative care services (Faulkner et al., 2023; PCA, 2022).

Older Australians generally live healthier lives than previous generations, however, many people live with chronic health conditions. The ABS estimated that in 2017–18, 1.1 million older Australians lived with one chronic condition, 831,000 had two and 1.0 million lived with three or more (AIHW, 2021d). Corresponding with an ageing and growing population living with chronic conditions is the expectation that more people will be diagnosed with chronic illnesses and substantially increase the demand for palliative and end-of-life care (AIHW, 2023b; Nevin et al., 2019). The estimated demand for palliative care in Australia is expected to increase by 50% between now and 2035, and double by 2050 (KPMG, 2020). The trend for older Australians to relocate to peri-urban areas highlights the need to revise current healthcare services and methods of service delivery and reinforces the significance of this research.

One of the difficulties for healthcare and palliative care services providing care and treatment for people with chronic conditions in locations outside of urban centres, is the low level of exposure to the conditions by some primary care providers and the differing care needs of the illnesses. Most people die from chronic diseases that progress along one of 3 typical illness trajectories – chronic disease management, to treatment of advanced illness, to a palliative approach, end-of-life care and terminal phase (Reymond et al., 2018; Royal Australian College of General Practitioners (RACGP), 2023). The trajectories influence all facets of service provision, care needs and treatment provided, with pre-emptive planning for end-of-life care difficult for clinicians who lack specialist expertise. The trajectories are shown in Figure 10 and are as follows:

Trajectory 1: Cancer (short decline). This typically progresses steadily with slight decline in physical health over months to years and periods of positive or negative effects of cancer treatment. This is followed by a short period of evident decline with a clear end-of-life phase of increasing symptoms and rapid decline in weight and functional status in the last weeks or months of life (RACGP, 2023).

Trajectory 2: Organ failure (intermediate with acute episodes). Organ failure typically occurs in non-malignant, life-limiting illness (e.g. advanced heart disease, lung disease). There is an intermediate rate of decline in function over years with long-term limitations and acute, often life-threatening exacerbations and hospital treatment, followed by further deterioration. Death often seems 'sudden' and may occur at any time along the trajectory, with symptoms of end-stage organ failure (RACGP, 2023).

Trajectory 3: Frailty or dementia (gradual dwindling). Typically, this trajectory is a gradual dwindling decline of physical and/or cognitive function. People with dementia have a long, variable disease course up to 6 to 8 years prior, early impairment of memory and reduced capacity for decision-making and communication. The last year of life is characterised by a steady slow decline in overall function, rather than a sudden decline in any one domain. Frailty and dementia together predict a more rapid decline (RACGP, 2023).

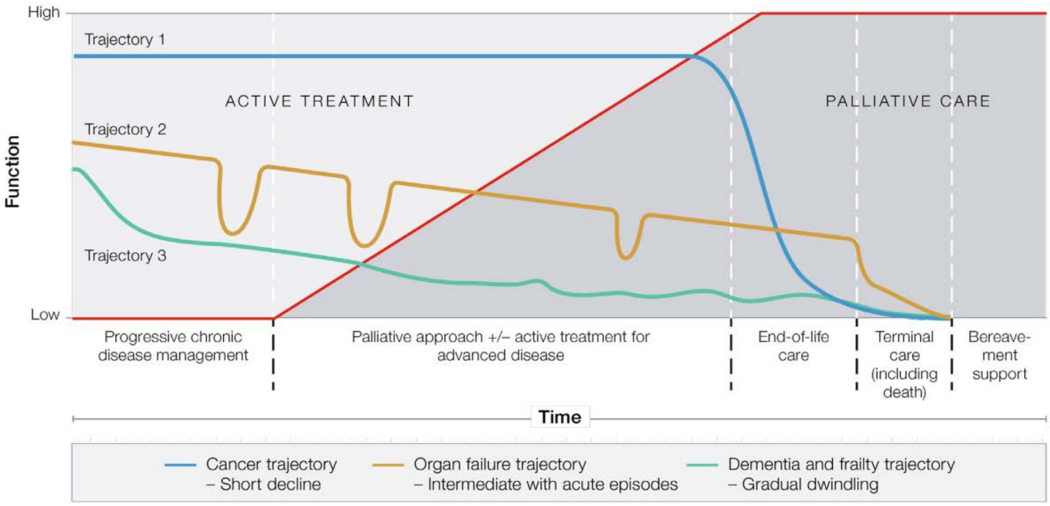


Figure 10 Typical illness trajectories towards end-of-life (RACGP, 2023)

3.5 Mortality rates

The concept of a good death or 'dying well' has been described as a multifaceted and unique experience for each person, shaped by individual attitudes, spirituality and cultural background (Meier et al., 2016). A good death gives people dignity, choice and support to address their physical, psychological, social and spiritual needs (Swerissen & Duckett, 2015). A good death involves being able to choose and control the location of death, who is present, and what support, care and treatment is provided (Robinson et al., 2016). Dying well also requires good end-of-life care which involves palliative care involvement with support and services to optimise quality of life and reduce pain and suffering (Swerissen & Duckett, 2015).

Australians consistently voice a preference for a home death, surrounded by loved ones, yet over the past 100 years home deaths have declined and institutionalised deaths have increased (Swerissen & Duckett, 2015). There are multiple reasons why a person changes their preference for place of death; however, it is important to understand if barriers to accessing in-home palliative services are a significant factor. It is therefore important to explore mortality rates and places of death to provide a more holistic picture of peri-urban community requirements and to encourage more investment in community-based support to carry out people's wishes to die at home.

Figure 11 outlines all deaths across Australia from January 2022 to August 2023. There were 190,939 deaths in Australia in 2022, which is 20,000 higher than 2021 and is not considered to be a typical year for mortality in Australia; COVID-19 was a significant contributor to the mortality rate during this period (ABS, 2023b). In 2023, there were 122,112 deaths that occurred by 31 August, which is 11,974 deaths (10.9%) more than the baseline average (ABS, 2023f). In August 2023 there were 15,736 deaths, 1.5% more than the baseline average, and 13,856 of these deaths were doctor certified with the remainder coroner certified (ABS, 2023f). COVID-19 had a significant impact on life expectancies in countries other than Australia; in the US life expectancy fell by 2 years for males, and in the UK it fell by 1.5 years (Centre for Population, 2022a). The medium- and long-term effect of future COVID-19 waves and variants on mortality in Australia is unclear.

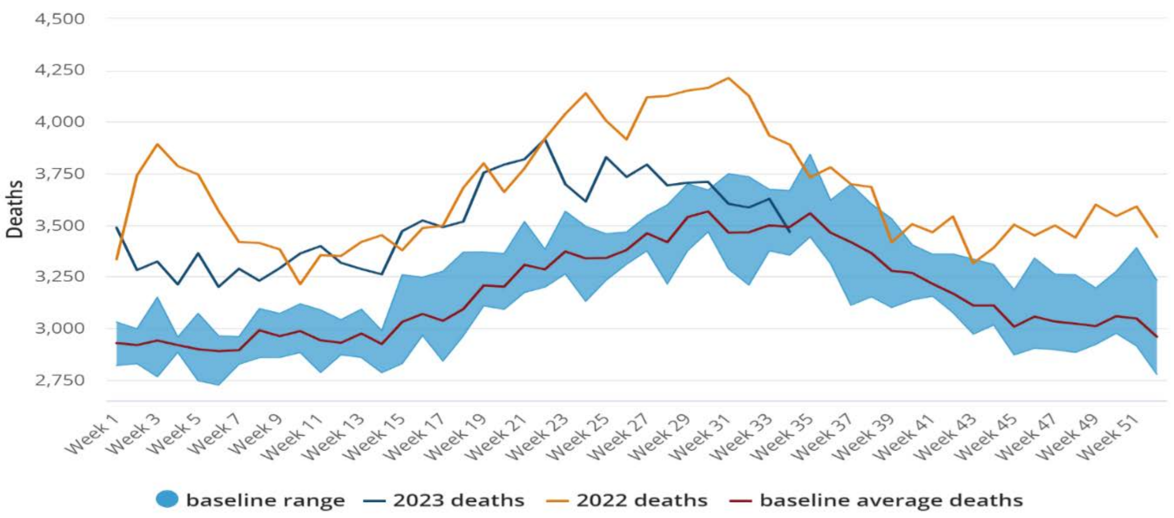


Figure 11 All deaths, Australia, 3 January 2022–27 August 2023 vs baseline benchmarks (ABS, 2023f)

The Australian Hospital Statistics provide numbers of deaths in hospitals and the National Coronial Information Systems for coroner-referred deaths (ABS, 2023f). Place of death can also be collected through the Civil Registration system on either a Death Registration Form or the Medical Certificate of Cause of Death for provision to the ABS by the Registries of Births, Deaths and Marriages (RBDMs) (ABS, 2023f).

It is important to consider that indicators related to place of death do not acknowledge patient preference, and emergency department presentations or number of hospitalisations may not reflect accessibility issues (Barbera et al., 2015). The ability of a service to maintain overall patient volume may represent effective maintenance of services, however, it may not represent quality person-centred care provision (Barbera et al., 2015; Lally et al., 2021). Statistics for place of death do not capture any important factors which contribute to the end-of-life experience. These include if the place of death was the person's preferred place of death, pain or comfort levels, psychological care, spiritual aspects or family support. Statistics do not include reasons for transfer, or who made the decision to transfer if place of death was not the patient's preference. Regardless of this lack of additional factors, the place of death results for 2019 were as follows:

- The majority (51.0%) of deaths in Australia occurred in a hospital/medical service area.
- Residential aged care facilities were the second most common place of death, accounting for 29.5% of all deaths.
- Other specified locations were the least common place of death (1.4%).

- Of the 169,301 records in scope, 5,792 records (3.4%) did not contain sufficient free text place of death information to be assigned to a specified place of death category in the Civil Registration system.
- Despite 60–70% of Australians expressing a wish for end-of-life care and a home death, only 14.8% of all registered deaths in Australia, or 24,970 deaths, were registered at a person’s home or place of residence (not including aged care facilities) (AIHW, 2021a).

3.6 Impact and challenges of COVID-19

3.6.1 Background

The global scale of the economic and social disruption and devastating impact on life from the SARS-CoV-2, the virus that causes COVID-19, was unprecedented. More than 3 years into the pandemic, COVID-19 continues to have direct and indirect impacts on health and dying, particularly in areas outside of major Australian cities. COVID-19 was declared a Public Health Emergency of International Concern on 30 January 2020 with an official death toll of 171 (WHO, 2020b). As of 2 November 2023, there were 6,977,023 deaths reported to WHO globally – a number that is likely to be a gross underestimation (WHO, 2023). The first case of COVID-19 in Australia was confirmed by the Victorian Health Authorities on 25 January 2020 and was linked to an international flight from Wuhan to Melbourne (DoHAC, 2020). The first wave began in early 2020 and ended in April, the second wave emerged from 11 June 2020 and variants of the virus have continued to evolve.

3.6.2 Government response

Australian State and Federal Governments responded quickly to the impending health crisis with a whole of government response, aiming to minimise the number of people becoming infected, manage the demand on the health system and make COVID-19 vaccines available to everyone (DoHAC, 2022b). The result was sudden social, economic and technological changes across Australia, which significantly changed life for all Australians (Brousselle et al., 2020; Infrastructure Victoria, 2021). Government responses included developing guidelines and action plans to guide the response to COVID-19 from organisations and individuals. International travel restrictions and border control were a strong focus of the Federal Government’s response, with a ban on travel from China implemented on 1 February 2020 (Costantino et al., 2020). Regular reviews resulted in travel advice and border restrictions rapidly adapting as situations evolved, culminating in a complete border closure to all non-citizen/non-resident international arrivals on 20 March 2020 (Costantino et al., 2020).

At the national level, economic support packages were released to secure jobs, financial support packages were made available to upgrade healthcare services, COVID-19 testing centres were established, traditional models of health service delivery were changed with telehealth services established, adequate medical supplies were made available and up-to-date information and education were provided to the public (DoHAC, 2023b). At State and Territory levels, responses included testing all suspected viral infections to ensure early detection, contact tracing and non-pharmaceutical intervention measures were implemented, such as quarantine, mandatory lockdown, social distancing and mandatory mask (Errett et al., 2020). Interstate and intrastate travel restrictions were initiated to protect vulnerable communities (Nguyen et al., 2022) and State and Territory Governments implemented policies such as the South Australian Acute Care Response Strategy, to support decanting patients to peri-urban hospitals in an effort to retain capacity at metropolitan acute sites for COVID-19-related care at peak infection times (SA Health, 2021).

3.6.3 Impact of counter-urbanisation

A relationship between the start of the COVID-19 pandemic and an acceleration of counter-urbanisation has been established (Beck & Hensher, 2021; McManus, 2022). Increased population growth in these peri-urban areas has had a direct influence on the quality and accessibility of palliative and end-of-life care due to the corresponding increase in the number of people potentially impacted by urban–rural inequity.

Media used the term ‘urban refugees’ to describe the unprecedented population growth in rural and regional areas due to people fleeing to the assumed safety of rural life (Argent & Plummer, 2022; Regional Australia Institute, 2021). People relocated away from densely populated urban areas solely to escape the risk of infection (Argent & Plummer, 2022; Denham, 2021; McManus, 2022; Nagel, 2020). Population statistics reflect the accelerated trend of counter-urbanisation in those metropolitan fringes which were previously viewed as rural (Guaralda et al., 2020). Reduced housing prices in peri-urban areas in comparison to metropolitan centres, increased the viability of relocation which was reflected in increased demand (Nygaard & Parkinson, 2021).

Improved road networks increased viability for relocating home for those employed in Fly-in Fly-out (FIFO) and Drive-in Drive-Out (DIDO) arrangements, thereby changing the traditional relationship between place of work and home (Charles-Edwards, 2021). The pandemic also influenced choice of permanent home location for those with dual residences such as a holiday house, and for couples living apart together (LAT) (Charles-Edwards, 2021).

Relocation was also a viable option as more people were able to work remotely from home; the routine of a daily commute was removed by integrating digital technologies into work routines (Amirinejad et al., 2018; Attorney-General's Department, 2021; Davies, 2021). Prior to the pandemic, approximately only 8% of employees worked from home, however, government requirements resulted in many finding the experience beneficial and effective (Productivity Commission, 2021).

The flexibility of working remotely provided the opportunity to choose a residential location based on lifestyle and affordability rather than commute distance and time (Beck & Hensher, 2021; Centre for Population, 2020). Remote working options offered the potential for increased autonomy, job satisfaction and significant financial and time benefits for employees, which could be invested into activities that improve quality of life for individuals and families (Beck & Hensher, 2021; Nagel, 2020). Major employers have indicated that flexible remote working arrangements are likely to remain in place, forcing employees that otherwise may have been reluctant to work from home, to adapt quickly to new technologies (Centre for Population, 2020; Nagel, 2020).

Working from home includes flexible working arrangements, which require employees to be present in the office for a portion of a working week. This practice, also known as telecommuting or hybrid, needs to consider whether the existing digital infrastructure can meet requirements. It also limits the choice of location for those seeking a rural lifestyle and working from home options to areas within commuting distance to urban centres (Denham, 2018). Peri-urban locations subsequently have become a long-term location of choice for many because it can generally support remote working or study options (Ruiz-Martínez & Esparcia, 2020).

COVID-19 unexpectedly accelerated the expansion of Australian major cities with growth in peri-urban locations increasing the already blurred lines between urban and rural (Argent & Plummer, 2022; Attorney-General's Department, 2021; Infrastructure Victoria, 2021; Wynne et al., 2020). Large high-density residential developments had already begun as land became available in areas previously viewed as rural (Walters, 2021). Development planning included required infrastructure to meet the needs of growing residential developments; however, infrastructure and service growth consistently lagged behind housing construction prior to the unanticipated growth from COVID-19 refugees (Newton et al., 2017).

The need to accelerate development of services and infrastructure in outer fringe locations should be an investment priority, given the scale of likely growth (McDougall & Maharaj, 2011). However, development creates a challenge for planning due to the need for a coordinated approach between the many local and state authorities involved (Reinhard &

Buckland, 2022; The Committee for Sydney, 2017). Financial and investment constraints further complicate decisions about whether to initiate a program of investment to retrofit ageing existing urban infrastructure or to develop peri-urban areas to meet community needs (Newton et al., 2017). People often have preconceived views of rurality – often a psychological construct of a lifestyle interacting with nature, a false belief of understanding life in areas previously designated for agricultural purposes (Gregory, 2009). There are benefits to rural living, but these locations lack uniformity in characteristics, demography and available services due to varying distances to urban centres (Hart et al., 2005; Taylor et al., 2017). This often results in deep chasms between expectations based on beliefs and goals, and the actual lived experience (Proulx et al., 2012; Ragusa, 2010). These tree- or sea-changers may not consider the possibility of poor mobile reception or unreliable internet or the time required to commute to friends and family, or actual proximity to local amenities, utilities and services, including pharmacies, medical clinics, tertiary hospitals or hospice facilities (Ragusa, 2010).

There is a view that the pandemic did not cause but merely accelerated an already existing trend of counter-urbanisation, especially when the daily commute was not an issue due to upgraded road networks (Amirinejad et al., 2018; Attorney-General's Department, 2021; Davies, 2021). In the 2020–21 financial year, internal migration resulted in 49,200 people leaving Australian capital cities, which contributed to the 70,900 people that moved to regional Australia (ABS, 2022d). The pandemic prompted people to change lifestyle. Many individuals realised that location was no longer a factor when they had to stay at home, social distance, and work, and study remotely (Guaralda et al., 2020; McManus, 2022).

A survey of internal migration patterns in Victoria post COVID-19 found that people aged 18–24 years were more likely to be influenced in choice of location by employment opportunities and those older than 45 years seeking lifestyle changes (Ghin & Ainsworth, 2022). Eighty percent of the surveyed population relocated to within 125 km of Greater Melbourne, which is considered peri-urban and within the distance considered as commuting distance and accessible to goods and services (Ghin & Ainsworth, 2022).

Financial year data from 2020–21, also suggests that COVID-19 impacted decisions to relocate, although it is unclear if the response will remain a temporary or a permanent transition as control measures change over time (ABS, 2022d; Davies, 2021; Guaralda et al., 2020; McManus, 2022). The ABS is also projecting that populations in major Australian cities will double between 2018 and 2066, with strong links between peri-urban areas and adjacent cities (ABS, 2018b; Thornton et al., 2022).

3.6.4 Modes of service delivery

The beginning of the COVID-19 pandemic posed significant and unexpected challenges for all healthcare services but particularly palliative care clinicians planning the delivery, availability, and quality of palliative and end-of-life care. At the commencement of the pandemic, the projections of hospitalisations and deaths due to COVID-19 posed enormous challenges to provision of person-centred care. The pandemic caused traditional primary healthcare services to dramatically change in a short timeframe (Stockdill et al., 2021; Taylor et al., 2021a). Primary care providers had access to very little evidence to inform, guide and support the required changes, resulting in negative reports from providers who felt that they were unable to provide appropriate care (Halcomb et al., 2021) The result was a rapid transition to telehealth for palliative clients at particularly high risk of poor outcomes through exposure to the virus (Lally et al., 2021).

The transformation of healthcare delivery to digital health had the potential to remove the barriers of time and location, to provide after-hours support and education and to remove feelings of isolation for palliative patients (Guenther et al., 2020; Lally et al., 2021; Namasivayam et al., 2022; Schulte et al., 2022). Telehealth provided the opportunity to enhance the number and quality of patient–physician encounters in the patient’s own home and enabled family members to participate in clinical encounters, regardless of their location, with reduced risk of infection (Lally et al., 2021). Palliative care community providers were able to maintain contact with specialists in tertiary centres and participate in education via video conference. Multidisciplinary meetings were also able to continue in a virtual and safe environment (Milch et al., 2021; Ray et al., 2014). Other potential financial benefits to providers included reduced travel, shorter interactions and economies of scale (Snoswell et al., 2020).

The ability to maintain effective communication and collaboration between patients, families and palliative care service providers is crucial for shared and informed decision-making, which is essential when providing person-centred care (Saurman et al., 2022; Schulte et al., 2022). It is important to provide advocacy for people to participate in needs assessment and development of local initiatives to improve wellbeing and quality of life interventions in palliative care (Erdiaw-Kwasie & Alam, 2016). Transitioning to phone and video consults was necessary for palliative care services to maintain communication and complex care needs in a convenient and safe environment for patients and practitioners (Dolan et al., 2021).

The sudden change from a predominantly face-to-face method of community palliative care service delivery to one that incorporated telehealth was generally well accepted by clinicians; however, some voiced concerns which added stress to an already fragile health service (Bate et al., 2021). Practitioners and consumers were concerned about privacy, security and a lack of accessibility and capability to use digital technologies (Dolan et al., 2021; Lally et al., 2021; Milch et al., 2021; Organisation for Economic Co-operation and Development (OECD), 2020). Other concerns were about the difficulty in conveying empathy and communicating sensitive information, particularly due to a lack of physical contact when touch is often used to support someone in distress (Collier et al., 2016; Milch et al., 2021). Practitioners faced difficulties responding to body language and facial cues due to an inability to view patients during telephone consults when video consultations were not possible (Eastman et al., 2021; Lally et al., 2021).

Cultural, psychological and disease-related factors influence the communication styles adopted by practitioners to convey necessary information to patients who may have misunderstandings about their prognosis and hold unrealistic hopes of a cure (Ghandourh, 2016). A review of people receiving community end-of-life care during COVID-19 identified feelings of concern about finances and infection but it was the loss of direct connection with their regular healthcare providers at that time that triggered increased distress and anxiety (Mitchell et al., 2021). Feedback has been sought by health services to understand practitioners' experiences and expertise with using digital technologies in palliative care provision so that programs can be developed and improved but feedback may be biased and not necessarily reflect the patient's or family's unmet needs (Dolan et al., 2021; Weng et al., 2022).

Whilst the change from a traditional face-to-face method of service delivery to digital health improved accessibility in the short term, it is important to refrain from viewing digital health as the panacea to removing the inequities of heath service access in all situations over the long term. Policies regarding service delivery need to consider the benefits of maintaining face-to-face contact, regardless of the geographic location of care, and instead view digital health as a complementary service method (Collier et al., 2016; Mills et al., 2021). Services such as palliative care are founded on respectful relationships developed through face-to-face delivery and generally include interdisciplinary face-to-face encounters (Lally et al., 2021; Milch et al., 2021; Namasivayam et al., 2022).

The Australian Government had already recognised the potential of telehealth in meeting the needs of Australians experiencing access barriers to healthcare services prior to the pandemic when they introduced a policy on telehealth funding in 2011 (Bradford et al., 2016). During the years that followed, Australian healthcare providers increasingly adopted digital health technologies in an effort to meet stakeholder needs and respond to issues in the health system (Hii et al., 2022). The COVID-19 pandemic, however, had an unintentional consequence of accelerating the national program of digital technology development as health services sought methods to maintain service delivery (OECD, Beck & Hensher, 2021; 2020). The use of digital technologies removed the barriers of time, location and accessibility to all health care services whilst providing the benefit of reduced risk of exposure to the virus (Cherry et al., 2018; Hambleton & Aloizos AM, 2019; Schulte et al., 2022; St Clair & Murtagh, 2019).

All Australian healthcare providers were encouraged to move away from traditional face-to-face health care delivery due to risk of infection and develop their available digital technology to enable delivery of healthcare services during the pandemic (Petrie et al., 2021). Research found that rural Australian medical clinics developed their use of digital technology as the need arose and per the available technology (Petrie et al., 2021). Globally, the potential impact of digital transformation on future health reforms is tremendous (Nwosu et al., 2022; Taylor et al., 2021a). However, COVID-19 highlighted the challenges facing Australians living outside of major cities that may not be able to access reliable internet connections or have the digital literacies and skills required, particularly those aged over 65 years (Marshall et al., 2021).

A study in 2021 found that older people often fail to employ the full functionality of electronic devices such as the software tools required to enable video consultations, preferring the familiarity of telephone interactions (James et al., 2021). From a provider viewpoint, the uptake of digital health was limited to a trained workforce, the willingness of healthcare services to change healthcare delivery from face-to-face to digital, and the quality and accessibility of existing high-speed digital infrastructure in rural areas (Ruiz-Martínez & Esparcia, 2020).

3.6.5 COVID-19 deaths

The growing demand for palliative care from Australia's ageing population was already leading to an increase in demand for quality care prior to the COVID-19 pandemic. In 2019–20, around 43,400 or 50% of all palliative care hospitalisations were cancer-related (AIHW, 2022a). Of the cancer-related hospitalisations involving palliative care, 52% ended in death, 13% were transferred to another facility, and 30% were discharged to the person's home (AIHW, 2022a). In the initial stages of the pandemic, cancer screenings, including breast ultrasounds, mammography breast magnetic resonance imaging and colonoscopy, were suspended in an effort to reduce the risk of infection to patients and healthcare workers (AIHW, 2020; 2022). Delays in screening not only increased stress in patients but also had the negative effect of potentially delaying diagnosis and treatment and consequently allowing the disease to advance to a higher stage, which increases risk of death (Luo et al., 2022). Delaying cancer treatment by even one month may increase the risk of death by 6 to 13%, with the risk increasing as the delay progress (Hanna et al., 2020). A 4-week delay in accessing cancer treatment is associated with increased mortality and an increase in demand for palliative care (Hanna et al., 2020).

In Australia, from January 2020 to 2 November 2023 (as shown in Figure 12), there were 11,629,977 confirmed cases of COVID-19 with 23,289 deaths reported to the WHO (2023). The following figure presents the distribution of daily new cases and numbers of deaths, from the beginning of the Australian pandemic experience to November 2023.

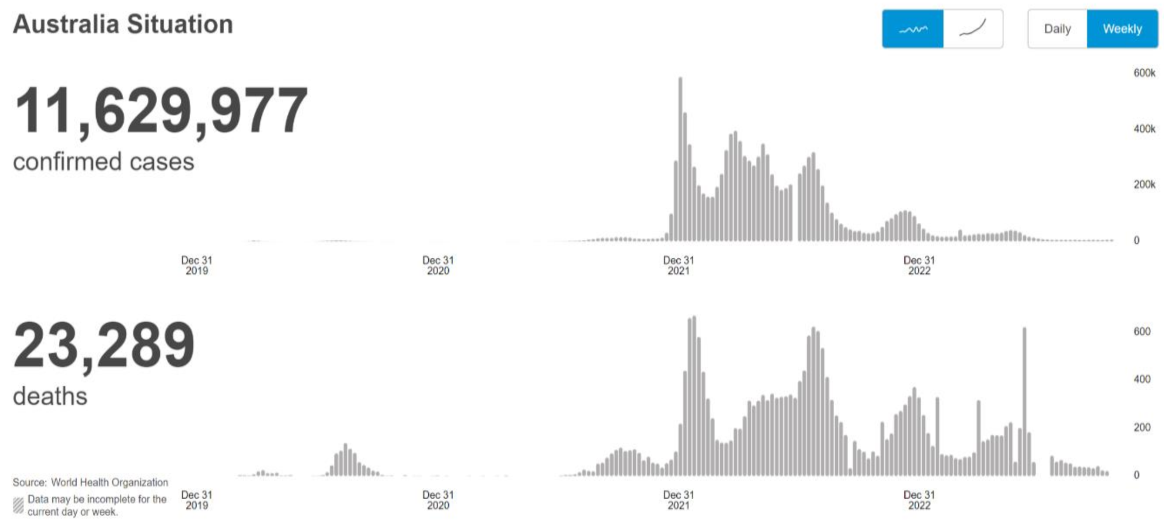


Figure 12 COVID-19 confirmed cases and deaths in Australia until November 2023 (WHO, 2023)

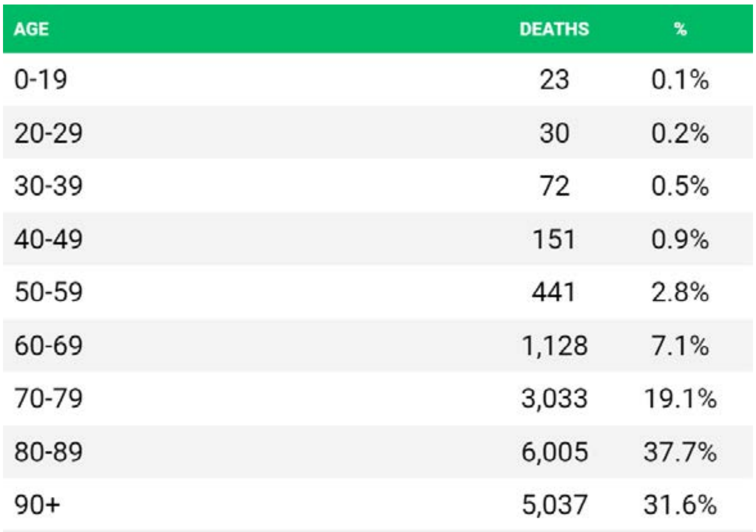
Key Statistics

- 20,170 of the 627,645 death registrations received by the ABS between March 2020 and September 2023 were people who died from or with COVID-19.
- The underlying cause of death for 15,920 (78.9%) of these people was COVID-19.
- There were a further 4,250 people who died of other causes (e.g. cancer) but COVID-19 contributed to their death.
- Chronic cardiac conditions were the most common pre-existing chronic condition for those who had COVID-19 certified as the underlying cause of death.
- 369 Aboriginal and Torres Strait Islander people died from or with COVID-19 since August 2021 (ABS, 2023c).
- Australia experienced low mortality during the early years of the COVID-19 pandemic. However, as infection rates increased significantly from the beginning of 2022, deaths

from both COVID-19 and other causes increased. ABS provisional mortality data shows that in 2022, the total number of deaths (191,000) was 10.9% higher than in 2021 and 15.5% higher than the historical average.

- The number of monthly deaths in Australia peaked in July 2022 at 18,000 deaths and then slowly declined before rising again slightly in December 2022 (ABS, 2023c).

Evidence suggests that the risk of severe disease, hospitalisation and death increases with age: 1.04% for people aged 20–29 years, increasing to 18.40% for those aged 80 years and older (Holt et al., 2020). Australians aged over 65 years and those with comorbidities remain disproportionately vulnerable to hospitalisation and death due to COVID-19 (as shown in Figure 13) (Holt et al., 2020).



AGE	DEATHS	%
0-19	23	0.1%
20-29	30	0.2%
30-39	72	0.5%
40-49	151	0.9%
50-59	441	2.8%
60-69	1,128	7.1%
70-79	3,033	19.1%
80-89	6,005	37.7%
90+	5,037	31.6%

Figure 13 Confirmed COVID-19 deaths by age group in Australia November 2023 (ABS, 2023c)

3.7 Summary

Most people will be touched by death in their lifetime, either personally or through family and friends. The benefits of accessing palliative care services in the location of choice, early in the palliative journey are well known (Hui & Bruera, 2020). However, delays in diagnosis and treatment are likely to result in difficulties supporting patients and families in the transition to end-of-life (Pesut et al., 2017). The full impact of the potential delays in cancer diagnosis due to COVID-19 and the impact on excess mortality in patients with cancer will not be known for several years and will require long-term monitoring (Lai et al., 2020). What is known is that the risk of being diagnosed with cancer increases with age. With more Australians living to an older age, the number of cancer cases diagnosed each year is estimated to increase by 22% by 2031 (AIHW, 2022a).

The social impact of barriers to accessing quality, person-centred care on health and dying are substantial and significant. The risk for physical and emotional distress is real for those individuals seeking palliative care but facing accessibility barriers. The removal of personal choice and preferences in care, treatment and locations for care and death has the potential to impede quality of life, wellbeing and the grieving process. The demand and need for community palliative care services is increasing and geographic location should not be a barrier to access. After all, the way we treat our vulnerable, our sick and those that are dying is a measure not only of ourselves, but of the society in which we all live. As Dame Cicely Saunders said, “How people die remains in the memory of those who live on” (cited in Berry, et al., 2017, p. 1).

Current research largely focuses on the barriers to accessing healthcare for vulnerable populations and the geographical location barriers in rural and remote areas of Australia. Few studies have focused on access barriers in outer fringe or peri-urban locations of Australia. The aim of this study is to explore the challenges to community palliative care provision in these peri-urban locations. In doing so, the research aims to understand how the classification of peri-urban locations influences health service policy and the impact of methods of service delivery, including digital technology.

Chapter 4: Methodology

4.1 Introduction

Chapter 4 outlines the research process and explains the corresponding methods applied to each stage. The research process employed an exploratory, inductive, and interpretative approach to respond to the research questions and meet the aim of the research. The chapter will outline the research design and discuss why the researcher chose to first conduct a literature review to provide evidence to confirm the problem space that was initially identified by the researcher's lived experience and to conduct a pilot study to confirm feasibility of the larger study. An ethnographic approach to the pilot study was adopted to understand the experience of clinicians providing community palliative care. To fulfil the aims of this study however, it was important to adopt a methodology that enabled the researcher to understand the views and experiences of people involved within the community palliative care setting.

It was deemed appropriate to develop a survey to collect data for the larger study and validate results from the perspective of participants from both service providers and recipients of care, including family caregivers and patients. The survey design, method of distribution, recruitment of participants and data collection will be discussed. The next stage outlines the qualitative and quantitative data analysis tools, in particular the use of a thematic analysis to allow the overriding challenges to emerge from qualitative data from the lived experience of participants. Descriptive statistics data analysis was used as a tool to compare and contrast emerging qualitative themes.

4.2 Exploratory, inductive, and interpretive approaches

The objective of a qualitative inquiry is to explore and explain the phenomena and the complex reality for those involved (Renjith et al., 2021). Qualitative research methods are often used in healthcare research to help understand health-related behaviours and to describe lived experiences by examining the 'how' and 'why' through the narratives provided (Creswell & Creswell, 2018; Miller et al., 2023). The use of free text and open-ended questions in a survey, allows participants to explain their intended meaning and offers an important opportunity to reveal issues that might otherwise go uncaptured (Rich et al., 2013; Riiskjær et al., 2012). One of the chief reasons for conducting a qualitative study is that it is exploratory, allowing the researcher to explore the research topic which has had minimal coverage within the literature (Renjith et al., 2021). In this study, the flexibility of this approach guided the research priorities and helped the researcher to develop definitions of location – a key component of the research (Casula et al., 2021).

Stebbins (2001, p. 3) defined exploratory research as ‘a broad-ranging, purposive, systematic, prearranged undertaking of an area designed to maximize the discovery of generalizations leading to descriptions and understanding of an area of social or psychological life’. A qualitative exploratory approach illuminates how a phenomenon is manifested and allows the researcher to listen to the voices of participants to uncover the full nature of the phenomenon and contribute to the development of new knowledge in the area (Polit & Beck, 2017). To conceptualise the problem, the exploratory approach was broken down into stages (Miller et al., 2023). The first stage involved identifying and clarifying the problem space through a literature review, observation of clinicians in the field of research and input from experts in their respective relevant fields. This guided the next stage, which was formulating the research aim and questions. The final stage involved developing data collection methods which were based on the initial stages of research, and subsequently data analysis.

An inductive research approach was also undertaken. The primary purpose of an inductive approach is to allow findings to emerge from observation and the data provided, rather than rely on predefined expectations (Brantnell et al., 2019). An inductive approach helps the researcher to develop views and an understanding of the problem space and is used to guide exploratory research. Understanding is gained by observation and gathering data, and analysis searches for patterns and emerging themes to generate findings. The researcher did not compare or analyse emerging themes in the data until the intended data collection process was completed. The inductive approach provides additional rigour to the exploratory approach used to guide the research direction. Qualitative data analysis was conducted via organising data into themes by categories which allowed the researcher to discover emerging connections and similarities and compare aspects of the data (Gioia et al., 2013).

The interpretative approach was then applied to support the exploratory and inductive approaches to promote a better understanding of the identified problem space. An interpretative approach focuses on the tentative reality gained from the meaningful account of an experience provided by an individual that is intended to yield applicable insight into the collective experience (Hunt, 2009).

4.3 Conceptualising the problem space

The problem space was identified by the researcher’s lived experience as a healthcare professional employed in community palliative care in peri-urban locations. The researcher drew on this experience to explore the perceptions of others involved in the clinical or operational aspects of care provision in peri-urban locations. The potential for bias or prejudice towards a position based on a personal viewpoint rather than a truth was recognised by the researcher. Subsequently, methodology was selected to ensure appropriate fit for the research questions developed and to reduce researcher bias throughout the process (Florczak, 2021).

A pilot study was conducted to assist with developing methodology for the larger study and to ascertain the feasibility of the research (Hassan et al., 2006; Polit & Beck, 2017). Due to the exploratory nature of the pilot study, an ethnographic approach was used to examine the experiences, views and perceptions of health professionals involved in the clinical and operational aspects of providing community palliative care. Focused ethnography is the study of social interactions, perceptions and behaviours that occur within the particular culture being observed, including shared attributes relating to gender, customs, experiences and beliefs (Goodson & Vassar, 2011; Reeves et al., 2008). A focused ethnography is useful within a healthcare setting as it provides the social context and explores the social conditions in which participants live and work, their perceptions and how they are influenced by a diagnosis, treatment, or service (Holloway & Galvin, 2017; Wall, 2015). In this study, the cultural groups are involved in community palliative care; the philosophy of palliative care differs from other approaches to care (Friedrichsen et al., 2021).

Data was collected over the period January 2021 and July 2023 through observation and informal conversations, with overall concepts and relevant verbatim data documented in a diary. Multidisciplinary palliative team members were observed individually and in team meetings, both face-to-face and via on-line video communication platforms. Indirect conversations were conducted randomly and often in a reflective context during the debrief of a complex situation. The exploratory approach was supported by a thematic content analysis of diary notes. This identified patterns and connecting themes that supplemented the lived experience of the researcher (Mishra & Dey, 2022; Pope & Mays, 2020).

Themes emerged during the process of the researcher reading and re-reading data. This helped to identify the interrelatedness between and overlapping nature of the themes and their relationships to the problem space and guided the research design (Pope & Mays, 2020). However, experience, interactions, observation and discussions could lead to unintentional bias when developing research questions and analysing data, influencing the outcome (Simundić, 2013). The researcher first conducted a literature review that was used as an evidence base for the research (Elliott & Timulak, 2005).

4.4 Literature review

To guide the search strategy and ensure that a broad range of literature was identified, the following research questions were developed:

– How are peri-urban areas defined?

– How is a peri-urban location defined in community health policies?"

A systematic review of the peer-reviewed and grey literature was carried out with the aim of identifying and collating empirical evidence within the pre-specified eligibility criteria to address the research questions (Liberati et al., 2009). A review protocol was developed and followed, based on the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement to increase clarity, transparency, quality and value of the review (Liberati et al., 2009; Page et al., 2021). PRISMA is a standardised collection of essential elements for documenting findings in systematic reviews and meta-analyses, based on solid evidence (Page et al., 2021). The review was conducted in five phases: – planning, searching, screening, appraisal and synthesis – to minimise bias, provide reliable findings and allow conclusions to be made (Page et al., 2021).

The online databases PubMed, CINAHL, Web Of Science and Scopus were selected for the literature review to provide comprehensive results. An initial literature search revealed that the term 'peri-urban' is not used consistently; instead a number of terms are used interchangeably, often depending on the classification system being used. Alternate terminology included urban fringe, semi-urban, exurban, peri-urban, metropolitan fringe, country living and rural, which add to the lack of clarity (Buxton & Butt, 2020). Therefore, key search terms used were 'peri-urban', 'rural', 'outer urban', 'outer metropolitan', 'outer urban', 'fringe', and 'definition', (policy or policies or strategy or planning).

A search of Australian Government websites determined that health service delivery is based on geographical statistical data provided by the ABS. This data is used to define locations as urban, rural, or remote, purely by population density and physical distance from urban centres. Non-metropolitan areas are viewed as those with less than 100,000 inhabitants and are further differentiated by a calculated level of remoteness. Peri-urban areas are not specifically classified in geographical statistical data.

Studies were eligible for inclusion if they were published in English, published after 1985, and set in locations deemed relevant by the researcher. 1985 was selected as a start date as it coincided with the commencement of the ASGC (ABS, 2009a). The initial search criteria were not confined to Australia and included global classifications of location searching for a common theme of rurality/peri-urban because there are common global issues related to peri-urban locations.

The researcher undertook all data extraction and all article analyses. The researcher read and reviewed articles for content and relevance to peri-urban location definition and relationship to health service delivery. It became evident very early in the research that excluding the rural element would limit the effectiveness of the review. Information pertinent to the PRISMA review process was captured in a Microsoft Excel spreadsheet (Microsoft Corporation, 2018; Page, 2021).

4.4.1 Results

Figure 14 outlines the PRISMA process used for the literature review. 1,245 articles were identified using the search terms. Following removal of ineligible records due to language and duplication, abstracts were screened for relevance to the research questions, resulting in 59 full-text articles screened for eligibility by the researcher. An additional 45 articles were removed in this process, with 15 articles remaining. One article was removed because it was deemed irrelevant to the research and 4 articles added following a review of cited references. This resulted in 18 papers deemed eligible for the study (refer to Appendix B).

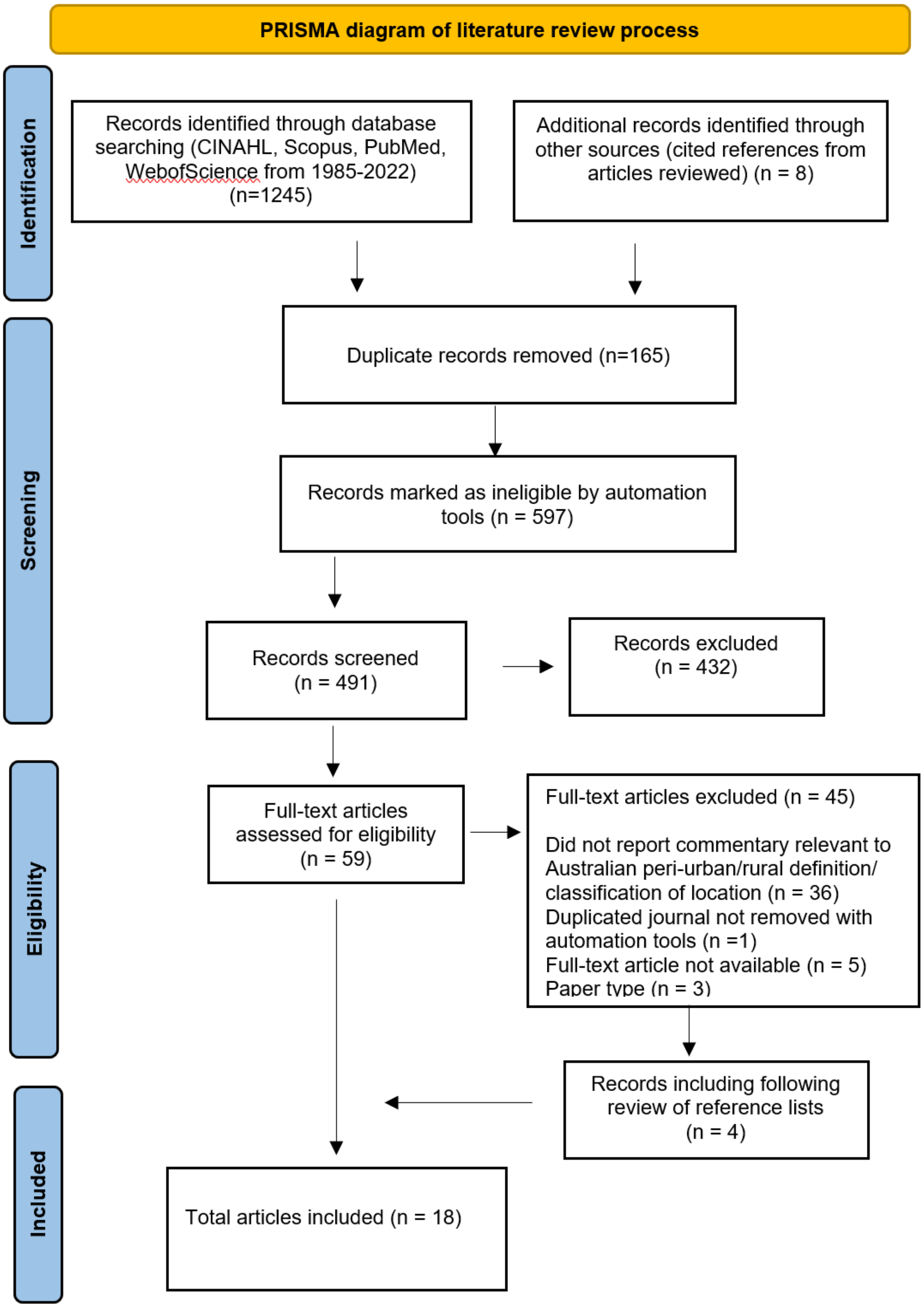


Figure 14 PRISMA diagram adapted from ‘The PRISMA 2020 statement: an updated guideline for reporting systematic reviews’ (Page et al., 2021)

Of the 18 articles used for this review, five were identified which discussed classification of peri-urban areas and the lack of consensus on a clear definition. The remaining 13 articles partially fulfilled the criteria by discussing the current methods used to classify rural areas or suggested improved methods of classification to meet the specific needs of rural locations for service delivery.

4.4.2 Data analysis

Using an inductive approach, extracted data relating to the research questions were grouped thematically to identify recurring elements in relation to peri-urban location classification and definitions. Thematic analysis required the researcher to read and re-read the full-text articles, code using complete thoughts and sentences derived from texts, and identify themes from the codes (Saunders et al., 2023). Three general themes emerged from the overall evidence by comparing and contrasting the data:

- There is no clear definition/classification of peri-urban areas for policy and planning,
- Classifications are geographical and in terms of accessibility are limited to population size, density and distance to urban centres, and
- Measures need to be developed to enable a clear definition of rurality so that meaningful policy and planning can occur. Measures would assist with workforce planning and GP clinic placement.

Development of themes identified themes-within-themes, or sub-themes, which demonstrate the hierarchy of complex meaning within the data (Braun & Clarke, 2006). A consistent sub-theme throughout all articles was the diversity in non-urban areas, regardless of the classification of peri-urban or rural. Two articles discussed the urban–rural health divide and the corresponding difficulties with resource allocation with use of geospatial classification derived from census data. Neither article suggested changes to current methods of measuring rurality based on population size and density, and distance from metropolitan centres.

The inadequacies of using SA2s as the smallest measure of an area as urban or non-urban was a common theme, with many authors voicing suggestions for alternative methods to be used in addition to current classification methods. Suggestions included thematic mapping, urban–rural gradients, spatial analysis or inclusion of other local factors that are deemed as relevant to the specific policy being developed. Additional factors to be considered included infrastructure characteristics, economic diversification, rate of urbanisation, and local employment. Five of the 18 articles discussed the need to recognise the uniqueness of peri-urban locations and the importance of classifying the area in a way that doesn't rely on the urban–rural perspective.

4.4.3 Discussion

The literature review supported the identification of a problem space, in terms of understanding the barriers to accessing healthcare services in peri-urban locations. What becomes clear in the literature is the importance of a definition of peri-urban areas that considers the unique characteristics of that area. Current population density indicators are not reliable guides of populations living in a mix of high density, planned residential developments, rural living allotments and agricultural dwellings (Buxton & Butt, 2020). Defining peri-urban areas as rural infers low-density living, lower population sizes and a reliance on primary health care. The historical view that rural populations constitute an older and lower socio-economic demographic and high-risk, agricultural employment are no longer relevant in rural areas within high-density peri-urban locations. COVID-19, the ability to work from home, and housing prices in outer city locations have changed the demographic of the population moving from urban centres to these outer fringe areas, which lack appropriate access to infrastructure and services (Argent & Plummer, 2022).

Current classification methods rely on census data and may not encourage healthcare providers to make allowances for the culture, mindset or expectations from the populations moving from high-density urban centres to a rural living or country living area. There is an expectation that healthcare services would be accessible at a level available in urban centres. Measuring physical road distance between where people live and the urban centre locations where people need to travel in a straight line and viewing that as a reasonable commute distance appear to lack consideration of the multitude of challenges to service provision (ABS, 2001b). Physical road distance itself is not a clear and reliable indicator of the time taken to travel, the physical capability of the driver or passengers, the road conditions, the influence of climate conditions, geographic characteristics or socioeconomic factors, which ideally need to be factored into the measurement (ABS, 2001b).

Health service delivery based on a whole of population view of peri-urban areas as rural would appear to be doing a disservice to the communities because it does not focus on providing person-centred care for the individuals concerned. The development of PHAs, PHNs and LHNs appear to be a step in the right direction, but the areas involved continue to rely on SA2s which remain a significantly large area for which to provide adequate in-home services (ABS, 2020). There ABS also recognizes the need to provide access to relevant data about peri-urban areas to decision-makers and they are planning to release experimental boundaries in future ASGS data releases.

4.5 Theoretical framework

Access to palliative care services can be broadly defined as the capacity of people to obtain appropriate services in response to recognised care needs at any given time along the palliative journey (Corscadden et al., 2017). Subsequently, access represents a fit between supply and demand, the interaction between patient needs and the services that meet those needs (Corscadden et al., 2017). There are many concepts and methods of measuring access to healthcare, demonstrating the importance of accessing health service performance worldwide. Some methods conceptualise access by utilisation of services due to characteristics of the provider, whereas others consider the roles of the consumers and providers in accessing services (Tanner et al., 2020). Penchansky and Thomas (1981, p. 128) define access as ‘a concept representing the degree of “fit” between the clients and the system’.

Access to healthcare is vital, the Australian health system’s key role is to provide safe, effective, appropriate and accessible treatment and other services to all Australians (AIHW, 2022d). In this context, access is defined as an attribute of the health services providing the opportunity to reach and obtain appropriate services in proportion to individual needs for care. Others remove the emphasis of access from the health provider and view access as the result of the interface between the characteristics of individuals and their environments and the characteristics of the providers and health systems involved (Penchansky & Thomas, 1981).

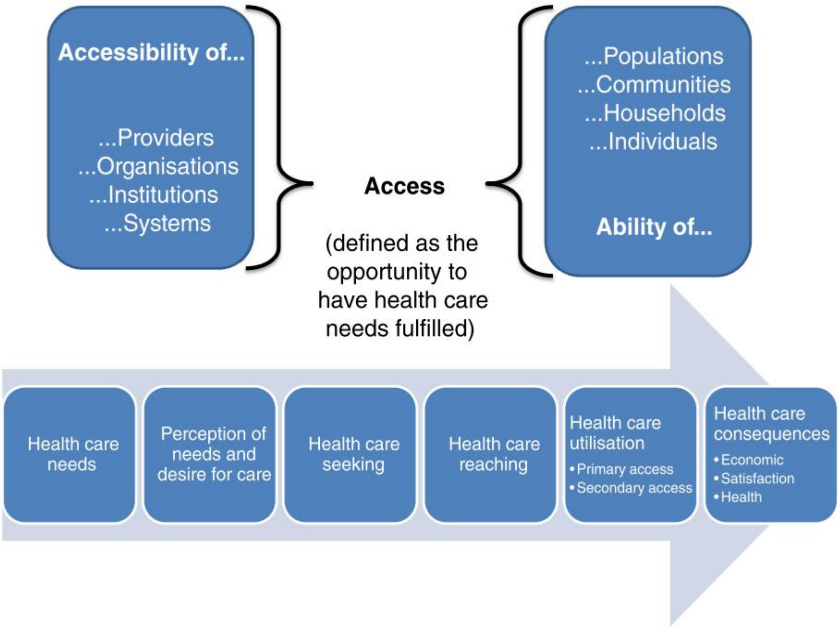


Figure 15 shows the Levesque model, highlighting how Levesque and colleagues define access as the opportunity to identify healthcare needs, seek, obtain or use services, reach resources and be offered appropriate health services to have the need for services fulfilled (Levesque et al., 2013b).

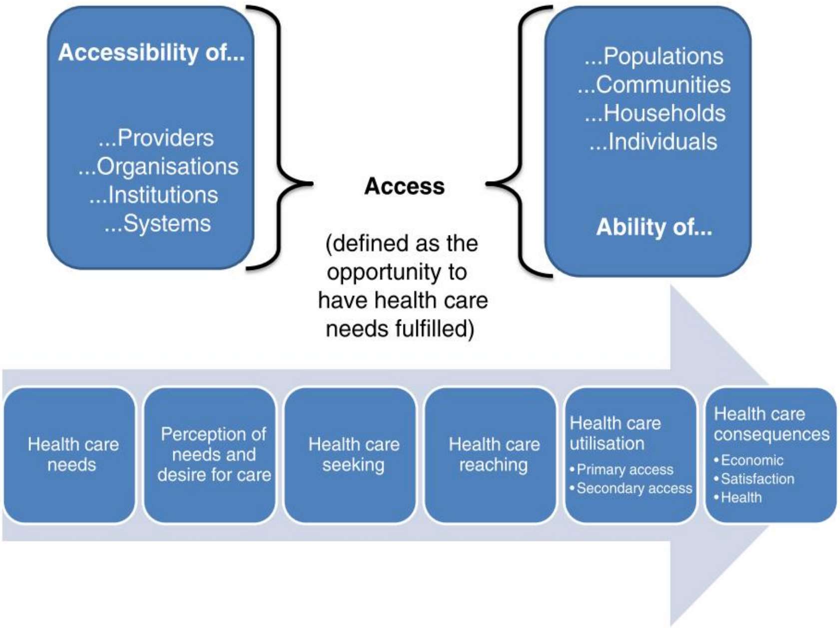


Figure 15 A definition of access to health care (Levesque et al., 2013b)

Levesque's framework (2013b) expands on the view of access as opportunity to reach and obtain services and explores the notion of accessibility. This suggests healthcare access is a complex concept of utilisation of services to realised access (Levesque et al., 2013b). The framework describes dimensions and determinants that integrate variations in access from demand and supply factors (Levesque et al., 2013b). Five dimensions of accessibility are proposed, which are inter-related, continuous and fluid (Levesque et al., 2013b). The 5 dimensions as represented on the upper part of Figure 16 are as follows (Levesque et al., 2013b):

- Approachability: services within reach, how the provider ensures that services meet the constraints and preferences of the client, including hours of operation.
- Acceptability: social and cultural acceptance of services and providers.
- Availability: timely delivery of services, the extent to which the provider has the resources to meet client needs.
- Affordability: financial capacity and willingness to use services.
- Appropriateness: fit between services needed and obtained.

The Levesque framework (2013b) proposes that five corresponding dimensions of abilities of populations interact with the dimensions of accessibility to generate healthcare access. They are represented on the lower part of Figure 16 and as follows:

- Ability to perceive: level of health literacy, knowledge and beliefs about healthcare and ill health.

- Ability to seek: personal autonomy, the capacity to choose to seek care.
- Ability to reach: personal mobility, availability of transportation and occupational flexibility.
- Ability to pay: economic resources to pay for health services.
- Ability to engage: participation and involvement in decision-making and treatment options.

The five dimensions of abilities are inherently person-centred, attempting to mirror the actual process of seeking the care needed by a patient on their palliative journey (Haj-Younes et al., 2022). The dimensions of accessibility and abilities are not independent constructs, often influencing each other and acting at different times during the episode of care (Levesque et al., 2013b). The conceptual framework guided the development of the research questions.

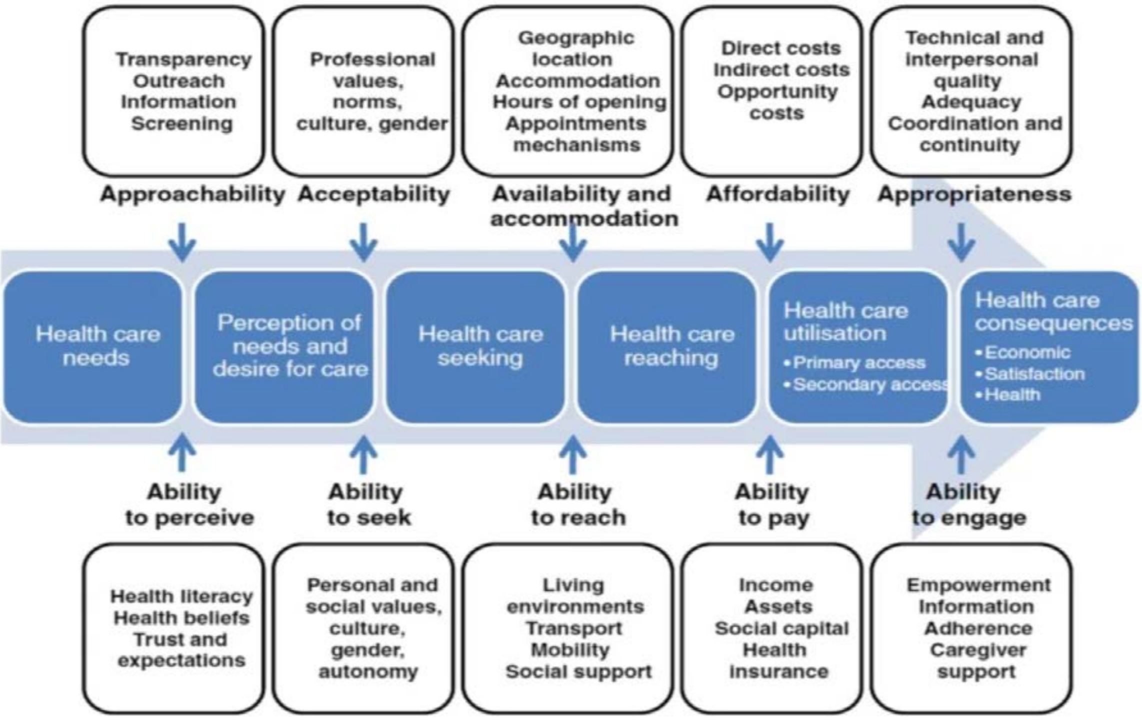


Figure 16 Levesque conceptual framework of healthcare access (Levesque et al., 2013b)

4.6 Study design

To reach the research goal, it was important to explore the expectations, feelings, and opinions of the people within the community palliative care setting. Therefore, a qualitative approach was deemed appropriate (Taherdoost, 2022). Qualitative data collection enables researchers to study the nature of phenomena from the lived experience of individuals (Busetto et al., 2020; Gehman et al., 2018). Quantitative data, on the other hand, allows the researcher to determine cause-and-effect relationships, test hypotheses and generalise the opinions, attitudes and experiences of a large group of people (Verhoef & Casebeer, 1997).

The subject of death and dying is difficult and for some individuals and groups it is inappropriate to discuss the topic for personal, cultural, or religious reasons. The methodology adopted in this research was developed to reduce the risk of emotional distress to participants due to the research subject. The survey was voluntary, online and accessed via a URL link provided. Participants were able to leave the survey at any time, data collected was not linked to participants, and contact details for grief and bereavement support services were provided (Braun et al., 2021; Koenig et al., 2003). The requirement for a mandatory response was reduced to the questions which determined eligibility to participate in the survey, as per the National Statement on Ethical Conduct in Human Research guidelines (National Health and Medical Research Council, 2007). The research project ID H8936 received approval from the HREC at James Cook University (JCU). Refer Appendix C.

Figure 17 outlines the research design employed in this research. An exploratory design was used to develop an online survey as the data collection tool for the study. The researcher’s lived experience, observation and informal discussions with community palliative care clinicians and a literature review guided the feasibility of the research and the development of the survey questions. Reliability and validity of the study were addressed by pretesting the questionnaire (*n = 10*) with multidisciplinary clinicians working in a community palliative care context, including clinical nurses, a social worker and a psychologist experienced in grief support (Hu, 2014; Kistin & Silverstein, 2015). The pretesting determined whether questions were clear, unambiguous and met the aim of the study (Shakir & ur Rahman, 2022). After feedback, minor revisions were made to the number of questions in the survey to reduce the length of time needed to complete. Other changes were made to improve clarity and the wording of individual questions (Choi & Pak, 2005). The survey was developed using the web-based software Qualtrics (2020). A copy of the survey can be found in Appendix D.

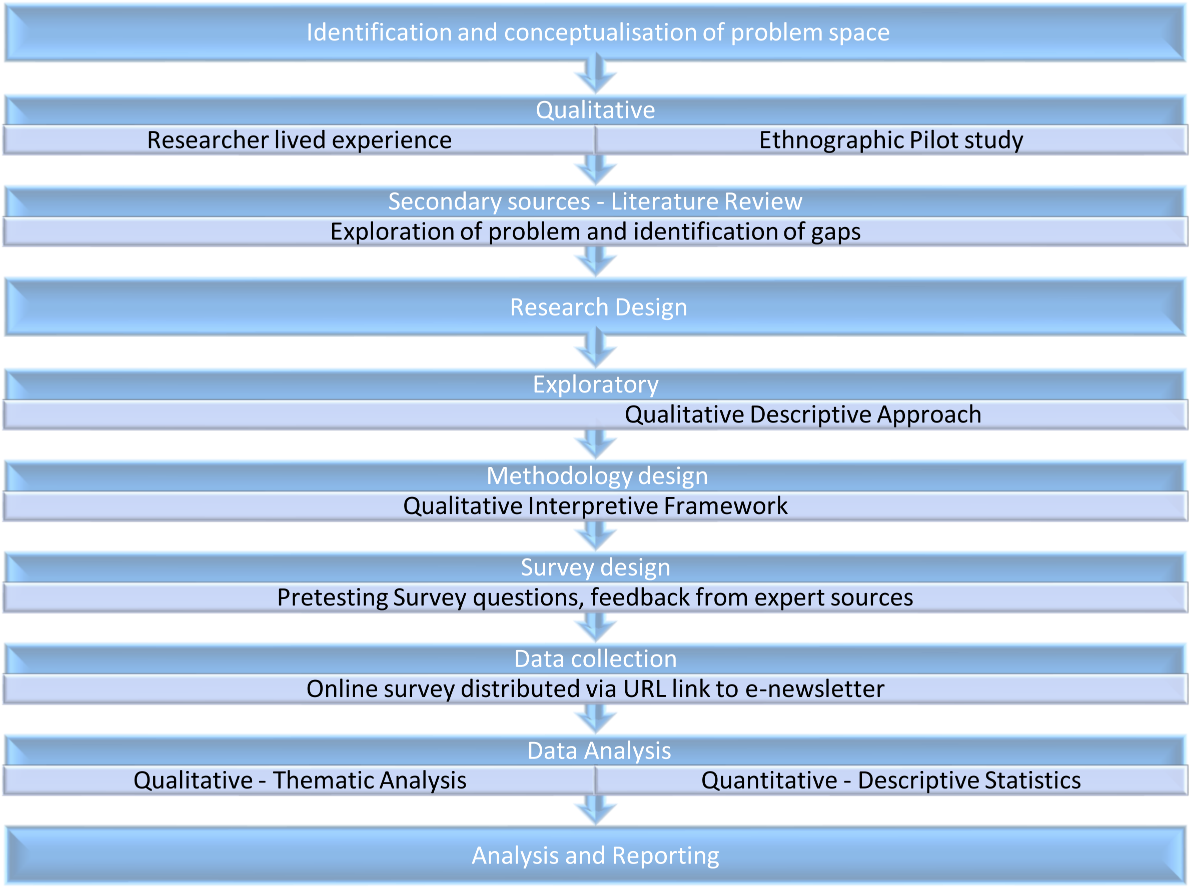


Figure 17 Research Design

4.6.1 Study inclusion criteria

To gain an understanding of the way people view their experiences accessing community palliative care, this study targeted those involved in both providing and receiving care, as follows:

- Health professionals employed in any role within a multidisciplinary health team, both paid and unpaid, full-time, part-time and casual, who provide in-home (community) palliative care services to patients and/or family members in Australia.

- Family members or care-givers of people who were currently receiving or had received, in-home (community) palliative care (this included direct patient care and bereavement care) in Australia. This group of people may have received community palliative care for bereavement support for an indefinite period following the death of the person diagnosed with a life-limiting illness and would have had all direct patient services stopped at the time of death.

- People diagnosed with a life-limiting illness and receiving in-home (community) palliative care, including those receiving active treatment and those who had ceased treatment.

Exclusion criteria for all groups:

- Children and young people under the age of 18 years were excluded from the study due to the increased risk of psychosocial problems associated with this age group and grief and loss.

- Patients/persons requiring extensive medical interventions for effective symptom management due to either their current treatment regime or advanced illness stage were not excluded but were not actively recruited.

- Participants in any group, who lacked capacity to provide informed consent due to cognitive, intellectual or mental impairment.

- Persons who deemed themselves as vulnerable to emotional upset due to the nature or subject of the study and questions being asked for any reason, or who were experiencing diagnosed depression or PTSD, receiving ongoing psychological support to manage uncontrolled grief and loss, or cultural or religious reasons. Those recently bereaved, or at risk of chronic grief, were requested to exclude themselves.

Specific disease diagnosis, culture, gender, age (other than ensuring that the participant was over 18 years), specific health conditions or stage of disease were not sought in survey data to remove the risk of participant identification. Access to all methods of care, including face-to-face and digital health, were included and the type of care was not differentiated between symptom management, psychological support, or terminal, pre-terminal, comfort or bereavement care when identifying groups as patients, family members/caregivers or support persons/care givers who had received, or were receiving, community palliative care. Patients and family members were not excluded if active medical treatment was provided at the same time as community palliative care.

4.6.2 Sample descriptors

At the commencement of the survey, participants were asked to identify their role within one of 3 groups: healthcare professional, family caregiver or patient. Questions were allocated to participants depending on the group selected. A free text box was available prior to survey submission for every participant to include additional details if they desired to do so. Participants were asked to identify their location by State/Territory, or LGA and location type as either rural, remote, peri-urban, metropolitan, unsure or other. The researcher allocated participants to a location using the participants' identified LGA if location was identified as 'unsure'. Allocation was made using a manual search of the identified LGA in an online search of individual LGA determinations of location and peri-urban groups or networks of rural council lists (Peri-Urban Councils Victoria, 2022; Wollondilly Shire Council, 2022). Questionnaires collected information on participant characteristics, their perceptions of barriers to services, models of service delivery including digital health and impacts to wellbeing, choice of location and care received in the participant's location of care. The use of the term quality was not used in reference to care provided in the questionnaire, despite quality and palliative care being intrinsically linked. Individual perceptions of what constitutes high quality care are likely to be fluid and subject to change, therefore perceptions of care were related to individual expectations, values and needs, and subsequent satisfaction, to understand barriers to access (Elwyn et al., 2007).

The questionnaire directed at health professionals consisted of a combination of 20 Likert and multiple-choice questions. Quantitative data was sought to support the descriptive data. Open-ended comments were invited at 12 points in the survey and responses to all questions were voluntary. Two Likert questions with strongly agree–strongly disagree statements were included so that participants could rate their personal view of how services met the needs of the local community and how easy it was to interact with digital health services.

The family caregiver questionnaire consisted of 22 Likert and multiple-choice questions with open-ended comments invited at 10 points in the survey.

The patient questionnaire consisted of 20 Likert and multiple-choice questions with open-ended comments invited at 10 points in the survey.

4.6.3 Recruitment

To reach the research goals, it was critical to gather perceptions of access to services during the palliative care journey directly from everyone involved in the provision and receipt of care. It was not possible to identify, or contact every potential participant in the targeted population, due to the emotional subject involved in this research. There was potential for participants to find the subject and the questions or responses provided by participation in the survey, to be a grief trigger (Wilson et al., 2021). This may have resulted in an unexpected rekindling of emotions of joy and gratitude of happier times or feelings of sadness, loneliness, regret and longing (Labott et al., 2013, 2016).

People cope with grief in different ways and some individuals, including those with diagnosed depression or someone who has only recently lost a loved one, will be more vulnerable to emotional distress from participation in this research. The researcher is an experienced palliative care clinician and was aware that the feelings of grief stirred up by the survey was likely to be of a short duration for participants who were not deemed vulnerable to emotional distress and they were unlikely to require ongoing support. The researcher chose to send the survey link to connections via an online community who was already interested in the research subject in order to minimise the risk of upsetting participants.

Palliative Care Australia is the national peak body for palliative care and represents all those who work towards high quality palliative care for all Australians who need it. Consent was obtained from the PCA to include the survey link in one e-newsletter (see Appendix E). Potential participants would only be able to access the link if they were accessing PCA online, had voluntarily subscribed to the e-newsletter or received the e-newsletter in a professional capacity (see Appendix F). The researcher acknowledged the potential for participants to post the link on social media sites or promote access in some other method so, a statement requesting that this did not occur was included in the Participant Information Sheet (Appendix G). Those with pre-existing emotional vulnerabilities, PTSD, depression or believed that they were in immediate danger were asked to not participate and to seek assistance, with contact details provided, including those for immediate assistance. Questions in the survey asked about the length of time services had been provided with responses linked to a message requesting participants reconsider participation if deemed at increased risk of emotional upset due to early or chronic grief. (Refer to the grief support information page included in the survey in Appendix H.

The risk to potential participants was reduced by including reminders in the survey link, the survey questions and the Participant Information Sheet, that participation was voluntary and to consider not participating or withdrawing at any time prior to submission. A link to the PCA resource on grief and loss was included in the Participant Information Sheet and grief support page, with participants able to download and/or print information. Further contacts for support were provided in the Participant Information Sheet with links that respected diverse cultures and genders and one link specifically for First Nations people. Risk was also minimised by making participants aware of anonymity in the survey and the choice to not answer questions.

The potential for any participant to voluntarily refer the survey link to anyone in their online network, outside of the targeted population pool, was outside the control of the researcher, and would be considered snowball sampling. The researcher did not actively request participants to recruit other participants, as it was possible that would generate bias (Gile et al., 2018). This form of recruitment does have the potential to increase the participation numbers but was not actively sought by the researcher (Gile et al., 2018). The researcher is unable to clarify the contribution of snowball sampling to survey responses.

PCA has over 22,000 subscribers and social media followers and participants were recruited from this pool. There was no way of estimating how many followers and subscribers are health professionals, patients, family caregivers or interested community members. Participants were given 10 weeks to access the e-newsletter via the PCA website to ensure adequate exposure within Australian States and Territories. The survey link was available between 9 February and 20 April 2023. The data collection method, convenience sampling, relied on the willingness and motivation of participants to provide information so it can be associated with poor participation rates. However, a benefit of this type of data collection is anonymity which potentially reduces social desirability bias and encourages participants to give honest and detailed responses to sensitive experiences (Luckett et al., 2021).

The study aimed for a sample size of 90 health professionals and 90 patient/family caregivers. This number of health professionals was chosen because the palliative care workforce is relatively small and approximately 52% of palliative nurses work in hospital settings (AIHW, 2022e). National 2019 workforce data showed that 9 in 10 (87%) palliative medicine physicians and 3 in 4 (72%) palliative care nurses worked in major cities, which may have swayed participation rates for a survey looking at peri-urban locations (AIHW, 2022e). Due to the emotional subject of this research, it was difficult to estimate the number of responses that would be received. Ultimately 94% of people who commenced the survey, submitted a completed questionnaire with 2 withdrawing at the initial research description, 4 declining consent, 4 failing to submit and 1 excluded as ineligible.

4.6.4 Data collection

All questions relating to access to services and models of service delivery were voluntary to reduce risk of possible grief triggers, to rule out any false claims and to increase the reliability and validity of the results (Wilson et al., 2021). Qualitative and quantitative data was captured concurrently, in the one survey, using Qualtrics (2020). The online survey was closed on the advertised closure date to ensure that no additional responses were received outside of the targeted date range. Any details provided by participants in the free text boxes that could potentially lead to identification was removed by the researcher during reporting (Rich et al., 2013; Riiskjær et al., 2012). Reports were developed for completed surveys only, using Qualtrics and qualitative and quantitative data transferred to Excel spreadsheets for analysis by the researcher (Microsoft Corporation, 2018; Qualtrics, 2020). A total of 182 participants commenced the survey; 2 withdrew at the initial research description, 4 declined to give consent, 4 failed to continue to completion and 1 was excluded as location was identified as outside of Australia. A total of 171 participants submitted a completed survey, 50 identified as health professionals, 91 as family caregivers and 30 as patients (people diagnosed with a life-limiting illness). A total of 21 participants accessed the Participant Information Sheet and 32 accessed the grief support information page.

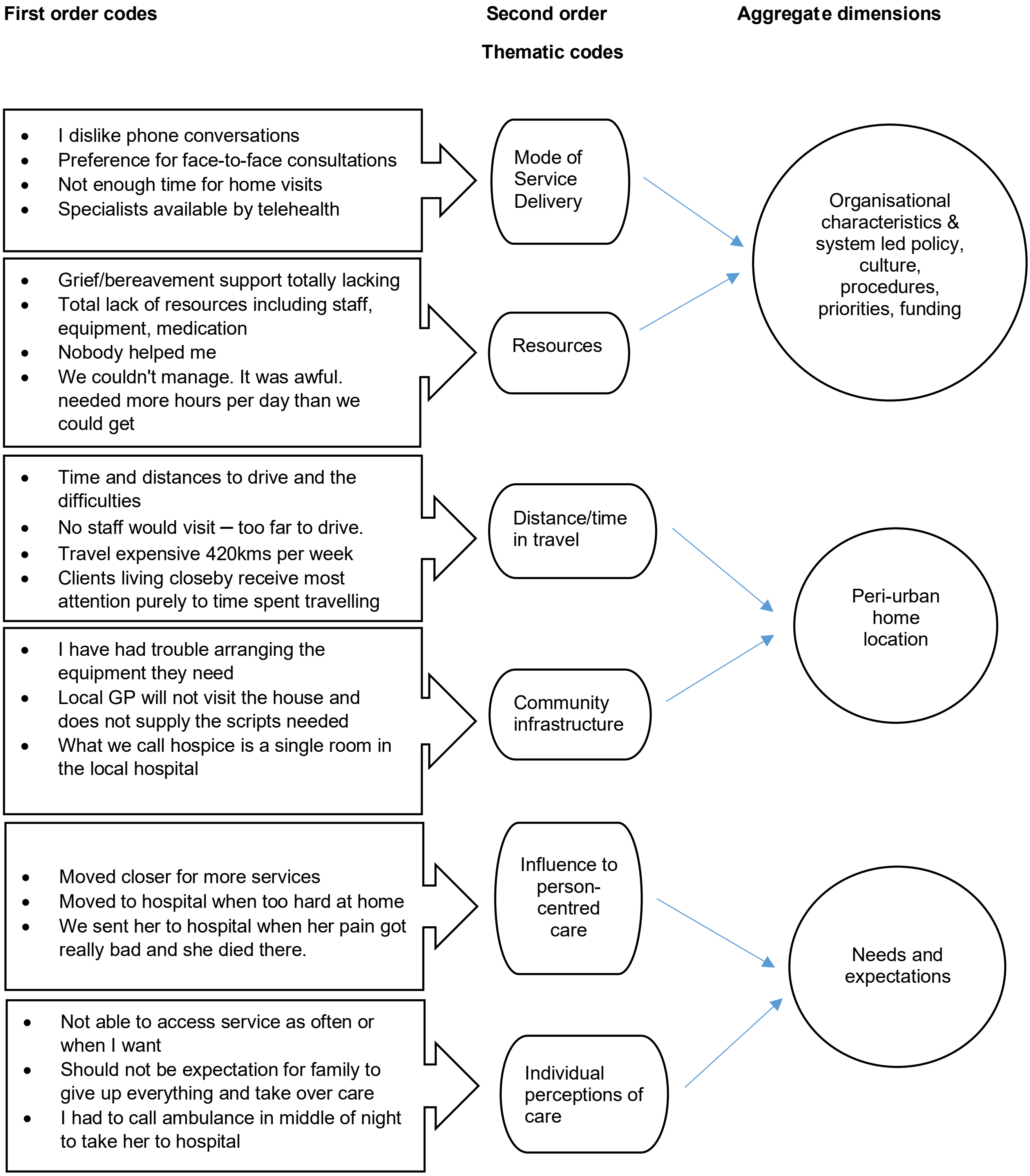
4.7 Data analysis

4.7.1 Qualitative analysis

The exploratory and descriptive approach was supported by Gioia's method for qualitative rigour which enables the researcher to find structure in unstructured qualitative forms (Gioia et al., 2013). The Gioia method requires the researcher to categorise the data into 3 different phases (first, second and third order or aggregate dimensions) (Gioia, 2021). First order concepts are identified from the data, using the voice of the participant to allow terms, phrases, and meanings to emerge as building blocks that form patterns (Gioia et al., 2013; Waeraas, 2022). The second order analysis looks for similarities and differences in the terminology, words and phrases used by participants, seeking commonalities that lead to patterns and themes in meaning and experiences provided. Finally, the third order or aggregate dimensions, reveal the common underlying patterns which comprise all of the second and first order elements (Gioia, 2021).

The researcher analysed the data using Qualtrics and Excel spreadsheets to manually search for common words and phrases (Microsoft Corporation, 2018; Qualtrics, 2020). Using Latent Semantic Analysis (LSA), the third order dimensions were identified by word frequency, based on the hypothesis that words and phrases occurring within similar text have similar meaning (Landauer et al., 1998). Phenomenological themes and sub-themes emerged during the process of reading and re-reading data, and the researcher was able to derive the range of factors that contributed to the whole lived experience of participants and identify the interrelatedness and overlapping nature of the themes. The researcher then interpreted the findings, seeking to find meaning and respond to the research question whilst also taking into account the available literature to describe the phenomena involved (Gioia et al., 2013).

The Gioia methodology was developed with the purpose of creating an approach that enables a systematic and coherent presentation of both a first order analysis (using terms and codes based on participants' perspectives) and a second order analysis (using concepts, themes, and dimensions based on the researcher's perspective). The process of theme development is flexible and evolves through familiarity with the data (2006). It is possible for the researcher to provide a comprehensive and accurate classification of the connections between the data and the development of new ideas and themes (Gioia et al., 2013). Using the Gioia methodology, a data structure detailing the first order concepts, second order themes and third order dimensions and their relationships, is provided in Figure 18.



- I dislike phone conversations
- Preference for face-to-face consultations
- Not enough time for home visits
- Specialists available by telehealth

- Grief/bereavement support totally lacking
- Total lack of resources including staff, equipment, medication
- Nobody helped me
- We couldn't manage. It was awful. needed more hours per day than we could get

- Time and distances to drive and the difficulties
- No staff would visit – too far to drive.
- Travel expensive 420kms per week
- Clients living closeby receive most attention purely to time spent travelling

- I have had trouble arranging the equipment they need
- Local GP will not visit the house and does not supply the scripts needed
- What we call hospice is a single room in the local hospital

- Moved closer for more services
- Moved to hospital when too hard at home
- We sent her to hospital when her pain got really bad and she died there.

- Not able to access service as often or when I want
- Should not be expectation for family to give up everything and take over care
- I had to call ambulance in middle of night to take her to hospital

Figure 18 Gioia thematic analysis survey results

4.7.2 Thematic analysis

The results of the thematic analysis demonstrated the relationship between peri-urban locations and barriers to access. The data demonstrates some key areas that need to be addressed by the healthcare organisations involved, related to the influences of organisational characteristics and healthcare system-led support, culture, funding, policies and procedures, community infrastructure and individual needs and expectations. These factors will be discussed in the following chapters using direct participant quotes to directly connect data to theory and reaffirm the existence of relationships. Figure 19 demonstrates the relationships between themes and aggregated dimensions and their level of influence.

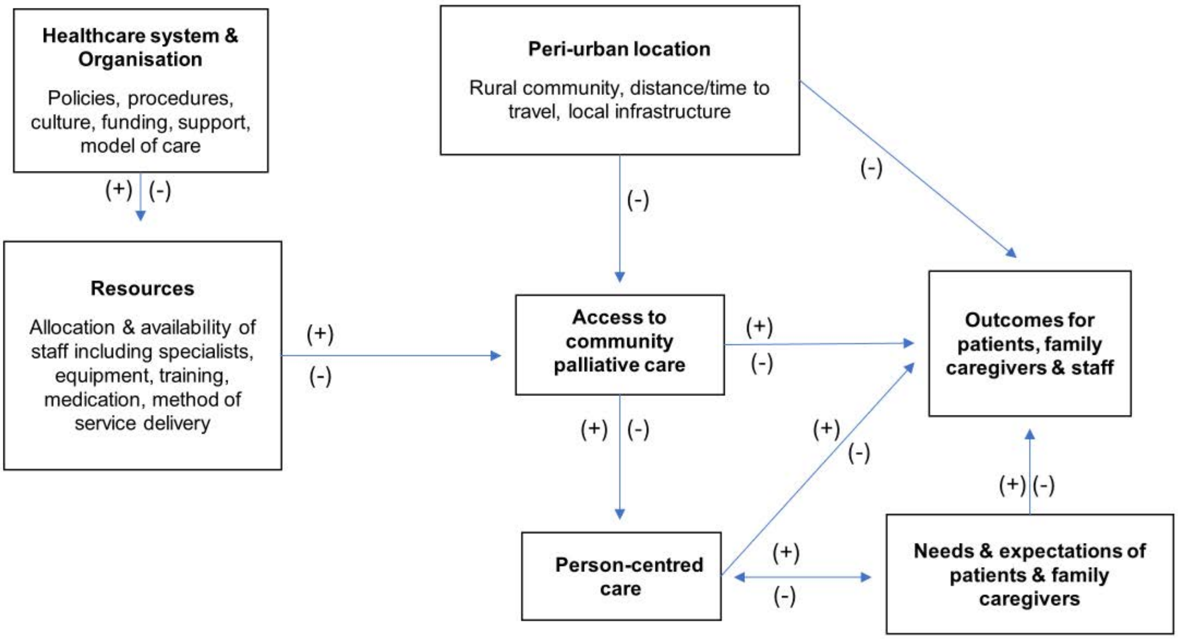


Figure 19 Aggregated theme relationship

4.7.3 Quantitative analysis – Descriptive Statistics

An objective and systematic approach was used to analyse responses to closed-ended questions in the online survey. Closed questions require participants to choose from a predefined set of responses, provided by the researcher (Creswell & Creswell, 2018). To help the researcher understand the participants’ views and attitudes, this research utilised dichotomous, multiple-choice and Likert-scale questions to collect data. Dichotomous questions typically invoke a quick answer to a choice of two responses; in this study, this included ‘yes/no’ and ‘agree/disagree’ (Schaeffer & Dykema, 2011). Multiple-choice, including radio-choice, questions were used. For some questions, participants could only choose one answer among a set of predefined options and checkboxes, and for other questions participants could choose multiple options from a given set of options (Strunk & Mwavita, 2021). Validity of the responses from multiple-choice questions was provided by pretesting questionnaire with (*n* = 10) multidisciplinary palliative care clinicians, to reduce potential for researcher bias (Considine et al., 2005).

Responses were filtered within each of the three groups of participants by Qualtrics, to locations identified by participants. These consisted of peri-urban, rural, regional and metropolitan. The number and percentage of responses were calculated using actual response numbers to each question provided by Qualtrics (2020) reporting and percentage calculated following export of data to Excel (2018), using the following formula:

$$P = \frac{F}{N} \times 100\%$$

P: Number of percentage

F: The frequency of answer

N: Number of responses

Likert-scale questions were also used in the survey, to measure the extent to which participants agreed or disagreed with a given statement regarding a particular topic (Strunk & Mwavita, 2021). Participants were asked to indicate their level of agreement by way of an ordinal scale with 5 options as alternative answers. They were: Strongly agree, Somewhat agree, Neither agree nor disagree, Somewhat disagree, and Strongly disagree.

Descriptive statistics attempt to aggregate data into groups to measure typical values and the spread of values within each dataset (Guetterman, 2019). In this study, measures of central tendency were used to analyse Likert-scale responses as interval data (Creswell & Creswell, 2018). A core element of descriptive statistics is the measure of central tendency which attempts to measure an entire sample to determine the collective attitude or opinion of the participant group with a single number (Strunk & Mwavita, 2021). The three most common measures of central tendency are the mean, median and mode, with the mean or average being the most frequently used. Results of analysis of quantitative data will be displayed in tables reporting mean and standard deviation for Likert scale responses, which were calculated using Qualtrics and Excel (Microsoft Corporation, 2018; Qualtrics, 2020). The spread of values is represented through measures of variability including standard deviation, which calculates the extent to which the values differ from the average (Guetterman, 2019).

The researcher used convergent parallel design to capture both quantitative and qualitative data within the one survey (Creswell & Creswell, 2018; Fetters et al., 2013). Data was collected simultaneously and remained separate during analysis, which was conducted using Qualtrics reporting tools, Excel spreadsheets and manually by the researcher (Microsoft Corporation, 2018; Qualtrics, 2020). The intent was to merge, compare and contrast results from data analysis to add a greater depth of understanding to participant meaning and experiences reported in emerging themes from the qualitative analysis (Creswell & Creswell, 2018) – a process called triangulation. In this research design, validity of the research arises from capturing three different perspectives from three distinct groups of participants (Jick, 1979; Schoonenboom & Johnson, 2017).

4.8 Summary

This research applied an exploratory descriptive approach to provide an in-depth analysis of the problem space. The problem space was identified and conceptualised through qualitative analysis of the researcher's lived experience and observation and informal discussion with palliative care clinicians who work in peri-urban locations. To confirm the research gap and problem space, an extensive literature review of secondary sources was undertaken. This supported the development of the overarching research design, which is comprised of a qualitative descriptive approach, applying the qualitative interpretive framework. This informed the design of the survey, which was pre-tested with a group of 10 community palliative care clinicians and experts in their field, to ensure validity and reliability prior to distribution of the final questionnaire (Shakir & ur Rahman, 2022).

The broad data collection was undertaken through an online survey, which was distributed via an e-newsletter to provide anonymity of participants and to encourage honest and open feedback. Qualitative data analysis focused on thematic analysis applying the Gioia Methodology for Qualitative Rigor to ensure that the identified core themes and aggregate dimensions were reflective of the words of participants. The analysis of quantitative data identified the core statistical data, used to provide insight and understanding into responses provided by participants. The analysis and reporting were used to develop a number of recommendations with the aim of informing future policy and practice.

4.9 Limitations

Several limitations must be considered when interpreting our results. The finding that peri-urban areas are a factor contributing to barriers of access to community palliative care services must be interpreted within the limits of the study methodology and relatively small number of participants (n = 171). As this was an online survey, the researcher is unable to calculate response rates. It is possible that the views of people who do not access PCA e-newsletters and non-participants differ from those who did respond, with respect to accessibility of services and the outcome. Voluntary participation could represent participant bias, potentially contaminating results by being motivated to voice grievances and negative opinions. This research did not differentiate between specific disease diagnosis, a patient's care needs, prognosis, patient age or existing family relationships and extent of available support network, with potential for responses to differ depending on circumstances.

Chapter 5: Pilot study

5.1 Introduction

As discussed earlier, palliative care aims to minimise suffering and optimise quality of life for people diagnosed with a life-limiting illness and their family unit. Any barrier to access can result in anguish, reduced quality of life, and unresolved grief, and it removes choice of and preference for place of care. This chapter will discuss findings and focus on the challenges identified in peri-urban community palliative care from a pilot study conducted prior to developing the larger research study (Hassan et al., 2006). The study involved a small group of professionals providing community palliative care in a peri-urban region of South Australia which included in-home palliative and bereavement care. Evidence is presented by clustering and presenting the views of this group of community palliative care practitioners from South Australia to support the feasibility of a larger research study. A brief summary extracted from chapter 2 will be provided of the main features of the peri-urban location in order to present underlying accessibility limitations for peri-urban residents and palliative care service delivery.

As a reminder, it is worth noting at this point that health services typically base their policies on classifications of location, but the data is general and includes only two classifications – urban or non-urban – based on population size, density, and an index of assumed accessibility to goods and services (AIHW, 2022b; McGrail & Humphreys, 2009). The implications of this reliance on location classification methods, to accessing person-centred palliative care services in peri-urban areas will be discussed as findings are presented. Practitioners believed that challenges existed in care provision that could be directly attributed to geographical location and allocation of resources.

5.2 An overview of palliative care provision in peri-urban areas

A diagnosis of a life-limiting illness is distressing, and patients and family members often need health professional support in referrals for in-home services. In-home palliative care may be provided for days, weeks, or months and on some occasions for years (Tieman et al., 2016). However, not every person chooses to receive community palliative care and available care depends on the needs, available services, and location.

It is important to note that any factor which influences patient accessibility to in-home services may not only impact preferred end-of-life care and place of death, but also impact patient quality of life, remove patient choice, and impede the grieving process of family and friends (KPMG, 2020; Saurman et al., 2022). All people have a right to dignity, comfort and privacy, to direct their own care or have their wishes acknowledged, refuse medical treatment, and expect equitable access to respectful and compassionate care at any point in their life journey, including at the end-of-life (ACSQHC, 2023a; Wenham et al., 2020). Evidence has shown that access to palliative care improves patient outcomes, including quality of life, and caregiver outcomes, including reduced stress and financial savings (Hawley, 2017). This basic right, however, is challenged by access inequities due to geographical location for those choosing to live outside metropolitan areas, as noted in the literature review.

The ability to physically access palliative care and/or the ability to travel is important for ensuring quality of life and wellbeing (Gerber et al., 2019; Miller et al., 2021). Geographical statistical data defines accessibility to healthcare services using the traditional Euclidean distance to model accessibility (Khashoggi & Murad, 2020). This approach is simply a measure of road distance in a straight line between home and the location of care (ABS, 2022a). This definition, however, appears to be too simplistic. Instead, access can be a complex concept, involving issues that include distance and time.

This research adopts Levesque et al.’s (2013a) concept of access to healthcare. Access is defined as the opportunity to identify healthcare needs, to seek, reach, obtain or use services and to have healthcare needs fulfilled. The Levesque framework broadens this definition by viewing access to healthcare services as the result of interaction between individuals and healthcare services. The framework proposes dimensions of accessibility and abilities that are interrelated and fluid (Levesque et al., 2013b). The 5 dimensions of accessibility are as follows; affordability, availability, accommodation, acceptability, and appropriateness. The corresponding dimensions of abilities of the population to utilise healthcare services are; the ability to perceive, seek, reach, pay and engage with the health services (Levesque et al., 2013a). The view of healthcare access described by Levesque and colleagues, suggests factors related to peri-urban location, structural constraints and characteristics of both individuals and services need to be considered to remove access barriers (Levesque et al., 2013b).

5.3 Study design

Due to the exploratory nature of the research, an ethnographic approach to the pilot study was selected to examine the experiences of health professionals providing community palliative care in one peri-urban region within South Australia. The researcher drew on her own lived experience as a community palliative care clinical nurse to explore perceptions of others involved in the clinical or operational aspects of care provision to support the feasibility of a larger study. Ethnography is the study of social interactions, perceptions and behaviours that occur within communities, teams and organisations (Reeves et al., 2008). A focused ethnographic approach is useful within a healthcare setting, such as community palliative care, as it provides the social context and explores the social conditions in which participants live and work, their familiarity with the setting, their perceptions and how they are influenced (Holloway & Galvin, 2017; Kovan & de Vries, 2010).

5.4 Participants

The research was conducted in a peri-urban region in South Australia. The region extends into seven LGAs within commuting distance of metropolitan Adelaide and has experienced increased population growth. The region is characterised by picturesque countryside, high-density residential developments, small townships, and agricultural areas serviced by a road network of major highways, sealed and unsealed roads. The participants involved worked in three teams and were experienced in providing community palliative care in roles including registered nurses, social worker, occupational therapist, nurse consultants and home support workers/paramedical aids from two providers – one public and one private. **Error! Reference source not found.** provides a visual representation of the areas designated as peri-urban in South Australia and their proximity to metropolitan Adelaide.

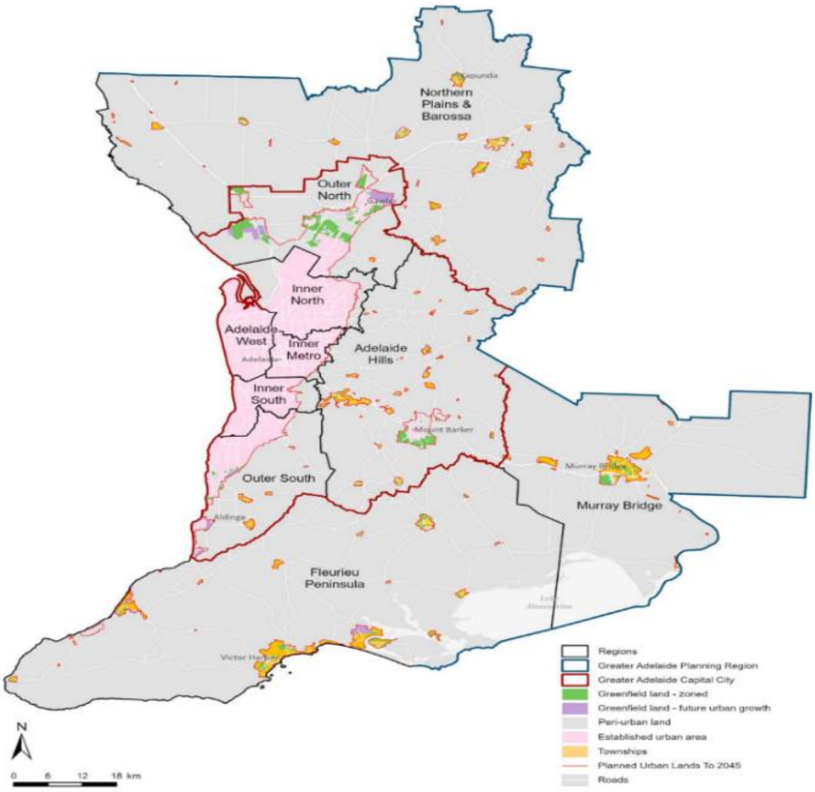


Figure 20 Greater Adelaide Development Area Map (Attorney-General's Department, 2021)

5.5 Data collection

Data was collected from January 2021 to May 2023 through observation and informal conversations. Overall concepts and relevant verbatim data were documented in a diary. Participants were observed individually and in team meetings, both face-to-face and via Zoom and Teams (Barbu, 2014; Microsoft Corporation, 2019). Indirect conversations were conducted randomly and often in a reflective context during a debrief after a complex or traumatic situation. Demographic data with the potential to identify participants was not collected.

5.6 Data analysis

A thematic analysis was conducted to supplement the lived experience of the researcher. The process involved becoming familiarised with the data, developing codes and identifying themes as they emerged. Analysis involved the researcher reading and re-reading the hand written diary notes to identify recurring words, sentences and their meanings from the perspective of participants (Pope & Mays, 2020). Interrelated primary themes were identified including (a) risks to related to location, (b) challenges related to distance, and (c) lack of resources.

5.7 Results

The perceptions of community palliative care practitioners working in this region, supported the evidence from the literature that peri-urban locations influence access to care, services and support. Frequent comments were made about the level of care being akin to a lottery, where the level of care was predetermined by geographic location. The literature also describes this phenomenon as a ‘postcode lottery’ of locational disadvantage (Javanparast et al., 2022). This is despite palliative care standards which dictate that provision of person-centred care should not be challenged by limitations, including location (PCA, 2018a). Practitioners voiced their frustration at their perceived lack of support from policymakers, the difficulties of providing care in peri-urban locations and the increased risks to both practitioners and patients.

Risks to health professionals exist in all community care settings, due to complex care needs and family situations. However, practitioners clearly voiced the view that potential risks are exacerbated in the rural and isolated locations within peri-urban areas (AHA, 2019). Palliative care professionals often work autonomously, in unfamiliar environments, with a likelihood of a delayed response by emergency services or support services due to location and poor mobile phone coverage. Practitioners discussed the difficulties and lack of confidence they often faced due to working in isolation and travelling long distances to enter unfamiliar environments, containing any number of extended family and friends, who are often highly emotional, overwhelmed, and unpredictable. There is great potential for any home to include domestic violence situations, weapons, domestic and working animals, people with mental health conditions, drug and alcohol addictions and generally unsafe working and living conditions (Terry et al., 2015).

Nurse D during a team meeting advised:

> … need to reject this referral due to all the safety issues detailed … The client also lives at … a remote location with minimal mobile phone reception.

This view was supported by an informal discussion:

> …Seriously I am not comfortable working with this gentleman…All history highlights the risk to workers, especially health workers. Also mention of sexual assault and physical assault history … access to weapons … but they are friends so how is this ok? (Social Worker A)

Evidence supports the benefits of relational continuity of care for optimal patient outcomes (Hudson et al., 2019). Small communities in rural locations promote an environment where overlapping relationships are inevitable and valued but potentially problematic when maintaining safe and ethical care (Campbell & Gordon, 2003; Szumer & Arnold, 2023). Urban healthcare professionals are generally able to separate their personal and professional lives, but rural workers tend to live, shop, and work amongst their patients, peers, and possibly extended family members, resulting in the need to navigate overlapping relationships (Campbell & Gordon, 2003; Cook & Hoas, 2019). The lines between maintaining professional, ethical behaviour to protect patients from harm and remaining objective by ensuring a clear separation between clinical and personal worlds in a small community can become problematic (Endacott et al., 2006). Many voiced a view that leadership either ‘downplayed’ or dismissed any potential risks voiced by staff, with many comments linking a perceived lack of support to overlapping professional and social relationships.

Home support worker X stated in an informal meeting:

> … I was scared at the house but I didn’t have a choice … we were told to go.

Community palliative care professionals in peri-urban areas are more likely to experience physical hazards such as smoke, chemical and mechanical exposure related to agricultural activities, and physical injury related to manual handling (Terry et al., 2015).

Providers are required to complete a home risk assessment prior to a home visit, to mitigate risk and promote worker safety. However, risk assessments rely on access to an accurate history and an honest response from potential clients. Providers have a legal obligation to ensure that workers have a safe workplace and that risks are mitigated; however, practitioners recognised that the workplace in community palliative care is also the patient's home.

It is important to allocate resources so that quality, person-centred palliative care can be provided safely to those diagnosed with a life-limiting illness and their families. Current practices involve practitioners working in isolation and travelling long distances, with potential for impaired communication with specialists or emergency services. Difficulties exist in providing access to the services, support and equipment required to assist family members to provide quality in-home care:

> …would like to spend more time … instead of rushing through a shower …. And running out the door. It makes me sad. (Interview Paramedical Aide P)

Ideally, any person making the decision to receive care at home has considered the increased risk to themselves from receiving care at home rather than in a hospital or facility (Coombs et al., 2017). Community palliative care services can support individuals to make an informed choice of location for care and reduce this risk; however, this ability depends on accessibility:

> I am over capacity and don't have time to follow up care coordination needs. (Nurse G, informal discussion)

Policies that influence all aspects of community palliative care are developed and implemented using classifications of location which generalise areas as urban or rural (National Rural Health Alliance (NRHA), 2022). Health policies on clinical procedures, medication management and digital health often fail to consider the implications of policy in areas outside of high-density urban locations. These implications include the accessibility of 24-hour care, in-home services, hospice care, and specialist input; the availability, storage, and transport of medications; and grief and bereavement support and choice of provider. In a team meeting, Nurse J outlined the policy requirements for nursing staff and the inferred implications for family members from clinicians following this medication policy:

> Never, ever collect medication for a client … You leave and tell family to ring when meds in house. They can go to hospital. Not our problem.

A lack of access to expected services in peri-urban areas results in distress and relocation for patients and families, especially when services to support in-home care is inadequate, insufficient, or unavailable:

> This location adds increased difficulty to service provision, with difficulty delivering equipment needed … finding staff … telehealth doesn’t work … clients are sometimes moved to hospital because there is no other option. (Nurse L, informal discussion)

Health professionals discussed their frustration and stress when unable to provide the right care to patients and families, both face-to-face and via telehealth, including grief counselling and bereavement support that might otherwise be available in another location:

> We have decided that palliative care involvement with a family ceases the moment a client dies and no further visits needed. (Nurse Consultant J, team meeting)

This was critiqued by many, for example:

> Desperately need a … grief/bereavement counsellor …we are not meeting needs. I am frustrated that I cannot do what I am trained to do. (Nurse E, informal discussion)

The perspectives of health professionals demonstrate that we need to have a deeper understanding of challenges in peri-urban environments and promote the importance of future research into policy development.

5.8 Discussion

These findings provide insight into the views of community palliative care practitioners in a peri-urban region and support the feasibility of a larger study. Increased population growth in this peri-urban region, correspondingly increases the number of people potentially impacted by the urban–rural inequity, with the demand and expectations for healthcare challenging existing services. The literature demonstrates the known challenges associated with geographically rural locations that influence the accessibility and quality of healthcare provision for peri-urban residents (Schulte et al., 2022). Practitioner views highlighted the difficulties for populations in the rural and peri-urban locations involved, which have historically relied heavily on health services from primary health providers, including General Practices and community-based health services (Halcomb et al., 2021).

Current geographical classifications of locations as urban or non-urban are calculated using data such as population size, density, and an index of accessibility. Classifications are the result of an aggregation of spatial units that must also ensure residents' privacy and confidentiality. The large size of these spatial units results in broad generalisations of population density which influences the classification and ultimately affects health service provision. Practitioners discussed the implications of failing to consider access to community palliative care in peri-urban areas from a complex perspective.

Services such as community palliative care are based on person-centred care which these clinicians believed could not be provided in a safe, timely, reliable, or appropriate manner unless barriers to access are removed. The level of frustration with current policies that promoted a 'one size fits all' approach in service delivery was evident. Themes demonstrated the need for policy which considered the complexity of the area, the dynamic mix of high- and low-density urban living, the rural locations, distances involved, the available infrastructure and resources, and appropriate models of delivery for that specific location (Collis et al., 2013; Hart et al., 2005).

Findings from observations and informal discussions with clinicians highlighted the importance of developing strategies to improve access in peri-urban locations. Planning needs to be responsive to local community needs and include the experiences of local GPs, community members and the health workers providing the physical care. Development and planning for methods of palliative care service delivery need to consider feedback from community members to ensure that funding is available to provide appropriate resources in the form of trained staff, equipment, and infrastructure. Consideration is required to understand community needs regarding grief counselling and choices of location for end-of-life care. Furthermore, the risks identified by practitioners to both healthcare staff and patients need to be addressed as a matter of urgency, to maintain safety and to retain trained staff.

Digital health access played an important role in ensuring equitable access; however, digital health needs to be viewed as an important supplementary tool and not a panacea to access. Multiple factors influence the use of and access to digital technology, including motivation and willingness to embrace digital technologies and access to resources such as a reliable, trained, and qualified workforce and access to reliable internet (Bradford et al., 2016). There will always be a need for people to travel for specialist medical treatment that is only available in major metropolitan centres, but many voiced a preference for services, including palliative care, to be provided face-to-face. Given the expected growth in peri-urban areas and the challenges to health services to provide more services, it is important to work proactively to ensure vital community services such as palliative care are delivered effectively.

5.9 Summary

This study has explored the view of clinicians who provide community palliative care, obtained through an ethnographic pilot study. Views were obtained from observation and informal discussions conducted with a small group of clinicians, working in one peri-urban region of South Australia, to support feasibility of a larger study. This pilot study demonstrated the existence of a problem space, with the views of practitioners closely aligned with evidence from the literature. The voices of healthcare professionals promoted a view that the one-size-fits-all approach in service delivery methods in the peri-urban region under review was problematic. They also provided a depth of emotion related to the issues in service delivery that was not anticipated by the researcher. Themes highlighted the need for further research to consider the complexities involved with service delivery from a broader range of peri-urban locations and participants from both provider and consumer groups. Analysis of the data collected in diary notes from this small study not only reinforced the existence of the problem space but guided the development of the data collection method, participant recruitment and survey questions to be used in the larger study.

This study will continue through the following chapters which adopted an exploratory and descriptive approach to discuss the key issues from the larger study, derived from data collected from three clusters of participants: healthcare practitioners, family caregivers and patients. Chapter 6 will discuss the views of practitioners on accessing community palliative care in peri-urban locations, which aligned closely with the results from this pilot study. Key issues identified include the home location influencing accessibility to resources, including medication and staff, and the resulting impact on the healthcare professionals themselves. The results identified the common issues to care provision in many peri-urban locations, regardless of the State or Territory or organisation involved.

Chapter 7 will discuss barriers to access services from the perspectives of family caregivers, including the key issues associated with a move from face-to-face service delivery to telehealth. Chapter 8 concludes the survey results with the perspectives of patients on access to care and their expectations of service provision. Given the expected growth in peri-urban areas and the challenges to health services to provide more services, it is important to work proactively and listen to the voices of all involved, to ensure that vital community services such as palliative care are delivered effectively.

Chapter 6. Practitioners’ perspective: barriers to access

6.1 Introduction

The complexities involved in palliative and end-of-life care provision invoke potential for differing priorities, needs and perspectives among patients, family members and the various healthcare professionals regarding treatment and services. Health professionals are in the unique position of understanding the access barriers from a systemic, workplace and patient viewpoint. Regardless of the differences, every viewpoint is important in gaining an understanding of barriers to accessing quality community palliative care in peri-urban locations. Therefore, the following three chapters aim to expand on the findings from the pilot study, discussed in chapter 5. The views of survey participants supported those identified in chapter 4, which identified the existence of barriers to accessing resources in peri-urban locations. However, participants in the survey expanded on the simple discussion of barriers to access and detailed their perceptions of associated risks and emotional toll for care providers in peri-urban locations. Many viewed the source of risk as a perceived inability to provide appropriate care.

6.2 Analysis of survey data

A qualitative approach was utilised to collect and capture data collected via an online survey. Participants were divided into three distinct groups, depending on their self-identified role. An exploratory and descriptive approach to analysing qualitative data supplied in the form of responses to open-ended questions and free-text fields was supported by a thematic content analysis to present the patterns and connecting themes of the details provided by participants (Mishra & Dey, 2022; Pope & Mays, 2020). Themes and sub-themes emerged during the process reading and re-reading of data, identifying the interrelatedness and overlapping nature of the themes and their relationships to the experiences of healthcare professionals (Pope & Mays, 2020). The findings are interpreted to detail the meaning within the criteria of the scope of the research question and positioned within the available literature to describe the phenomena involved.

Quantitative data was analysed using Qualtrics (2020) reporting tools, Microsoft Excel spreadsheets (2018) and manually by the researcher. The use of voluntary responses to questions to reduce risk of grief triggers resulted in varying response numbers to each question, which is reflected in the statistical results. A descriptive approach enables the voices of the individuals to be understood within the context of their lived reality and experiences and then compared with factual data to establish cause and effect (Busetto et al., 2020; Verhoef &

Casebeer, 1997). The next stage outlines the participants and provides the results of analysis, in particular the overriding challenges to emerge from the lived experiences of participants.

6.3 Profile of practitioner participants

Table 3 outlines the demographics of the participants who identified as health professionals. Of the practitioner participants (*n* = 52) who commenced the survey, one was withdrawn automatically because they worked outside of Australia and one voluntarily withdrew prior to completing the demographic questions. Of the remaining (*n* = 50) number of health practitioners who submitted a completed questionnaire, 70% (*n* = 35) self-identified as working in a peri-urban area, 16% (*n* = 8) in other non-urban (rural and regional) and 14% (*n* = 7) in metropolitan centres. Data that could reveal participant identity, such as gender and organisation name, location by postcode and specific age, were not requested to aid anonymity. The term 'non-urban' will be used to refer to participants who identified location as rural or regional, due to the small number involved. The median survey completion time for the group identifying as health care professionals was 662.5 seconds or 11 minutes 04 seconds. Table 2 presents the demographic details of the participants who identified as health care professionals.

Table 2 Health care professional demographics

Characteristic	**Total family caregiver participants (*n* = 50)**		**Peri-Urban (*n* = 35) (70.0)**		**Other non-urban (Rural & Regional) (*n* = 8) (16.0)**		**Metropolitan (*n* = 7) (14.0)**	
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Age								
18–34 years	5	10.0	2	5.7	1	12.5	2	28.6
35–49 years	14	28.0	9	25.7	3	37.5	2	28.6
50–64 years	15	30.0	11	31.4	2	25.0	2	28.6
65+ years	0	0	0	0	0	0	0	0
Prefer not to answer	16	32.0	13	37.2	2	25.0	1	14.2
Years working palliative care								
Less than 1 year	4	8.0	2	5.7	1	12.5	1	14.3
1–5 years	17	34.0	12	34.3	1	12.5	4	57.1
>5 years	29	58.0	21	60.0	6	75.0	2	28.6
Role								
Clinical:								
General Practitioner	1	2.0	1	2.8	0	0	0	0
Nurse Practitioner	2	4.0	1	2.8	0	0	1	14.3
Nurse Navigator	4	8.0	2	5.7	2	25.0	0	0
Clinical Nurse/ANUM	9	18.0	7	20.0	2	25.0	0	0
Registered Nurse	14	28.0	8	23.0	1	12.5	5	71.4
AIN/Carer/Home support	6	12.0	5	14.3	1	12.5	0	0
Allied Health-OT, physio	3	6.0	2	5.7	0	0	1	14.3
Psychologist/Social Worker	4	8.0	2	5.7	2	25.0	0	0
Clinical support:								

Volunteer	3	6.0	3	8.6	0	0	0	0
Admin/referral	2	4.0	2	5.7	0	0	0	0
Equipment/transport	2	4.0	2	5.7	0	0	0	0
Location by State/Territory								
Queensland	6	11.6	2	5.7	3	37.5	1	2.0
South Australia	42	80.8	33	94.3	5	62.5	4	8.0
New South Wales	2	3.8	0	0	0	0	2	4.0
Type of Organisation employed								
Specialist Palliative Care Team	16	32.0	11	31.4	4	50.0	1	14.3
Community Health	10	20.0	9	25.7	1	12.5	0	0
Public hospital	7	14.0	5	11.4	2	25.0	1	14.3
Private hospital	1	2.0	0	0	0	0	1	14.3
GP/Medical clinic	1	2.0	1	2.8	0	0	0	0
Home Care Provider	10	20.0	7	20.0	0	0	3	42.8
RACF Community team	3	6.0	1	2.9	1	12.5	1	14.3
Mental health service	1	2.0	1	2.9	0	0	0	0
Charity	1	2.0	1	2.9	0	0	0	0

6.4 Findings

Two initial questions were mandatory (informed consent and identification by participant group) in all three groups of participants, with the remaining questions all voluntary and differing in number and wording, pertinent to the participant role. All participants, regardless of role, were requested prior to consenting to participation, during the survey, and on submission, to read the information in the Participant Information Sheet (see Appendix G) and grief support page (see Appendix H) and withdraw from the study and seek assistance if required. The voluntary nature of the questions means that response numbers vary by question, therefore all responses provided were used and all percentages calculated from responses provided. There were 20 voluntary questions allocated to healthcare professionals with quantitative results provided in Appendix I.

Analysis of the data provided by healthcare professionals resulted in identifying two main themes that characterised the barriers to access experienced by people working to provide community palliative care – namely, the role of the home location in influencing resource access and the resulting risk to health care professionals. Sub-themes emerged related to the resources involved – namely, difficulties accessing staff, equipment, medication and training. These factors all increased access barriers for patients and families. Participants also noted a lack of support and recognition of staff needs by organisations involved in peri-urban care provision.

6.4.1 Home location

The factors associated with the location of the patient's home emerged as an important and complex issue. Of all palliative care professionals, 63.3% overwhelmingly highlighted that the need to travel long distances influenced patient and family decision-making about treatment options, indicated with the low variance (m=4.7, sd=.7, v=.5, ci=.1) (refer Appendix I: Table 50) which aligns with the response from those specifically working in peri-urban locations: (*n* = 30) or 85.7%. Concerningly, 75.5% of all professional respondents indicated that their patients have been forced to relocate to avoid travelling long distances for healthcare services, demonstrated by the moderate variance in responses (m=3.8, sd=1, v=1, ci=.14) (refer Appendix I: Table 50); the responses from those in peri-urban locations was even higher, with even more believing that travel distance resulted in relocation: (*n* = 33) or 94.3%.

Participants were asked if they were aware of any of the following scenarios with the high number of responses from peri-urban professionals representative of the existence of access barriers in peri-urban locations. Table 3 outlines their responses.

Table 3 Scenarios related to access barriers

Scenario	**Peri-urban respondents (*N* = 50)**	
	N	**%**
Hospital admissions extended due to in-home services unable/unavailable to support discharge	30	85.7
Clients needing to attend medical clinics or outpatient clinics as no in-home services to provide medication administration	23	65.7
Clients needing to attend medical clinics or outpatient clinics as no/insufficient in-home services available to assist with wound/catheter/stoma care	25	71.4
Ambulance being called for assistance with pain/symptom control as community services unable to be contacted	29	82.9
Respite in aged care facility as no/insufficient services available in-home to support hospital discharge	28	80.0
End-of-life care provided in hospital as appropriate services unable to be provided in the home	31	88.6
People relocating due to services being unable to provide the level of support needed in the home	32	91.4

Provision of quality palliative care services requires access to the resources required by health care professionals when needed, regardless of setting or geographical location (ACSQHC, 2021a). Research has identified five categories of resources: (a) organisational characteristics and healthcare system-led resources, (b) social resources, (c) job resources, (d) home resources, and (e) personal resources (Lee et al., 2020). The categories are interrelated, with characteristics of organisations determining leadership support and culture, and system-led policies, legislation, funding incentives and clinical practice guidelines directly influencing task-related resources required by clinicians to meet patient needs (Lee et al., 2020; Scholl et al., 2018). Task-related resources can be defined as all the materials, equipment, medication, personnel, facilities, funds, training, educational resources and anything else that can be used to provide healthcare services (Ransom & Olsson, 2017). Equipment used for in-home palliative care includes pressure relieving devices, oxygen concentrators, mobility aids, beds and syringe drivers, which are all vital for quality end-of-life care (ACSQHC, 2021a). Access to training, education, networking and support improves knowledge and self-efficacy which contributes to delivery of safe and quality care, and is crucial to those clinicians who do not routinely provide end-of-life care (Dehghani et al., 2020; Latter et al., 2020; Moorhouse et al., 2000; Prem et al., 2012).

Locations outside of urban centres challenge palliative care providers because of the increased travel times which impacts effective use and availability of resources and provision of quality care (Cinnamon et al., 2008). Health care resource allocation is influenced by funding arrangements, organisational structure and policies and are based on geographical statistical data which uses population density and distance from services as a guide to ascertain accessibility. Accessibility to healthcare is calculated on a straight-line measure of the road distance between home location and the boundary of the closest urban centre (Cerni et al., 2023). Equitable access to a hospital in Australia is calculated from home location to the closest hospital, which may or may not be able to meet the complex healthcare needs of the patient (Barbieri & Jorm, 2019; Cerni et al., 2023). What is not considered in this measure of access is the time and the financial cost involved and the subsequent influence on available in-home services and location of care.

In response to the statement ‘Home location does not influence access to services’, the response was low, with only (*n* = 2) or 5.7% of peri-urban participants in agreement. According to healthcare professionals, the distance and time involved in travelling to/from patient homes in rural areas was not factored into their pre-prepared schedule or roster of home visits for the day, subsequently limiting the time spent providing one-to-one care and the number of home visits possible in one day. When asked ‘What barriers to accessing services do you believe apply in your location’, one Assistant in Nursing (AIN) responded:

> Rural location of some homes severely impacts ability to provide services in the home and how frequently. Peri-urban locations are viewed as urban with associated amenities and infrastructure, but in reality there are often areas of unsealed and poorly maintained roads that are also impacted by extreme weather conditions, roaming livestock and wildlife.

When asked ‘What barriers to accessing services do you believe apply in your location’, one Volunteer responded:

> The roads and I don’t drive in bad weather.

Other AINs explained how travel time influenced care provision:

> Unable to visit when clients want me to, time is given to me to attend without consideration of distance needed to travel or ridiculous routes expected to take which waste time and petrol and annoy clients.

Provision of equipment and support services are aimed at lessening the burden on families; however, not all families appreciate the home becoming a hospital environment and the ‘swinging door’ of staff that may be in the home at any given time (Morris et al., 2015). A person-centred approach ensures that families have access to all services, supports and equipment that practitioners believe will assist during the carer journey. These caregivers are enabled to assert their right to choose which resources are provided and when, depending on their individual needs and wishes.

Regardless of preference, effective management of symptoms, including pain, breathlessness and fatigue, is an essential aspect of palliative care in any location, but particularly in the home environment (Baillie et al., 2018).

Any failure to address symptoms due to poor communication or planning will have tragic results, namely unnecessary pain, discomfort and suffering for the patient, distress for family members, and potential for relocation to hospital. The goal of palliative care is symptom control which is provided by a combination of non-pharmacological and pharmacological measures, with drug therapy an important component (Masman et al., 2015). Every patient has individual needs, however, many acute events during the palliative journey can be predicted by the experienced practitioners providing care, and anticipatory measures can be put in place. These include ensuring a supply of medications are available in the patient’s home, the patient and family caregivers are educated in the use and administration of the medications, and appropriate supports are available (Ding et al., 2019).

Timely access to anticipatory medication is vital in assisting people with emergent symptoms, and access to these essential medications are vital to those who wish to die at home (Latter et al., 2020). A reasonable number, (*n* = 8) or 22.8%, of peri-urban participants reported difficulty accessing medication required for palliative and end-of-life care. There are multiple barriers to accessing medication in rural locations which has a detrimental effect on palliative care provision and symptom management. Access to prescriptions becomes problematic in areas outside of metropolitan locations, particularly those with GPs who lack experience in caring for palliative patients and may lack the confidence to prescribe opioids (Latter et al., 2020; Le et al., 2017). A multidisciplinary approach to developing organisational policies and procedures to promote best practice in community medication management is advisable to meet needs (Caring@home, 2020).

Palliative care is a fundamental component of general practice with the GP assisting with the transition from chronic disease management to end-of-life care, including symptom management, a terminal care plan, care after death and bereavement support for patients, families and colleagues (RACGP, 2023). Research has shown, however, that despite close relationships with patients and a willingness to provide care, many rural GPs lack the training and skills required for optimal palliative and end-of-life care (Abbey et al., 2020; Ding et al., 2019). GPs must deal with the time factor challenges of visiting patients in their own homes because they're not mobile; travel distances impact their time spent with the patient (Ding et al., 2019; Näppä et al., 2023). Access to specialist palliative care physicians can be difficult, with the benefits of digital health options depending on the willingness of medical staff seeking support and the availability of mobile phone and internet in the location involved (Ding et al., 2019).

Local community hospitals are generally smaller and often lack access to a hospital-based pharmacist or pharmacy stock (Tan et al., 2012). This results in a reliance on smaller, community pharmacies that do provide strong community support but may delay access to medication via reduced opening hours, and a reduced range of palliative medication or available stock (Kuruvilla et al., 2018; Masman et al., 2015; Ogi et al., 2021; Tan et al., 2012). Essential medications for symptom management in palliative patients are generally well understood by clinicians; however, the choice of medication, dose and method of administration are tailored to meet the needs of individual patients at any given time (Masman et al., 2015). The medication, dose, timing and model of delivery are likely to change frequently, depending on need, and it is difficult for smaller pharmacies to provide timely access to a core standardised list of medications for the terminal phase (Masman et al., 2015; Tait et al., 2020).

Medication safety standards, principles, legislation and organisational policies determine administration, storage, dispensing, documentation and transport related to safe medication use (DoHAC, 2022a). All authorised activities involving controlled medications must be within 'the lawful practice of their profession', as determined by the standards and guidelines from all registration boards and professional practice peak bodies (Caring@home, 2020). Individual clinicians must also consider their personal scope of practice related to lawful practice (Department of Health (DoH), 2020). Restrictions on use of controlled substances are necessary to prevent illicit use, but these need to be carefully considered, as excessive restrictions have been found to hinder access to palliative care (Gomez-Batiste, 2017).

System-led standards and policies influence access to medication outside the metropolitan centres, but there are factors that can effect how well these are maintained in peri-urban areas. There is a lack of trained staff to administer drugs, difficulties related to safe storage due to challenging family dynamics and prescribing, dispensing and transport issues related to distance and time (Scholl et al., 2018). The home location potentially increases stress on family members faced with the dilemma of leaving patients on their own at home or driving to the pharmacy if home delivery options are unavailable. Access to imprest or emergency medication for home visits would alleviate issues for clients impacted by location barriers, but these are subject to organisational, State, Territory and national policies, guidelines and legislation (Caring@home, 2020). Despite the common wish for end-of-life care at home, many people in the terminal stage are transferred to acute settings because of distressing symptoms that are unable to be adequately managed in the home (Champion et al., 2015).

Barriers to access which negatively influenced the ability of health professionals to provide quality person-centred care were evident in the responses to several statements. A high number of participants, (*n* = 25) or 71.4%, wanted the opportunity to provide a choice of day/time of service to patients and only 14, or 40.0%, of peri-urban professionals agreed that the choice for end-of-life in the home was supported, regardless of location. The importance of a person-centred approach to care is fundamental in end-of-life care, and the needs and wishes of the individual in all decision-making regarding treatment and care and the location of care, including a home death, should be the highest priorities (Slater, 2006).

Person-centred care is a core value in palliative care. It ensures individuals' autonomy, dignity, respect and choice and supports family needs, cultural and religious preferences (Agllias, 2018; Wilson et al., 2014). Provision of person-centred care supports a choice of options for care, with only 14, or 40.0%, of peri-urban professionals believing that choices for end-of-life care, including hospice, home death and voluntary assisted dying, were supported in their peri-urban location.

Participants pointed out that distance and time to attend a face-to-face visit influenced the model of service delivery, with one Assistant Nurse Unit Manager (ANUM) responding to the question 'What barriers to accessing services do you believe apply in your location' thus:

> Specialists only providing care digitally.

A digital model of service delivery was a contentious issue with many participants voicing strong opinions about the importance of providing a face-to-face service. Over half the participants, or 57.1%, agreed that digital health is an important tool for ensuring regular communication with patients, and 67.4% of all professionals believe that digital health supports contact with patients, demonstrated by the low variance (m=3.8, sd=.9, v=.7, ci=.1) (refer to Table 4).

Table 4 Descriptive statistics survey Question 6.19 How much do you agree with the following statements?

Statement	n	min	max	mean	SD	Variance	Confidence Interval
6.19(1) (Professional) Digital health is an important tool in ensuring regular communication with patients	46	2	5	3.8	0.9	0.7	0.1
6.19(2) (Professional) I have the resources and confidence to use digital health options effectively	47	2	5	4.0	1.0	1.0	0.1
6.19(3) (Professional) Telehealth consultations are an acceptable alternative to face-to-face consultations with medical professionals	46	2	5	3.4	0.9	0.8	0.1
6.19(4) (Professional) Telehealth means that patients can access medical support that would not be readily accessible due to distance	47	3	5	4.0	0.7	0.5	0.1
6.19(5) (Professional) I feel that patient's choice of place of care is supported with digital health options	47	1	5	3.8	0.8	0.8	0.1
6.19(6) (Professional) Patients and family members are comfortable to remain at home knowing that they can access support at any time	47	1	5	3.4	0.9	0.9	0.1

These views supported the literature that found that, whilst the change from a traditional face-to-face model of service delivery improved accessibility in the short term, it was important to view digital health as a means of complementing current service methods (Collier et al., 2016). Services such as palliative care are founded on relationships developed through face-to-face delivery to convey empathy, communicate sensitive information and enable an appropriate response to body language and facial cues (Lally et al., 2021; Milch et al., 2021; Namasivayam et al., 2022).

Participants were asked to select problems they had experienced with digital health options. Over a third, (*n* = 13) or 37.1%, reported poor mobile coverage and 11, or 31.4% reported unreliable or non-existent internet issues. Participants also reported digital health service delivery issues relating to patients with hearing and language difficulties and people not answering their phones. Digital health problems reported by participants support the view that peri-urban locations retain issues known to exist in rural locations. The literature found that people living in rural areas have limited or no access to high-speed internet infrastructure or reliable mobile phone coverage, despite programs to fund improved connectivity and coverage (Department of Infrastructure, Transport, Regional Development, Communications and the Arts, (DITRDCA), 2022; Guenther et al., 2020).

The National Palliative Care Strategy framework for palliative care service development recommends 24-hour access to palliative care services (DoHAC, 2019). The transformation from traditional healthcare delivery to digital health has the potential to remove some of the barriers of time and location, help provide after-hours support and education, and lessen feelings of isolation for palliative patients (Guenther et al., 2020; Lally et al., 2021; Namasivayam et al., 2022; Schulte et al., 2022).

In a worrying response to the statement ‘Access is available for support 24/7’, only 4, or 11.17%, of peri-urban participants agreed. Ongoing 24/7 support is viewed as the ‘gold standard’ of quality palliative care service delivery because it to ensures access is available to information, decision-making and support for real or perceived crises in the home (Phillips et al., 2008). Unfortunately, this level of support is often only available in larger specialist palliative care units in metropolitan centres (Phillips et al., 2008). The desire for changes in peri-urban palliative policy so that 24-hour access could be implemented was evident in responses, with 27, or 77.1%, wanting to be able to provide 24/7 contact for support and 29, or 82.8%, wanting 24/7 in-home care options.

In response to the question ‘What barriers to accessing services do you believe apply in your location?’*,* 33, or 94.3%, cited a lack of resources/capacity from providers and 30, or 85.7%, said that care needs had increased beyond capacity of existing services. A lack of resources and capacity could explain the high number of responses citing that it took too long for services to commence: (*n* = 28) or 80.0%. Although the commencement of services can be crucial for effective symptom management and quality care, the referral time can be outside the control of palliative care staff due to administrative wait times. One ANUM commented that;

> Time taken for assessments with MAC [My Aged Care] for in-home and ACAT [Aged Care Assessment Team] is ridiculous.

When asked to respond to the question ‘Thinking about the organisation in which you provide community palliative care, are there any changes you would like to see?’, the overwhelming response from participants in all roles was for more resources to support clients. They specifically cited the need for more staff, funding and equipment. Others wanted increased frequency of services (*n* = 30, or 85.7%), more available equipment (*n* = 22, or 62.9%) and higher staff numbers to support service available (100%). As one psychologist responded:

> More staff, more funding then we could increase the services and increase the distance we could cover.

Most participants did not believe that appropriate bereavement care was available, despite this being a core component of palliative care (PCA, 2020). Considering the value of bereavement support, it was concerning to find only 6, or 17.1%, of the participants believed that appropriate care was available in their location. The need for more palliative care personnel was a recurrent theme:

> More resources available to support clients, quick access to allied health.
> (Clinical nurse)

> More staff would mean more people could attend appointments
> (Transport Care Coordinator)

Responses were compatible with the literature; bereavement support is often suboptimal or non-existent and there is a lack of service capacity for sustainable care for those experiencing complex grief in areas outside of urban centres (Hall et al., 2012; Reid et al., 2023).

Participants expressed frustration at patients' and family members' expectations of the level, quantity and type of services that were available in their location, with only 13, or 37.1%, of the participants believing that existing health services were meeting the needs and expectations of people in the peri-urban location where they worked.

When asked 'What barriers to accessing services do you believe apply in your location?', one AIN responded:

> Clients tell me that they want me to come to their house for longer, at different times, and on different days.

The response from one Administrative Support participant was:

> Expectation from clients for services that are beyond our capacity.

Health expectations have been defined as 'beliefs about future outcomes, formed through cognitive processes and influenced by previous knowledge and past experiences' (Janzen et al., 2006). Current health models encourage consumers to seek health information, to be empowered in the healthcare process, with the person-centred approach encouraging individual preferences and values to be acknowledged. Information is abundant and easily available through social media, meaning that patient expectations are high and they are likely to complain if there are inconsistencies between expectations and experiences (Coulter &

Oldham, 2016; Proulx et al., 2012). Peri-urban services provided in a rural model of service delivery are not likely to meet the preconceived views and expectations of people relocating to peri-urban and expecting the same level of service provided in metropolitan centres.

6.4.2 Increased risk to healthcare professionals

The literature highlights the challenges and risks that exist in all community care settings, due to complex care needs and family situations and the fact that potential risks are exacerbated in rural and isolated locations (AHA, 2019). Palliative care professionals often work autonomously in unfamiliar environments, likely in locations with poor mobile coverage which delays any potential response by emergency or support services. Providers are required to complete a home risk assessment prior to a home visit, to mitigate potential physical risk of injury to staff and to promote worker safety.

Regardless of their role, all palliative care professionals face many challenging situations in addition to everyday stressors, including the need to break bad news and absorb negative emotions, recurrent exposure to death, situations which challenge personal and religious beliefs, and secondary trauma (Breen et al., 2014; Cross, 2019; Wilkes & Beale, 2001). Working in palliative care involves constant exposure to deep human suffering that encompasses physical, spiritual and psychosocial dimensions on a daily basis (WHO, 2020a). It is reasonable to assume that this constant exposure to suffering and death would predispose clinicians to emotional exhaustion, stress, burnout or compassion fatigue (Clayton & Marczak, 2023; Cross, 2019). Indeed, palliative and end-of-life care is an area of healthcare that evokes strong emotions and opinions amongst health professionals and communities alike.

While many palliative care health professionals agree that the role is challenging, many also find the experience emotionally rewarding, known as compassion satisfaction (Aparicio et al., 2022; Baqeas et al., 2021; Sinclair, 2011). This is due in part to the relationships that develop between the patient, family and health professionals throughout the palliative journey and the sense of satisfaction or achievement at making a meaningful difference in peoples' lives (Aparicio et al., 2022; Slocum-Gori et al., 2013; Webster & Kristjanson, 2002). The majority of professionals agreed that staff maintain good relationships with patients/family caregivers receiving care, demonstrated by a small variance in responses (m=4.3, SD =0.6) (refer Appendix I: Table 50).

Spontaneous expressions of gratitude from families are valued by healthcare professionals and add to the rewards and incentives of providing palliative care (Aparicio et al., 2022). Coping strategies aimed at finding a deep and inner meaning in the work they do are key to health professionals managing the emotionally challenging palliative care environment and not succumbing to burnout and compassion fatigue (DiTullio & MacDonald, 1999; Sapeta et al., 2022).

Peri-urban participants, regardless of role or location, recognised that the service provided was fundamentally beneficial to the community, using terms such as 'we do our best' and 'we provide good service'. However, in response to the question, 'Overall, are you satisfied with the access to palliative care in your location', peri-urban responses were poor with only 8, or 22.8%, of the participants feeling satisfied. A positive view of the service provided to the community through terms such as 'outstanding' and 'accessible to anyone' were provided only by the group that self-identified as working in metropolitan areas.

The overwhelming theme from peri-urban participants throughout the survey responses was frustration due to an inability to provide a level of care that they believed clients deserved because of a lack of resources, including equipment and staff. Research has shown that the perception of a poor outcome or 'bad death' is often viewed by clinicians as attributable to circumstances outside their control, including an inability to meet patient needs or patient characteristics (Semino et al., 2014). A perceived lack of support from leadership or an organisation was viewed by participants as contributing to poor outcomes. Research has demonstrated that a supportive leadership recognises the importance of their staff as not just a resource but as an asset to be developed, supported and retained (Sypniewska et al., 2023).

Organisations which equip nursing and other healthcare staff with the necessary resources, including equipment and appropriate staff levels, increase staff satisfaction and decrease the likelihood of adverse medical events, poor patient care and unmet patient needs (Duffield et al., 2011; Perry et al., 2018). Words such as 'sad', 'overworked', 'stressed' and 'exhausted' were used when talking about barriers to access. Sharing thoughts and feelings is a necessary coping strategy, but negative emotions indicate that there are barriers to accessing quality care and risk factors involved in palliative care delivery (DiTullio & MacDonald, 1999). As one peri-urban Occupational Therapist with 1 to 5 years' experience commented:

> Staff are overworked and stressed. Client needs are not being met properly…palliative care is not recognised as important by [organisation named].

This comment was supported by two Personal Care Attendants, each with over 5 years' experience:

> Would like to spend more time with them instead of rushing through a shower...and running out the door. It makes me sad that we can't do more.

> We do our best but it could be much better, more staff, more time, more client focused.

A clinical nurse with over 5 years' experience summarised:

> Worked for years to provide best possible care but it is disheartening not to be supported, no resources, no equipment, no staff, not supported financially for the work we do, not recognised, clients moving to hospital to die because family cannot cope and we cannot do anymore to help them, clients moving to aged care because family cannot cope and we cannot do anymore to help them, clients dying in pain because we just don't have time to get to them or given them the time they deserve, zero bereavement and grief support is pathetic and not good enough.

Caring for dying patients and the family dynamics involved can be difficult for any health professional. However, environmental stressors are magnified in peri-urban and urban locations because smaller communities are more likely to be closely tied together and it is more likely that there are pre-existing relationships between health professionals and their patients and family members (Campbell & Gordon, 2003; Szumer & Arnold, 2023). Overlapping relationships makes it more difficult to ensure a clear separation and setting of boundaries between clinical and personal relationships for staff; they are often unable to escape work-related situations and conversations in everyday social activities (Endacott et al., 2006).

Peri-urban locations retain the systemic difficulties associated with rural areas, including difficulties attracting and retaining experienced staff, heavy workloads, and peer isolation (Reid et al., 2023). The travel distances involved in rural locations further challenge staff in their ability to meet daily workload demands without compromising care or the flexibility to attend to the individual needs of dying patients (Sørstrøm et al., 2023; Wilkes & Beale, 2001). Working autonomously further increases stressors for staff, particularly those with limited experience and training, working to fulfil multiple roles, as clinician, friend and counsellor, with minimal or nil support for attending to the needs of patients and families.

Support for health professionals in these environments is vital to ensure that appropriate symptom control and personal care is provided to patients and families (Khalil et al., 2022). A supportive workplace culture is vital for promoting informal debriefing with peers, MDT meetings or structured and formal support (Wilkes & Beale, 2001). One administrative support worker did not feel able to express an opinion in the workplace with this response:

> I would personally like to see more staff, more equipment, more time and more care given to people in the community but I would not say that at work.

The literature demonstrates that personal factors such as experience, age, gender and character play a role in influencing attitudes and negative emotions which affect stress, frustration and burnout in the palliative care workforce (Baqeas et al., 2021; Frey et al., 2018). It is possible that providers are concentrating on physical risk mitigation and ensuring worker safety and promoting personal wellbeing and mindfulness, minimising or negating the role of the organisation.

Responses demonstrate the interrelatedness and overlapping nature of the themes. Many of the participants expressed negative emotions and thoughts about some of the themes. The influence of a scarcity of resources, combined with overworked staff and an emotionally challenging environment, cannot be overlooked when considering the prevalence of risks to palliative care clinicians (Gómez-Urquiza et al., 2020). The literature highlights the key issues required to meet the emotional needs of palliative care staff, including open communication with peers, organisational support with training and education, and access to resources (Yu et al., 2023).

6.5 Summary

This chapter has summarised the findings from healthcare professionals, focusing on the following key research questions:

- How does counter-urbanisation influence community palliative care provision in peri-urban Australia?
- What role does digital technology play in peri-urban community palliative care delivery?
- How does location influence accessibility to in-home palliative care services?

Those working in a palliative care provider role reported that distance in rural areas of peri-urban locations was a significant barrier to their ability to enable equitable access for patients and family members. Participants recognised that the difficulties accessing the equipment, medication, staff and support required to remain in the home environment ultimately have the potential to result in caregiver burnout, stress and relocation of patients. The level of negative emotion expressed by clinicians, regarding how difficult they found it to provide resources in these rural areas, was an unexpected finding. A lack of satisfaction and increased frustration due to an inability to provide appropriate palliative care have the potential to lead to burnout, stress and an inability to retain the experienced and knowledgeable staff required in the palliative environment. Resources, including experienced health professionals, are vital for providing optimal, quality community palliative care that ensures quality of life, relief from distressing symptoms, and the choice of dying at home.

Whilst the literature identifies that barriers to access exist in all locations, the responses from health professionals in peri-urban locations support the view that peri-urban areas suffer the same inequities of access as in rural locations. Levesque et al.'s conceptualisation of access to healthcare was used to support this research, recognising access as a complex framework with integrated barriers identified by five dimensions of accessibility and corresponding abilities of populations (Levesque et al., 2013b). Responses highlighted the existence of all five dimensions of accessibility on the provider or supply side, which are: approachability, acceptability, availability and accommodation, affordability, and appropriateness (Levesque et al., 2013b). The five dimensions of abilities attempt to mirror the process of seeking care needed by a patient on their palliative journey, which is inherently overwhelming and emotionally challenging (Haj-Younes et al., 2022). Notwithstanding the role of system-led influences, the organisational role as a resource in itself, is an important factor due to the implications of culture and policies on equipment, staff, training, and time allocated in this sector of healthcare.

Rural locations and the tyranny of distance are factors that providers need to seriously consider when developing appropriate funding and policies. The role of digital technology in community palliative care delivery was an issue for many, who perceived the role of digital health as secondary to face-to-face consultations. The lack of available resources that health care professionals can provide to patients and the resulting negative influence on the clinicians themselves becomes a negative cycle, with a poor patient experience being the outcome.

Chapter 7. Family caregivers' perspective: barriers to access

7.1 Introduction

Effective palliative care in the home environment is provided by an MDT which includes both clinicians and informal caregivers, who may or may not include family members (Hulme et al., 2016). Informal family caregivers are the foundation of the palliative workforce, providing the majority of the care throughout the palliative journey, including end-of-life care and facilitating a home death (C. Gardiner et al., 2020; Hulme et al., 2016). Family and caregivers are central to the care needs of a palliative patient throughout the journey, providing practical support, transport, financial assistance and emotional support (O'Sullivan et al., 2021). However, there are demands associated with caring for a loved one at home, and family caregivers are often unprepared for the physical care needs, are unfamiliar with medical terminology, lack the knowledge and skills required to deliver safe care, and are unaware of the type or amount of care needed by the patient (Appelin et al., 2005).

To ensure that quality of life for the patient is optimised, family caregivers must interact with and navigate the healthcare system to access required resources (Appelin et al., 2005). However, what constitutes required resources differs for every patient, influenced by the presence or absence of personal support, knowledge, needs and preferences. Therefore, while presenting a second set of data as evidence, this chapter aims to describe the perspective of family and caregivers receiving community palliative care to help evaluate and identify required resources and the barriers that exist in peri-urban locations.

7.2 Analysis of survey data

Data analysis for the group who identified as family caregivers, followed the same approach outlined in chapter 6. Questions in the survey were modified for each group to enable participants to respond to experiences relevant to their role, with similar questions enabling the researcher to compare responses between groups, if required.

7.3 Profile of family caregiver participants

Of the 92 participants who identified as family caregivers at survey commencement, one voluntarily withdrew prior to completing the demographic questions. Of the remaining (*n* = 91) who submitted a completed questionnaire, 49.4% (*n* = 45) identified the home location as within a peri-urban area, 33% (*n* = 30) in other non-urban (rural and regional) and 17.6% (*n* = 16) in metropolitan centres. Data that could reveal participant identity, such as gender, location by postcode and specific age, were not requested, to aid anonymity. The median survey completion time for the group identifying as family caregivers was 769.5 seconds or 12 minutes

08 seconds. Table 5 presents the demographic details of the participants who identified as family caregivers.

Table 5 Family caregiver demographics

Characteristic	**Total family caregiver participants (*n* = 91)**		**Peri-Urban (*n* = 45) (49.4)**		**Other non-urban** (Rural & Regional) **(*n* = 30) (33.0)**		**Metropolitan (*n* = 16) (17.6)**	
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Age								
18–34 years	9	9.9	5	11.1	2	6.6	2	12.5
35–49 years	21	23.1	10	22.2	7	23.3	4	25.0
50–64 years	29	31.9	13	29.0	8	26.7	8	50.0
65+ years	13	14.3	6	13.3	5	16.7	2	12.5
Unsure/PNA	19	20.8	11	24.4	8	26.7	0	0
Time receiving palliative care								
Less than 1 month	15	16.5	11	24.4	3	10.0	1	6.2
1–6 months	44	48.3	21	46.7	15	50.0	8	50.0
6 months to 1 year	18	19.8	8	17.8	6	20.0	4	25.0
>1 year	11	12.1	3	6.7	5	16.7	3	18.8
Unsure	3	3.3	2	4.4	1	3.3	0	0
Relationship to patient								
Spouse/partner	37	40.7	18	40.0	15	50.0	4	25.0
Child	38	41.7	20	44.4	8	26.7	10	62.5
Extended family/friend	16	17.6	7	15.6	7	23.3	2	12.5
Location by State/Territory								
Queensland	6	6.6	4	8.9	1	3.3	1	6.2
South Australia	59	64.8	30	66.7	23	76.7	6	37.5
New South Wales	11	12.1	4	8.9	3	10.0	4	25.0
Victoria	12	13.2	5	11.1	3	10.0	4	25.0
ACT	2	2.2	2	4.4	0	0	0	0
Tasmania	1	1.1	0	0	0	0	1	6.3

7.4 Findings

Family caregivers were asked to respond to 22 voluntary questions, following provision of informed consent. Analysis of data provided by participants in this group resulted in identifying two main themes that characterised the barriers to accessing services, as perceived by family caregivers – namely, (1) the influence of the home location and (2) the impact on family caregivers from unmet needs. The perceived need for specific resources was influenced by factors pertaining to the patient and family involved; the home location was identified as the underlying factor in all barriers to accessing the services and support required by peri-urban family caregivers. The impact on family caregivers emerged through identification of negative emotions and the need to relocate loved ones at end-of-life, due to barriers to access. Sub-themes emerged which related to the home location – namely, the influence of time/distance and the reliance on local medical clinicians. Ultimately, barriers to accessing the services and support perceived by family caregivers as essential to the caring experience left a lasting effect on the family unit.

7.4.1 Home location

Although providing care for a loved one in the home environment can be rewarding, it is not without challenges. In the context of in-home palliative care, the role of family caregivers far exceeds a simple caring role and often involves the responsibility and skills required to effectively recognise and manage symptoms and administer medication, including opioids (Hudson, 2003; WA Country Health Service (WACHS), 2021). Many family caregivers lack the skills, education, experience or knowledge to cope with the demands of caring for a person's physical and emotional needs (Becqué et al., 2021). There comes a time when family members come to the realisation that there is no hope for a cure, their loved one is no longer 'living with an illness' but 'dying from an illness' and that death is inevitable (Steele & Davies, 2015). The challenges of coping with physical care needs are then accentuated by simultaneously coping with the overwhelming emotions associated with the impending loss (Steele & Davies, 2015).

Family caregivers are forced into a situation whereby they are 'learning as they go', needing support and services from health professionals to provide information, education, services and assistance to maintain the family unit and effectively participate in the decision-making process (Becqué et al., 2021). An optimal outcome for the family unit requires access to services to assist family caregivers to be successful in their role (Miller & Porter, 2021; Steele & Davies, 2015). In response to the question, 'Overall, are you satisfied with the access to palliative care in your location?', family caregivers living in peri-urban locations expressed the highest level of dissatisfaction: (*n* = 21) or 63.6%. Non-urban (rural and regional) and metropolitan responses were unexpectedly similar, with 9, or 50.0%, of the non-urban family caregivers and 5, or 62.5%, of metropolitan family caregivers expressing dissatisfaction.

Additional descriptive responses provided by peri-urban participants demonstrated an underlying level of appreciation of palliative care input, regardless of the amount, quality or model of delivery. Words such as 'wonderful', 'happy' and 'amazing' were used, particularly when the support eventuated with a home death. However, the predominant theme that emerged was the influence and impact of limited access to services on the caring experience for family caregivers. Negative emotions, including feelings of dissatisfaction, disappointment and anger, were expressed, due to perceptions of poor, limited or a lack of access to community palliative care services that family caregivers believed were required in the home to provide appropriate support. As one spouse expressed:

> …appreciate palliative care nurses visiting and providing access to doctors… visits need to be more often and I need more help since he needs 2 people to wash him, clean up after using his bowels and to transfer him from bed to chair. I need someone 24/7 but palliative care provide someone 3 times a week for an hour...Can't get a hospital bed as he is not sick enough or about to die. I cannot cope.

Another spouse expressed the same view that access to services was limited in their peri-urban location:

> Palliative care were helpful but was nowhere enough support. I could not do it alone and I kept telling the nurse but I only received one person to assist with washing my husband who could not get out of bed. There was an expectation that I would help which I did not appreciate.

An extended family member responded:

> Too little, too much expectation for family to provide everything, took a long time to find anyone who would come to the farm and then they really didn't know how to look after someone in a wheelchair.

A child in the family caregiver role expressed:

> Didn’t like services just coming when they felt like it and sometimes just not turning up at all…

The quality of the care and the amount of support that is provided during the palliative journey lives on in the memories of the people left behind, long after death has occurred. So, it is imperative that palliative care service delivery meets the needs of the people involved. Considering the access to healthcare and medication needed by every person, when, and where they need it, is recognised as a basic human right, then family caregivers have every right to expect their loved one has access to the services needed (WHO, 2021). This expectation in the general community was reflected in survey responses.

All, (*n* = 45) or 100%, of peri-urban family caregivers agreed that ‘There was an expectation that health services were accessible’, highlighted by the low variance (m=4.8, sd=0.4, v=.16, ci=0.05) (refer to Table 6) which indicates that people believe that healthcare should be accessible across all locations. This was consistent across all locations, with 94.6%

of all respondents agreeing that health services should be accessible regardless of location, with a low variance (m=4.7, sd=0.5, v=.2, ci=.11) (refer to Table 6).

Table 6 Descriptive Statistics Survey Q2.7 How much do you agree with the following statements?

	n	**min**	**max**	**mean**	**SD**	**Variance**	**Confidence Interval**
2.7(1) (Family) Existing health services were considered when selecting the home location							
Peri-Urban	45	1	5	3.2	1.6	2.60	0.24
Rural	23	1	5	2.1	1.2	1.40	0.24
Regional	7	1	5	3.0	1.5	2.30	0.57
Metro	16	1	5	2.8	1.4	1.80	0.36
Total	91	1	5	2.8	1.4	2.00	0.35
2.7(2) (Family) The location was selected as health services were in the planning development stage							
Peri-Urban	45	1	5	2.5	1.7	2.80	0.22
Rural	23	1	4	1.7	1	0.90	0.20
Regional	7	1	4	2.0	1.1	1.10	0.40
Metro	16	1	3	1.7	0.7	0.50	0.26
Total	91	1	5	2.0	1.1	1.30	0.27
2.7(3) (Family) Consideration was given to accessing servicers for possible future health needs (eg hospice, aged care facility) when selecting the home location							
Peri-Urban	45	1	5	2.1	1.5	2.10	0.21
Rural	23	1	4	1.8	0.9	0.85	0.17
Regional	7	1	5	2.6	1.6	2.50	0.60
Metro	16	1	5	2.2	1.5	2.40	0.40
Total	91	1	5	2.2	1.4	2.00	0.30
2.7(4) (Family) There was an expectation that health services were accessible							
Peri-Urban	45	4	5	4.8	0.4	0.16	0.05
Rural	23	3	5	4.4	0.6	0.32	0.11
Regional	7	4	5	4.7	0.5	0.20	0.20
Metro	16	4	5	4.8	0.3	0.10	0.08
Total	91	3	5	4.7	0.5	0.20	0.11

Despite their expectations, a large number, (*n* = 32) or 71.1%, of peri-urban family caregivers reported difficulty accessing services when required, and only 11, or 24.4%, found that services met their needs and expectations. Of the remaining responses to needs and expectations being met, 16, or 35.5%, said they were partially met and 18, or 40.0%, said they were not met.

Almost half, (*n* = 19) or 42.2%, of the participants in peri-urban locations complained that they were unable to access the service they wished to use, at a time or day of the week they wanted, and (*n* = 18) or 40.0% were unable to access the service as frequently as wanted. A further 10, or 22.2%, did not believe the local providers had the resources to provide what they wanted. Concerningly, 12, or 26.7%, were unsure why access was unavailable, and 16, or 35.5%, believed that the service they wanted to access was not available in their location. As the child of a person diagnosed with a life-limiting illness expressed:

> Is it policy or lack of funding??? why is there not enough hours of help?? mum wants to stay home. she does not want to die in hospital or at my house with her grandchildren there. Tokenistic at best.

An optimal outcome can be difficult to achieve in any location, due to unrealistic expectations from patients and families. Information is abundant and easily available through social media, meaning that expectations are high and people are likely to complain if care and services fall short of expectations (Coulter & Oldham, 2016). This scenario often results when people relocate from urban centres to peri-urban areas with expectations that the same services will be accessible (Ragusa, 2010; Taylor et al., 2017). Often this group of people have been swayed by the ‘hype’ of ‘country living within commuting distance’ and have failed to consider the possibilities of poor access to required services and the distances involved in travel (Ragusa, 2010). As 2 spouses living in peri-urban locations said:

> Moved from NSW and expected better health services in the area we moved to…
>
> we probably lived a long way from everything but that was our choice… I struggled to give him all the meds he needed to ensure he passed peacefully and quickly.

A large portion of peri-urban family caregivers, (*n* = 25) or 55.5%, agreed that ‘existing health services were considered when selecting the home location’. In addition, 75.6% (m=2.8) of peri-urban respondents in this group did not select home location based health services that were still in the planning or development stage, but there was a relatively large variance (v=2.8, ci=0.22) (refer to Table 6). The decision to relocate to a peri-urban location, based on anticipated completion of required infrastructure to meet the needs of growing residential developments, can result in frustration due to unmet expectations (Newton et al., 2017).

Only 11, or 24.4%, of the peri-urban participants agreed that ‘consideration was given to accessing services for possible future health needs (e.g. hospice, aged care facility) when selecting the home location’. This type of response follows the view that people are more likely to plan for death through completing advance care directives, making funeral plans and writing wills, than they are to plan for any future illness or decline in functional ability (Carrese et al., 2002). Refusing to consider future needs by leaving the future in ‘God’s hands’ or having the ‘take it as it comes’ mentality, fails to consider the potential distress resulting from a lack of access to local services in peri-urban areas.

Table 7 lists the responses to scenarios which illustrate that barriers to access exist in peri-urban locations, with the potential to cause distress and suffering to patients and family caregivers.

Table 7 Scenarios related to access barriers

Scenario	**Peri-urban respondents (n = 70)**	
	n	**%**
One or more hospital stays have been extended as services unavailable in-home to support discharge	30	85.7
Needed to attend clinic or hospital outpatients for medication administration as in-home services unavailable	6	17.1
Needed to attend clinic or hospital outpatients for assistance with wound/catheter/ stoma care as in-home services unavailable	6	17.1
Needed to call an ambulance for assistance with pain/symptom control as unable to contact community services	18	51.4
Respite in aged care facility was required as in-home services unavailable to support hospital discharge	7	20.0
Will need to transfer to hospital for end-of-life care to remain in local area	35	18.0

Participants were asked 'What barriers to accessing services do you believe applies in their situation?'. A third of the peri-urban participants, (*n* = 15) or 33.3%, believed 'home location and the distance involved for service providers' was a barrier to access. Responses from non-urban (rural and regional) family caregivers also cited distance as a barrier (*n = 23)* or 76.7%. However, geographic locations are a known barrier to accessing quality and person-centred palliative care for Australians living in non-urban or rural, regional and remote areas (Schulte et al., 2022). Home location was not cited as a barrier by any metropolitan participants.

Corresponding to the previous question, 13, or 28.9%, of the peri-urban family caregivers cited 'distance and time involved in travelling to some health services not available locally' as a barrier to access in their situation. Again, non-urban responses were high, (*n* = 19) or 63.3%, and distance to health services was not considered a barrier to access for any metropolitan participants.

There is no current agreed definition of what constitutes reasonable access to healthcare services in Australia, regarding the time or distance a person needs to travel (F. Gardiner et al., 2020). There are multiple types of spatial measures of accessibility used in healthcare policymaking, with methods of measuring access including area-based or distance-based factors, as discussed in detail in chapter 4 (Wood et al., 2023). Only 5, or 11.4%, of the peri-urban participants travelled less than 50 kms to healthcare services, with the majority, (*n* = 35) or 79.5%, of participants, travelling 50–150km. The responses correspond within the general definition of peri-urban areas being situated at the broad interface between metropolitan areas and their rural surrounds, within a 150 km distance from urban centres (Liu & Robinson, 2016). The remainder, (*n* = 4) or 9.1%, travelled over 150km.

Around a third, (*n* = 14) or 31.1%, of peri-urban participants believed ‘time/distance influenced home location of the person requiring care’, with 17, or 37.8%, believing that ‘relocation closer to services that provide a higher level of care will be needed’. The need to relocate due to the peri-urban home location was expressed by several peri-urban family caregivers:

> …whole family relocated from rural South Australia to be closer to Adelaide for treatment. we moved as close as we could to the city but still a long drive which mum couldn't manage when she got sicker.
>
> We moved mum to a unit closer to…so she get more services as she got sicker.
>
> We relocated to a house in the township to be easier and closer.

The time and distance involved in travel to healthcare appointments, treatments and tests recommended for palliative patients also has the potential to influence the decision-making of patients and their families. Geographic distance increases the time required to travel, with poor road surfaces and weather conditions creating difficulties for patients in poor health and who already face discomfort when travelling in any form (Cerni et al., 2023; Lalani, 2022). Responses supported this barrier, with 34, or 75.5%, admitting that ‘travel was difficult due to pain, discomfort and exhaustion’.

Just over half, (*n* = 24) or 55.8%, of peri-urban family caregivers agreed that ‘distance influenced decisions’, which was similar to the non-urban responses: (*n* = 21) or 70.0%. For peri-urban family caregivers, decision-making about travel was further influenced by a lack of public transport options, (*n* = 37) or 82.2%, and managing the cost of petrol and parking, lost wages, and organising private transport options, (*n* = 35) or 77.8%. Family caregivers reported:

> Mum kept missing her FMC appts because they were too much for her.
>
> Mum has blood transfusions at hospital every 2 weeks and has other appointments. Travel is expensive 420kms per week.
>
> Need a taxi for appointments costs $10000000000.

Although only 6, or 13.3%, of the peri-urban participants reported financial barriers to accessing services, descriptive responses highlighted the number of family caregivers that believed that the only way to receive services needed to support their needs was to pursue private services, despite the financial outlay. Comments include:

> Can’t get anyone to help me overnight unless I pay for it and it is too expensive.

> Couldn't afford to get help privately.

> We needed more help at home but couldn't afford to pay for it so dad had to go to hospital.

> Palliative care were helpful but was nowhere enough support. I could not do it alone and I kept telling the nurse but I only received one person to assist with washing my husband who could not get out of bed. There was an expectation that I would help which I did not appreciate. When I got nowhere asking for more help I told the nurse I would pay for what I wanted and suddenly there was enough staff to cover 24 hours a day for a week. I could sleep well finally.

The responses highlight the view that resources were unavailable to meet the individual identified needs and choices of palliative care consumers in peri-urban locations. Some, (*n* = 6) or 13.3%, peri-urban family caregivers believed that ‘care needs were beyond the scope of existing services’, which corresponds with the small number, (*n* = 7) or 15.5%, believing that ‘physical symptoms were managed in the home’.

Research has shown that GPs and nurses working outside of metropolitan centres often lack knowledge and have limited confidence in managing end-of-life medication, including managing breakthrough medication for adequate symptom relief (Khalil et al., 2022). Palliative and end-of-life care in peri-urban and rural locations is often provided by generalist community nurses who are not routinely involved in palliative care (Khalil et al., 2022). As one peri-urban participant providing care to her mother responded:

> Mum’s GP didn’t really know what to do when mum was dying.

A digital model of service delivery has the ability to bridge the gap in available services and provide after-hours support to family caregivers in peri-urban locations and decrease the need to attend emergency departments or transfer to hospital for end-of-life symptom management (Guenther et al., 2020; Lally et al., 2021; Namasivayam et al., 2022; Schulte et al., 2022). To meet the needs of people living outside of urban centres, a national program of development and implementation of digital technology to enhance the Australian healthcare system is underway (Davies, 2021; Rainsford, 2019). Regardless of the plan to develop digital technology to support healthcare, only 3, or 8.1%, of the participants believed that 'digital health enabled access to medical support that would not be available otherwise due to distance' or that 'their choice of place of care was supported with digital health', The majority of peri-urban family caregivers, (*n* = 37) or 88.1%, reported receiving a face-to-face method of community palliative care service delivery. Many in this group, (*n* = 26) or 61.9%, also reported receiving phone consultations, video consultations (*n* = 8) or 19.0% and text messages (*n* = 5) or 11.9%. Despite the progress in digital transformation in healthcare, only 4, or 10.8%, of the peri-urban participants believed that 'digital health consultations were an acceptable alternative to face-to-face delivery'.

Regardless of location, 84% of family members felt confident in their ability to use digital health effectively (m=4.3, sd=.7, v=.5, ci=.2), demonstrated by a low variance (refer Appendix I: Table 35). All 45 peri-urban participants responded to the question regarding problems with digital health options, and multiple responses were allowed. Only 19, or 42.2%, did 'not perceive any problems using digital health', although problems were identified with the remaining participants. A small number, (*n* = 5) or 11.1%, reported 'a lack of computer access/skills', 13, or 37.1%, reported 'poor mobile coverage', and 11, or 31.4%, reported 'unreliable or non-existent internet access issues in home locations'. Problems identified by peri-urban family caregivers support the literature on digital access in rural locations (Guenther et al., 2020). Few participants, (*n* = 4) or 8.8%, reported 'not using digital options' themselves or having 'unreliable/non-existent internet access' in their location. The remaining participants, (*n* = 10) or 22.2%, were 'not offered digital options by their local providers'. As one participant responded:

> Phone and internet are dreadful. Need to use landline.

Only 7, or 18.9%, of the peri-urban participants agreed that 'digital health is an important tool in ensuring regular communication with the palliative care team'. This is contrary to the 100% of metropolitan participants who agreed. These views support the literature that has found that whilst digital service delivery improves accessibility in the short term, it is important to view it as a way of complementing current service methods (Collier et al., 2016).

Palliative care aims to control the significant symptom burdens, including dyspnoea, pain, nausea and fatigue that result from disease progression, the treatment provided, or a concurrent mixture of both, and which results in distress, suffering and decreased quality of life (Howie & Peppercorn, 2013). The literature has identified that the symptom burden also impacts the family caregivers, who often report anxiety and a need for more psychological and practical support to guide the patient and the family unit through the disease progression (Philip et al., 2021). Identifying and addressing the holistic needs of patients and their family caregivers, attending to advance care planning and committing to honest goals-of-care discussions should not be confined to the terminal phase (Pereira & Chasen, 2016). In 2002, the WHO recognised the need to implement palliative care earlier in the illness trajectory by modifying the definition of palliative care, replacing the term ‘terminal illness’ with ‘life-threatening illness’ (Pereira & Chasen, 2016).

Considering access to palliative care using the dimensions of ability involves ensuring that users, in this instance family caregivers, can identify that services exist, can be reached and will have the appropriate impact on the person involved (Haj-Younes et al., 2022; Levesque et al., 2013b). It is vital that family caregivers are provided with the information they require to perceive the need for palliative care services and support, which is determined by individual factors such as, health literacy, health knowledge and personal, cultural and religious beliefs about health (Levesque et al., 2013b). Many family members will be overwhelmed by a diagnosis of a life-limiting illness and have difficulty accepting that death will occur. Discussions with appropriate healthcare professionals can ensure understanding of the palliative phases and accessing services in a timely manner (Levesque et al., 2013b).

More than half, (*n* = 27) or 60.0%, of the peri-urban family caregivers reported ‘difficulty finding information about service/s and identifying what services were needed.’ A mother, aged 65 years and over, of a person with a life-limiting illness, described her experience as follows:

> GP or oncologist/unit should have completed referral earlier. Should not have been left for me to do when everyone in the house was struggling.

The majority of peri-urban family caregivers, (*n* = 37) or 82.2%, reported receiving information about available services from a health professional such as, GP, specialist, or clinic staff. A referral to palliative care or a coordinated approach for a GP-led palliative approach to care is required before services can commence, which involves perceiving the notion that care is required and understanding what services are appropriate and when. The literature demonstrates that Australian GPs in non-metropolitan locations are more likely to report having the skills to manage palliative patients without support, and less likely to be positive about a good outcome from specialist palliative care teams (Johnson et al., 2011). Subsequently, many exhausted and overwhelmed family caregivers in non-urban locations totally rely on their GP to provide information.

Relegating a palliative approach to only the end-of-life period, removes the patient's right to be informed about the illness and its likely trajectory, thereby influencing effective planning and decision-making (Philip et al., 2021). Delaying commencement of care increases the likelihood of unnecessary hospitalisations, costly and futile treatments, visits to emergency departments, increased suffering and the associated financial costs to patients and the health system (Mason et al., 2021; Namasivayam et al., 2022; Newton et al., 2020; Radbruch et al., 2020). Despite the evidence of the benefits, palliative care is often underutilised or initiated late in the palliative journey (Sarradon-Eck et al., 2019). A scarcity of palliative care resources may result in referrals being deferred to an advanced stage of the illness (Hui et al., 2022). Differing disease trajectories and subtle signals in a patient's dependency may influence recognition of the need for referral to palliative care, resulting in delayed support (Hui et al., 2022). Regardless of the reasons for timing of referrals, research demonstrates an increased risk of hospitalisation for those unable to access or receiving specialist palliative care services late in the disease trajectory (Earp, 2021).

Cancer trajectories are often characterised by a clear differentiation between curative and palliative stages, with a short period of decline and a foreseeable death (RACGP, 2023). This differs from diseases, such as cardiac failure which is characterised by a gradual decline in function and unpredictable periods of exacerbations and remissions, resulting in a sudden death (RACGP, 2023). Patients may rarely see their GP during treatment and the need for palliative care becomes evident when the curative phase ceases and the patient is returned to their primary caregiver for comfort care (Claessen et al., 2013). Signals that needs are changing may only be evident to the GP following reports from family members and home support workers and every patient has differing environments, needs and preferences that need to be considered (Claessen et al., 2013).

One participant, a spouse in the 18–34-year age group, voiced her frustration:

> …don't know where to look. Husband is 30 and doctor said everything is for old people.

Other family caregivers voiced similar responses:

> …want to access...tried to access…nothing to access. Friends, family, neighbours all help.

> Don't know how to access, what to access, where to start.
> Nobody ever said we could get help from palliative care. Told me package was more than enough but it isn't. I am nearly 80.

> If we are not using it then we either do not need or want it or know it is available if and when we need it.

> We didn't know help was available and so busy caring for mum we didn't know where to look.

Although initially the focus of palliative care was about relieving suffering at end-of-life, the practice of implementing care earlier in the illness trajectory is now considered best practice (WHO, 2013). Early focus on care is no longer relegated to cancer patients and is now integrated into symptom management for all life-limiting health conditions, ranging from advanced heart, liver, renal and neurological diseases (Pereira & Chasen, 2016; Radbruch et al., 2020). Care aimed at improving quality of life early in the disease progression has been shown to reduce depression and anxiety and improve patient satisfaction and quality of life (Howie & Peppercorn, 2013). Less than half, (*n* = 21) or 46.7%, of peri-urban family carers reported an improved quality of life due to accessing community services. As one spouse reported:

> We were so busy living that we didn't think about needing any help...only had 2 visits from palliative care nurse before sending my wife to hospital where she died.

Implementing palliative care early in the journey is more likely to result in person-centred care, consistent with patient preferences and a home death (Howie & Peppercorn, 2013). Studies have shown that early palliative care may improve survival rates in a comparison of 2 groups of cancer patients – one receiving palliative care and one receiving traditional care (Mason et al., 2021).

The desire for earlier intervention was expressed by 2 spouses:

> Wife relied on her spiritual healer and alternative methods so palliative care was very late in the journey. Might have helped more earlier but can't change the past.

> Palliative nurse was lovely but referral was too late. My wife was 63 years old we thought we had more time. Oncology nurse referred us to palliative care and 3 days later she died.

> Waited weeks for palliative care to contact then it was another week waiting for a visit to house. Then nothing happened. Husband went to hospital a week later and died there. I had to phone palliative care a week after he died to tell them he was dead.

The home location has the potential to significantly influence the timing of coordination and commencement of palliative care services required to meet the diverse needs of patients. Peri-urban areas retain the challenges known to exist in rural locations and research has shown that many rural GPs lack the training and skills required for optimal palliative and end-of-life care (Ding et al., 2019). The distance involved in travelling to the home location influences time constraints and the financial impact of being away from the clinic, which are barriers to accessing the in-home palliative care visits needed to assess patients and support family members (RACGP, 2016). Furthermore, the time/distance that patients must travel for specialist palliative care needs may influence GP decisions regarding referrals and commencement of services (Currow et al., 2012).

GPs in peri-urban clinics are often generalists, and require access to, and availability of, upskilling opportunities in palliative care. Access to GP-led coordination of palliative care services in these communities is limited by service deficits, including smaller clinics, less access to specialist input, and smaller, less equipped local hospitals and less exposure to palliative care patients and medications (Latter et al., 2020). The influence on outcomes, the lasting effect on families and the compromises made due to limited access to services required by palliative patients is evident in the following response from a peri-urban family caregiver:

> Wanted overnight care sometimes to have a break, the help we got in the house was great but more visits a day to help with incontinence would have been much better, it was wonderful having her home and we love that we could but we still sent her to local hospital at the end when it got too hard and she died there. It wasn't hospice but it wasn’t a big ward in town so it was a compromise.

The inability to access services when wanted or needed in the home, was reported by several family caregivers as contributing to not achieving a wish for a home death or visits to emergency departments due to the inability to manage symptoms in the home. It is often viewed as a privilege to fulfil a person’s wish to remain at home, surrounded by their loved ones, which would not be possible without the dedication and commitment of family members providing 24-hour care to ensure comfort, safety and dignity (Breen et al., 2018). A supportive family environment has been found to be one of the determinants of a good death (Meier et al., 2016; Saarinen et al., 2023). Family caregivers may not understand what resources are needed, what is available and how to access help, with a lack of resources resulting in a preference for relocation due to concerns regarding increased risk to the patient from poor care in the home (Coombs et al., 2017; Munday et al., 2007).

Despite the common wish for end-of-life care at home, many people in the terminal stage are transferred to acute settings because symptoms cannot be managed in the home 24/7 or because there are a lack of services to support the family (Champion et al., 2015). Whilst it is an option that provides quality, person-centred care, a hospital death may not be the patient's preference, and it is more intrusive than a home death and increases the burden on the health system (Mortel et al., 2017). Ensuring that family caregivers have access to appropriate palliative care means that they can avoid unnecessary hospitalisations and presentations to emergency departments (Khanassov et al., 2016; Taylor et al., 2021b). Based on 2020–21 National Hospital Cost Data, the total palliative care expenditure in public hospitals was $581.4 million (1.1% of total public hospital expenditure) (AIHW, 2023b).

Considering the importance of supporting family caregivers, the low responses from caregivers about access to help was concerning – only 5, or 11.1%, of the family caregivers living in a peri-urban area reported that they 'had access to support 24 hours a day, 7 days a week'. Furthermore, 60.8% of family members did not agree that digital health supported their choice of home care, highlighted by the low variance (m=3.3, sd=0.9, v=.9, ci=.3) (refer to Appendix I: Table 35).

Family caregivers said the following:

> Room to improve and provide more after hours instead of calling an ambulance or the local hospital.

> Wanted services in the house to provide 24-hour care. Didn't happen.

> I cannot cope. It is too hard. If his family weren't staying here 24/7 I would have just given up by now. He shouldn't have to go to a nursing home just because he can't walk, his mind is ok and he still enjoys life.

> Very unhappy being told that services not available to support my husband at home while I am at work in the city. He cannot remain home alone, particularly when I often stay overnight in the city due to distance involved with commuting.
> He now has to come to the city with me and stay at our daughter's home where someone can watch him. I thought palliative care could support us more than

> an occasional 1 hour. Not good enough. We now have to move from our forever home in a peaceful valley where we intended to stay and move into the city. 24-hour care should be available anywhere. We are less than 100 kms from the city so winery area that is rural but close to city for commuting.

7.4.2 Impact from unmet needs

Caring for a person with a life-limiting illness and the death of that person are stressful events and overwhelmingly emotional times for family caregivers (Aoun et al., 2018). Although palliative care professionals provide community support, family caregivers provide a significant portion of the practical, emotional and existential care in the home (Norinder et al., 2021). The literature, policies and standards, recognise the vital role that informal caregivers play as members of the multidisciplinary palliative care team (Bowen, 2014). However, it is unrealistic to expect that family caregivers are prepared to meet the physical care needs of the patient or have the knowledge and skills to deliver safe care. Most will not be emotionally equipped to manage the stress involved in a journey with their loved one which will ultimately end in an untimely death. The child of one person receiving care expressed:

> We didn't know anything. We were overwhelmed. No doctor told us about palliative care. We were struggling. Mum asked me to phone community health at the hospital and they asked if I wanted palliative care. I didn't understand what palliative care meant. I cried when they asked if mum was dying and she was listening and said yes. It was awful and I will never forget.

Every patient, every family unit will have differing knowledge levels, experience, available personal and community supports, financial capability, history, needs and preferences. It is essential that family caregivers interact with healthcare professionals to seek the information and knowledge they need and ensure that the quality of life for the patient and the family unit is optimised (Norinder et al., 2021). Research has shown that family caregivers benefit from information about prognosis and the challenges of providing end-of-life care, however, are unlikely to initiate conversations with clinicians and unlikely to understand or retain complex medical terminology (Mangan et al., 2003). Reducing the burden of caregiving by meeting physical, financial and emotional care needs and providing the information and knowledge to allow preparation for an impending death, results in reduced depression, anxiety and complicated grief in family caregivers (Aoun et al., 2018; Miller & Porter, 2021).

As 2 spouses expressed:

> It is too hard. If his family weren't staying here 24/7 I would have just given up by now…Not fair and not good enough.

> Nobody came to help even when I asked and I did everything they told me to. They said 3 months for services. He died 4 weeks after I asked. I am really disappointed nobody helped me.

A preference for end-of-life care and a home death is common, either by a desire to follow patient wishes or feelings of obligation (Woodman et al., 2016). Regardless of the reason to remain at home, many people are transferred to acute settings because symptoms cannot be managed in the home, or there is a perceived lack of services to support family (Champion et al., 2015). The preference and support provided by family caregivers is a known environmental factor consistently associated with a home death (Callisto et al., 2021). However, it is unrealistic to expect family caregivers to effectively manage symptoms in the home, particularly administration of breakthrough medication at end-of-life, without information, education and support (Miller & Porter, 2021; Munday et al., 2007; WACHS, 2021). Transfer to emergency departments or acute settings for end-of-life care, can increase distress, suffering and caregiver burden, with feelings of unmet needs being associated with complicated and traumatic grief (Hall et al., 2012).

The literature has identified the highest unmet needs reported by family caregivers, namely psychological issues and patient care and support, and unmet needs are associated with anxiety and decreased quality of life (Driessen et al., 2023; Hart et al., 2022; Robinson et al., 2018).

The reality for family caregivers providing end-of-life care in the home, is that the experience of caregiving and bereavement will be closely intertwined. Death may bring a measure of relief to exhausted family caregivers, seen as an ending of their loved one's suffering and to the strain and burden of the caregiving role, and many will find their own coping strategies to manage the symptoms of depression and grief (Boerner & Schulz, 2009). However, there will be a minority who will suffer long-term, with stress, anxiety, depression and complicated grief (Hall et al., 2012).

Family caregivers experiencing complicated grief will require assistance from skilled clinicians to develop coping strategies and validate their feelings (Johns, 2015). However, many participants reported difficulties accessing services, including bereavement and grief support, with only 6, or 13.3%, of the peri-urban family givers responding positively to the statement 'support has been provided with advance care planning, completing will and grief counselling'. One family caregiver, a mother in the 18–34 year age group of a young child reported:

> We don't qualify for any support at home. No NDIS. We need a home care nurse and the social worker is at the hospital. Financially we are in tatters even with carers payment which is so little. I am trying to get grief counselling through Carer Gateway before he dies so I can cope with his death.

A very small number, (*n* = 2) or 4.4%, of the peri-urban family caregivers reported receiving support from a psychologist or psychiatrist for anticipatory grief or bereavement care, and 6, or 13.3%, received bereavement care. The literature demonstrates the high value that family caregivers place on the close relationship developed with the palliative care team prior to the patient's death and the established 'lifeline' with staff that was expected to continue (Näppä & Björkman-Randström, 2020). However, it becomes 'luck of the draw' with some peri-urban or rural palliative care teams if a skilled healthcare professional is available for provision of psychosocial care. If a social worker is not available, or lacks the skills, competency or personal interest in providing bereavement support, then a nurse will assume the role (Johns et al., 2019). A skilled clinician in the MDT, regardless of their role, must be able to support family members and identify potential complicated grief (Sealey et al., 2015). The number of responses about the lack of support following a death supports this idea:

> Only 1 visit then a phone call after John died.

> I don't know why mum couldn't get more help. I don't know why we weren't offered help when she died.

> Palliative care did nothing. Nobody did anything to help us when mum died. The hospital referred mum to palliative care with advanced pancreatic cancer. She was going home for us to care for her at home until she died. Palliative care nurse came out before Christmas then never again. When she phoned we kept telling that mum wasn't doing well and she did nothing until she sent a dietician out because we said mum was losing weight and not eating. That was just perfect. next day we called an ambulance. She died next day. Didn't even get the hospital bed mum was promised. No help. No nothing. When she phoned days later I told her mum was dead and what I thought of her. Never heard another thing.

Palliative care should be person-centred care, and tailored to individual needs and preferences, with required information, services and support differing for every family caregiver and the person that care is provided for (Coulter & Oldham, 2016). The importance and necessity of any community palliative care support will differ, influenced by the presence or absence of personal support, knowledge, needs and preferences (Dionne-Odom et al., 2019).

Family caregivers were asked to respond about barriers to accessing services in their location. It is reasonable to assume that a response citing a barrier to access would be concerning a service or resource that the family caregiver perceived as important or necessary. The large number of participants that reported barriers to access in peri-urban locations highlights the number of family caregivers with the potential for long-term physical ill-health, anxiety, depression or complicated grief as a result of unmet needs.

7.5 Summary

This chapter summarised the findings from healthcare professionals, seeking to address the following key research questions:

- How does counter-urbanisation influence community palliative care provision in peri-urban Australia?
- What role does digital technology play in peri-urban community palliative care delivery?
- How does location influence accessibility to in-home palliative care services?

In addition, this chapter sought to respond to the research question:

- Do patients’ and family members’ expectations of peri-urban community in-home palliative care differ to the care that health professionals provide?

Participants reported the distress, emotional toll and eventual outcome on the patient and the family unit of barriers to accessing community palliative care in their location. A home location, the distance and time involved in travel, was identified as a significant barrier to equitable access for those living in close proximity to urban centres. The expectation that services would be available to meet their needs was evident, with many reporting difficulties accessing services when, as frequently, and for the length of time that family caregivers wanted and expected. Responses did not differentiate palliative care services between teams or providers, with no recognition of specialist palliative care teams as separate entities in service provision.

Unlike health professionals, family caregivers did not view a lack of equipment or medication as significant barriers to quality care provision, nor was blame attributed to the healthcare system or organisations involved; rather, the overriding theme that emerged related to supporting the carer experience. Participants reported a lack of resources related to generalised services and support, with 'palliative care' used as a term to refer to overall in-home support to improve the quality of the palliative care experience. Emotions were generally voiced as feelings of disappointment at assumed accessibility to services not meeting expectations and subsequently influencing person-centred care, in particular, choice of location of death for the patient.

Whilst the literature identifies that barriers to access exist in all locations, the responses from peri-urban family givers in peri-urban locations, support the view provided by health professionals that peri-urban areas retain the inequities of access known to exist in rural locations. Barriers to all 5 dimensions of abilities on the user or demand side were also evident in family caregiver responses, albeit in varying degrees, depending on the participant (Levesque et al., 2013b). The dimensions to abilities for users were the ability to perceive, ability to seek, ability to reach, ability to pay, and ability to engage (Haj-Younes et al., 2022; Levesque et al., 2013b). The influence of barriers is significant considering that the dimensions are interrelated and inherently person-centred, subsequently influencing quality of life and wellbeing.

Distance involved in travelling to/from a home location influenced decision-making about treatment and place of care, including end-of-life and local providers lacked the resources and the capacity to support community palliative care. Rural GPs' and generalist community nurses' limited experience in end-of-life care and use of palliative care medications influenced commencement of community palliative care services and symptom management in the home.

The significance of commencing community palliative care services early in the journey and quality of life has been discussed in the literature, and the home location was identified as a contributing barrier to access. There was a general consensus that digital technology played a minor role in service delivery and that face-to-face support remained the preference. The extent of the role of digital technology differed to that voiced by healthcare professionals but the preference to retain the face-to-face component was comparable. The barriers of geographic location and distance and the resulting long-term impact from unmet needs on family caregivers are factors which need to be considered by community palliative care providers. The experience of caring for a loved one at home will linger long after the person has died, and healthcare providers have an ethical and moral right to ensure the wellbeing of the community they serve.

Chapter 8. Patients' perspective: barriers to access

8.1 Introduction

The term palliative care can conjure visions of imminent death, however death does not always come suddenly (Collins et al., 2020). For most people, it is the inevitable result of one or more diseases that are managed by multiple clinicians over weeks, months or years. Evidence suggests that access to early person-centred palliative care reduces physical and emotional distress and optimises quality of life for the patient, family members and friends (Aoun et al., 2020; Hui & Bruera, 2020; Seow et al., 2020). Quality of life is viewed as an important overall measure of wellbeing and happiness in relation to an individual's perceived value and social context in which they live (Phyo et al., 2020). The role of the family and caregivers is recognised as vital to the care and psychosocial needs of a palliative patient throughout the palliative journey, but the patient is the focus of care (O'Sullivan et al., 2021). Commencing community palliative care involves consultations focused on patient needs, and building a relationship with health professionals to encourage open and honest conversations about illness and implications, physical and psychosocial care and coordinating the care needs and resources per need and patient preference (Gomes et al., 2013). Interactions with family caregivers may be purely incidental, non-existent or fully integrated in all face-to-face and digital health interactions.

As the journey continues and death approaches, the focus of palliative support shifts and intensifies to relieve the patient's physical, spiritual and psychosocial suffering by controlling pain and other symptoms and avoiding prolonging the dying process (Mitchell, 2021; Rome et al., 2011). Elements of a good death are individual, unique and different, although dignity and autonomy are common elements (Krikorian et al., 2020; Semino et al., 2014). Elements are shaped by the patient's culture, life experience, environment, age, financial situation and disease progression, with clinicians and family members all exerting an influence with their own notions of a good death (Meier et al., 2016). The importance, is therefore, to ensure provision of person-centred care which recognises and supports the views of individual patients and their preferences and needs. Although integrated with family caregiver requirements, the patient's preferences remain integral to optimising wellbeing and quality of life. Therefore, this chapter aims to describe the perspective of patients receiving community palliative care.

8.2 Analysis of survey data

Analysis of data for the third group of participants, identified as patients, followed the exploratory and descriptive approach used in chapters 6 and 7. The relationship between themes identified by the patients' experiences and that voiced in chapter 7 by family caregivers is discussed, to identify similarities or differences.

The following section outlines patient demographics and provides the results of quantitative and qualitative data analyses, allowing challenges perceived by the patients themselves, to accessing services, to emerge.

8.3 Profile of patient participants

People diagnosed with a life-limiting illness and receiving community palliative care services were invited to participate in the survey, Table 8 provides the demographics for the participants of this study. Nil participants who commenced the survey voluntarily withdrew, with 30 submitting a completed survey. Of these, 14, or 46.7%, identified the home location as within a peri-urban area, 13, or 43.3% in other non-urban (rural or regional) and 3, or 10.0%, in metropolitan centres. Data with potential to identify participants, such as gender, location by postcode, specific age, diagnosis or disease stage, were not requested to aid anonymity. The median survey completion time for the group identifying as patients was 658.0 seconds or 10 minutes 58 seconds. Table 8 identifies the demographic details of the participants who identified as palliative care clients (patients).

Table 8 Patient demographics

Characteristic	**Total patient participants (n = 30)**		**Peri-Urban (n = 14) (46.7)**		**Other non-urban** (Rural & Regional) **(n = 13) (43.3)**		**Metropolitan (n = 3) (10.0)**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Age								
18–34 years	3	10.0	1	7.11	1	7.7	1	33.3
35–49 years	4	13.3	3	21.40	1	7.7	0	0
50–64 years	11	36.7	5	35.80	4	30.8	2	66.7
65+ years	9	30.0	3	21.40	6	46.1	0	0
Prefer not to answer	3	10.0	2	14.30	1	7.7	0	0
Time receiving palliative care								
Less than 1 month	5	16.7	4	28.60	0	0	1	33.3
1–6 months	14	46.7	5	35.70	8	61.5	1	33.3
6 months to 1 year	2	6.7	1	7.20	1	7.7	0	0
>1 year	7	23.3	3	21.40	3	23.1	1	33.4
Unsure	2	6.6	1	7.10	1	7.7	0	0
Location by State/Territory								
Queensland	4	13.3	2	14.30	2	15.4	0	0
South Australia	20	66.7	9	64.30	8	61.5	3	100.0
New South Wales	2	6.7	1	7.10	1	7.7	0	0
Victoria	3	10.0	2	14.30	1	7.7	0	0
Tasmania	0	3.3	2	14.30	1	7.7	0	0

8.4 Findings

Participants who identified as patients were asked to respond to 21 voluntary questions following provision of informed consent. The data analysis process resulted in identifying 2 main themes that characterised the perspective of palliative care patients. These were 1) the appreciation of the support of palliative care professionals in maintaining a sense of normality, managing symptoms and providing information – being the 'ear' when needing to talk, and 2) the disappointment when services were not accessible or not able to meet individual needs, resulting in relocation. Sub-themes emerged which related to the home location – namely, the influence of time/distance on decision-making regarding treatment and place of care. Ultimately, however, the existence of barriers to accessing the services and support expected by people diagnosed with a life-limiting illness was perceived by patients as not ideal but not with the level of emotion that was expressed by family caregivers.

8.4.1 Patient perspective

A variety of complex emotional responses occur when a person receives bad news, including a diagnosis of an incurable disease, being informed of disease progression, or being told that their life is ending prematurely (Derry et al., 2019). Emotional reactions include anxiety, sadness, shock, denial and anger and people will develop strategies to manage their emotions in an attempt to achieve a sense of normality in their lives (Fringer et al., 2018). People receiving palliative care experience multiple changes or transitions during their illness trajectory. Change can be confronting and often occurs suddenly and unexpectedly, resulting in new situations, accompanied by distress and anxiety (Derry et al., 2019). Common misconceptions, knowledge gaps and fear of engaging in taboo conversations may deter people from accessing palliative care until late in the illness journey (McIlfatrick et al., 2021)

In an endeavour to preserve a balance in their lives, people focus on making the most of limited time, which often leads to defining their priorities and preferences (Groot et al., 2007). Early and open discussions about end-of-life issues with patients allows time for questions, planning and reflection, and can alleviate anxiety and fear (Cheluvappa & Selvendran, 2022). Person-centred palliative care then becomes very important to people receiving care because it promotes individual goals, including continuing to live a meaningful life with dignity and respect and as autonomously as possible (Nysæter et al., 2022). For many, a meaningful life means remaining in their own home, amongst memories and loved ones (Nysæter et al., 2022). Research has shown that the vast majority of people voice a preference to remain in their own home for end-of-life care and a home death (Swerissen & Duckett, 2015). Implementing palliative care early in the journey is more likely to result in provision of person-centred care, enabling choices in care and treatment consistent with patient preferences and choice for a home death (Howie & Peppercorn, 2013).

Supporting this view, 9, or 64.3%, of the peri-urban patients reported ‘my quality of life has been improved by remaining in my own home’. The same number agreed with the statement ‘I have been supported in my choice to remain in my own home’. This view was reiterated by the majority of all participants, regardless of location.

In response to the question, ‘Overall, are you satisfied with the access to palliative care in your location’, patients expressed a higher level of satisfaction than any other group of participants; 14, or 60.9% of all patients, regardless of location were satisfied with access to services in their location. Additional descriptive responses provided to support survey responses demonstrated the underlying level of appreciation and satisfaction with palliative care service delivery. Words such as ‘happy’, ‘wonderful’, ‘perfect’ and ‘grateful’ were used, particularly in relation to palliative care support for a home death. As one patient in the 35–49-year age group, receiving care for 1–6 months in a peri-urban location, expressed:

> My nurse comes out daily my aid comes out 3 times a week and will come more often if I ask her to. Social worker has made sure everything is ready for my daughter, a memory box, my funeral is arranged and paid for and my house will be signed over to my daughter next month when she turns 18. I have a massage therapist and my doctor visits. I love my comfort box he provides. I'm gonna die happy and peaceful at home. Palliative care is not a death sentence but a new beautiful beginning.

Another patient in the 50–64-year age group expressed the same sentiment:

> Aware that I am not eligible for aged services as I am under 65 however, I only need social worker support which palliative care are providing and she is wonderful. I know the nurses are there if I need them but I am hoping to remain well for as long as possible. I have moved closer to Adelaide to make travel to LMH easier.

A patient aged over 65 expressed their appreciation for the support received:

> Palliative care have been wonderful for over 18 mths. Have stayed in the background for support while I have remained independent including driving myself everywhere. Recently needed help with pain when treatment ceased and

> palliative care arranged for a specialist to see me. Couldn't be happier with their support.

Although most patients were satisfied with access to palliative care services, some recognised that relocation would be required when their disease progressed and care needs increased. An over 65 years patient, receiving care for 1–6 months said:

> Very happy with support from palliative care. My husband and I talk with the nurse regularly and are able to vent our frustrations and just talk openly which helps us greatly. I am managing well at home and have a good quality of life with support from family. I know that this will change in the future and I will need more help and will probably have to move into a nursing home or hospital as my husband will not be able to care for me at home, but for now am very grateful that we have someone to contact when we need anything.

Some negative emotions emerged in comments, within the group of peri-urban patients who were not satisfied with access to palliative care services. In general, comments were about their dissatisfaction with needing to relocate due to a lack of expected service access. A patient in the 18–34 age group provided the following succinct response:

> I have to move to get the help I should be able to get locally….is supposed to be modern and with all facilities.

A peri-urban patient under 65 years of age and ineligible for Commonwealth Home Support packages expressed their view:

> I have tonsil cancer but not sick enough for palliative care. Live alone and need help but can’t get any. Can’t afford petrol to drive anywhere and not well enough to drive. Have to sell my house and move but house at...not worth a lot so can’t buy anything and can’t afford to rent.

The importance of person-centred care to enable a meaningful life for the time remaining for people receiving palliative care highlights the importance of removing barriers to accessing services in a timely manner. The expectations of palliative patients were reflected in survey responses.

Similar to the family member and health professional responses, 86.6% of patients indicated that they had an expectation that healthcare services were accessible, regardless of location, with a low variance (m=4.5, sd=0.8, v=.6, ci=0.1) (refer to Table 9). The level of expectation of accessibility to health services was so high overall, that (*n* = 28) or 93.3% of all responses, regardless of location, had expectations of access to services. Of the remaining number of responses, (*n = 2)* or 6.7%, one in a peri-urban and the other in a non-urban (rural), location, responded with ‘somewhat disagree’. These responses were comparable with responses received from family caregivers, with 100% of participants having an expectation of access to health services.

Despite their expectations, however, only 7, or 50.0%, found that services met their needs and expectations. Of the remaining responses to needs and expectations being met, 16, or 35.5%, of the participants said their needs were partially met, and 18, or 40.0%, said they were not met. It is worth noting that palliative patients were generally happier with services received than family caregivers, with only 24.4% agreeing that needs and expectations had been met. Studies have shown that caregiver expectations associated with stress and caregiver burden can influence perceptions of the caregiving experience, which may be reflected in the differing responses between the 2 groups (Burns et al., 2015). Comments from peri-urban patients who said that services did not meet their needs and expectations revealed their frustration. Two 50 –64 year olds said the following:

> Palliative care accepted me but then did nothing as they said I wasn’t about to die from cancer so they left me with nothing even community nursing refused to come out to my house cos too far away.

> Need gardening, housework, help with transport to appointments and treatment, respite in my home so my husband can leave the house, meals and shopping and help with showers sometimes but cannot access as NDIS refuses and too young for My Aged Care.

Only 5, or 35.7%, of the peri-urban patients reported difficulty accessing services when required, with the same number also finding it difficult to access identified services when required. Although small in number, one very emotional response was received from a peri-urban patient:

> No social worker my body and mind isn’t coping I’m drowning internally and externally don’t know how I will get thru I can’t afford MRI. It cost $625 – they offered me a payment plan.

The importance of understanding patient perceptions of unmet needs is evident in the close relationship between patient and family caregiver responses to barriers to access; 85.2% of patients agreed that they have a good relationship with the professionals providing their care, highlighted by the low variance (m=4.3, sd=1) (refer Appendix I: Table 74).

What is perceived as an unmet need by palliative care patients may differ to family caregivers, due to personal preferences, culture and life experience. The effect of unmet needs includes increased or unrelieved pain and physical symptoms such as nausea, fatigue and dyspnoea, and emotional distress (Wang et al., 2018). The family caregiver role is to support the needs of the patient, therefore any perception of unmet patient care needs will increase caregiver distress and burden, which then influences the distress of the patient, impacting quality of life and negatively influencing the physical health of both patient and caregiver (Wang et al., 2018). Person-centred care involves the needs and preferences of the family unit as a whole, therefore understanding the needs and preferences of everyone involved and removing barriers to access will increase the wellbeing of the family unit, central to the aim of palliative care services (WHO, 2020a).

Only 6, or 42.9%, of the peri-urban patients reported 'difficulty finding information about service/s and identifying what services were needed.' However, no peri-urban patients agreed to being involved with seeking services or information, with the majority, (*n* = 11) or 78.6%, agreeing that they were referred to palliative care, with 64.3% of referrals coming from the health professional providing treatment. As discussed in chapter 7, the role of family caregivers is to support loved ones with physical, spiritual, psychosocial and financial needs and this cannot be understated (Norinder et al., 2021). Family caregivers require support to continue in their caregiving role and often make the decisions about services and supports for in-home palliative care in order to improve quality of life and enable the option of a home death (Steele & Davies, 2015).

Patients may not have a role in initiating access. This is often left to family caregivers and primary healthcare clinicians and GPs. Almost half, 42.2%, of family caregivers in peri-urban locations complained that they were unable to access the service they wished to use, at a time or day of the week they wanted, and 40.0% were unable to access the service as frequently as they wanted. It is unknown if this level of dissatisfaction was the view of the family caregiver or a report on behalf of the patient.

Studies have demonstrated that palliative care patients themselves often create barriers to in-home services due to personal preferences, reluctance to accept strangers in their home, an expectation of family support, misconceptions and the stigma associated with palliative care, and self-perceived views of their health and functional condition (Cardenas et al., 2022; Collins et al., 2020; Flieger et al., 2020). Denial or an unrealistic self-perception of their needs and abilities was evident in responses to the question, ‘If you are not using all available community services, why not?’ Half of all palliative care patients reported ‘I don’t need the service at this time’; 7, or 50.0%, of these respondents were peri-urban patients. As one patient, who did not provide any personal details responded:

> Not old enough for home help but can’t shower myself or go down steps to get to garden. Nurse said I have to pay for ramps myself but too expensive. Palliative nurse organised someone to come out and shower me but I don’t always want a shower when they get here so I tell them to go away. OT that came out was rude. Husband and I fight all the time. He cooks me food but that’s all. I have a car that takes me…for chemo and it costs me $50 each time. Nurse keeps asking me about moving to…[urban centre]...with my son but I don’t want to. His house is small and my grandchildren I love but they are noisy. I am too young for nursing home and don’t want to go there. Will die here on the farm. Nurse phones me sometimes but doesn’t visit. Doctor phones me and he doesn’t visit. Friends don’t visit.

Peri-urban patients were asked ‘if location was chosen as health services needed were close’ and only 5, or 35.7%, agreed. Even less, (*n* = 4) or 28.6%, agreed that consideration was given to services in the planning or development stage. High variance across responses highlights that, although people denied selecting their home location based on healthcare access (m=2.3, sd=1.4, v=1.9, ci=.25), the majority disagreed with this statement, which links to the assumption that healthcare will be easy to access, regardless of location (refer Table 9).

Table 9 Descriptive Statistics Survey Q5.6 How strongly do you feel about the following statements?

Statement	n	min	max	mean	SD	Variance	Confidence Interval
5.6(1) (Patient) I chose this location as health services I need are close by	30	1	5	2.3	1.4	1.9	0.25
5.6(2) (Patient) I chose this location as services I need/may need, are in the planning or development stage	30	1	5	1.9	1.3	1.7	0.24
5.6(3) (Patient) I chose this location as health services that provide for increased care needs are close by (eg hospice, aged care facility, specialist care)	30	1	4	1.7	1.1	1.3	0.20
5.6(4) (Patient) There was an expectation that health services were accessible	30	2	5	4.5	0.8	0.6	0.10

However, a theme relating to home location posing challenges to access emerged when answers relating to barriers to access were expressed. Although only 3, or 21.4%, of the patients perceived difficulties in accessing services in their peri-urban location, 8, or 57.1%, admitted that they 'have had one or more hospital stays extended as services were unavailable to support discharge home'.

A reasonable number, (*n* = 4) or 28.6%, of the peri-urban patients believed that 'home location and the distance involved for service providers' was a barrier to access. The majority, (*n* = 13) or 92.9%, were more concerned with the barrier from 'home location and distance involved in travel to healthcare services not available locally'. However, the response from non-urban or rural, regional and remote patients was as expected because geographic locations are a known barrier to accessing quality and person-centred palliative care for Australians living in these locations (Schulte et al., 2022). Home location was not cited as a barrier for service providers by any metropolitan participants.

Only one, or 7.1%, of peri-urban patients travelled less than 50 kms for healthcare services, with the majority, (*n* = 13) or 92.9%, of the participants, travelling 50–150km. No patients reported travelling over 150 km.

Geographic distance increases the travel time and associated difficulties for all patients already in poor health and facing pain and discomfort when travelling (Lalani, 2022). Responses supported this notion, with 6, or 42.8%, of peri-urban patients agreeing that 'time/distance influenced home location of the person requiring care' and 'the distance required to travel to some health services has influenced where I live'. Eight participants, or 57.1%, believed that 'relocation closer to services that provide a higher level of care will be needed'. The need to relocate due to the peri-urban home location and barriers to access was expressed by patients aged under 65 years:

> I can't access any other support. I have tried cancer council, Ferros care, NDIS and My Aged Care. Cancer Council helped with transport and a lawyer. When I need more help I go to hospital.

And another:

> Aware that I am not eligible for aged services as I am under 65 however, I only need social worker support which palliative care are providing and she is wonderful. I know the nurses are there if I need them but I am hoping to remain well for as long as possible. I have moved closer to Adelaide to make travel to LMH easier.

The time and distance involved in travel for health purposes has the potential to influence patient decision-making, particularly if they believe that their care needs are becoming a burden on family caregivers (Munday et al., 2007). Research has demonstrated the significant role of rurality as a predictor of low rates of outpatient chemotherapy and radiotherapy treatment (Cerni et al., 2023). Six, or 42.8%, of the peri-urban patients agreed that 'distance influenced decisions' which was similar to the non-urban responses: (*n* = 6) or 46.1%. For peri-urban patients, decision-making regarding travel was further influenced by a lack of public transport options reported by the majority, (*n* = 12) or 85.7%. Travel was also deemed complicated, which also affected decision-making, with the same number of participants saying that it was difficult for family caregivers to manage the cost of petrol and parking, lost wages and time with private transport options. An expectation that a community car would be available in peri-urban locations in proximity to urban centres was not met, with 9, or 64.3%, of the participants reporting a lack of availability.

The responses highlighted a lack of person-centred care, demonstrated by a lack of available resources to meet the individual identified needs and choices of palliative care consumers in peri-urban locations. Six, or 13.3%, of peri-urban family caregivers believed that 'care needs were beyond the scope of existing services,' which corresponds with the small number, (*n* = 7) or 15.5%, who stated that 'physical symptoms were managed in the home'.

In stark contrast to the negative opinions of family caregivers, palliative patients were supportive of the role of digital technology in community palliative care. Ten, or 71.4%, of the patients believed that 'digital health enabled access to medical support that would not be available otherwise due to distance' and 8, or 57.1%, said that 'they were comfortable to remain at home knowing that I can access support at any time.' Of all patients, 80.7% indicated that digital health provided access to supports that they would otherwise not have access to due to distance, highlighted by the low variance (m=3.9, sd=.8, v=.6, ci=.2) (refer to Table 10).

Table 10 Descriptive statistics survey Q5.20 How much do you agree with the following statements?

Statement	n	min	max	mean	SD	Variance	Confidence Interval
5.20(1) (Patient) Digital health is an important tool in ensuring I have regular communication with my palliative care team	27	1	5	3.6	0.9	0.8	0.2
5.20(2) (Patient) I have the resources and confidence to use digital health effectively	27	2	5	3.9	1.1	1.2	0.2
5.20(3) (Patient) Digital health consultations are an acceptable	26	2	5	3.5	0.8		

alternative to face-to-face consultations with medical professionals						0.7	0.2
5.20(4) (Patient) Digital health means that I can access medical support that I would not be able to access due to distance	26	2	5	3.9	0.8	0.6	0.2
5.20(5) (Patient) I am comfortable to remain at home knowing that I can access support at any time	26	1	5	3.6	1.1	1.2	0.2

Most peri-urban patients, (*n* = 10) or 71.4%, reported receiving a face-to-face method of community palliative care service delivery. This same number also reported receiving phone consultations, although other digital health technologies were not preferred. Despite the progress of the digital transformation in healthcare, only 6, or 42.9%, of peri-urban patients believed that ‘digital health is an important tool in ensuring I have regular communication’. It is unclear how much decreased function and increased need influences the method of service delivery to community palliative care patients who require face-to-face consultations to support end-of-life and terminal care. It is also worth considering that these views support the literature that posits that digital health is preferable complementary to current service methods (Collier et al., 2016).

8.5 Summary

This chapter has summarised the findings from the perception of a small number of community palliative care patients – all patients on a palliative journey with an inevitable ending. The goal was to address the overall aim of this research by focusing on the following key research questions:

- How does counter-urbanisation influence community palliative care provision in peri-urban Australia?
- What role does digital technology play in peri-urban community palliative care delivery?
- How does location influence accessibility to in-home palliative care services?

In addition, this chapter sought to address the following research question:

- Do patients’ and family members’ expectations of peri-urban community in-home palliative care differ to the care that health professionals provide?

Participants reported their disappointment at unmet needs and the need to relocate for additional services, to reduce travel time to treatment and appointments and for end-of-life care. The factors associated with travelling over 50 kms for healthcare were identified as a barrier to equitable access to services for those living in a community viewed as having appropriate healthcare access due to proximity to services. There was an expectation by patients that services would be available, to the point that many did not report factoring in a need to source healthcare access prior to their changing needs. Consideration was not given to available healthcare services in the local community when relocating or choosing to remain in their local area.

Patients reported satisfaction with the method of service delivery received and believed that digital health was an important tool in service delivery. These results are difficult to use for comparison purposes between groups, as that stage of the palliative journey may have influenced patient perspectives. However, comparable to family caregivers, there were no specific resources identified as barriers to access, merely a generalised view that access to palliative care services in their home were not available as expected or needed. No blame was attributed to the healthcare system or organisational characteristics involved in care provision. Emotions inferred a level of disappointment, rather than anger or frustration at an inability to source services as desired. Disease progression, increased symptoms including pain and fatigue, functional and cognitive decline could play a part in this virtual acceptance of the situation, as could the desire to not burden or upset family caregivers. Whilst the literature has identified that barriers to access exist in all locations, the responses from peri-urban patients does add support to the views provided by family caregivers and health professionals, that peri-urban areas retain the same inequities of access as rural locations.

Similar to family caregiver responses, patients reported varying levels of barriers to access in all 5 dimensions of access and abilities, from the user perspective (Levesque et al., 2013b). The dimensions are interrelated, continuous, and fluid throughout the palliative journey (Haj-Younes et al., 2022; Levesque et al., 2013b). Any barriers to access, at any point in the journey, will have an immediate effect on patient wellbeing, which ultimately influences the physical and emotional wellbeing of health professionals involved and the family caregivers.

Chapter 9: Conclusion

9.1 Introduction

Chapter 9 begins with a summary of the research methodology, which employed an exploratory, inductive, and interpretative approach, with the aim of responding to the research questions. The significance of the findings will be discussed, including the implications for public healthcare providers. This chapter will also propose recommendations for evaluation by providers in the form of a report, outline key implications of the research and suggest areas for potential future research.

The research sought to understand if home location in peri-urban areas in Australia influences access to community palliative care service delivery. The inequities of access related to geographical location in rural and remote Australia are well known. What is less understood, is the state of access in the rapidly growing outer urban and regional fringes (Rainsford, 2019). Often termed peri-urban areas, these locations are a popular choice for relocation, however, infrastructure and service growth in peri-urban locations has consistently lagged behind housing construction (McFarland, 2015; Newton et al., 2017).

This study was designed to describe, through an ethnological framework, the perceptions and experiences of barriers to access of those providing or receiving, palliative care in the community setting. An online survey was used for data collection, with the majority of participants citing peri-urban areas within South Australia as the location for provision or receipt of care. Qualitative data was collected using free text and open-ended questions to allow participants to explain themselves and reveal issues that might otherwise go uncaptured (Rich et al., 2013; Riiskjær et al., 2012). Providing the option of free-text feedback, as opposed to just closed questions, also helped overcome the limitations to potential data (Bowyer et al., 2019). Qualitative data was organised into themes by categories to allow connections, similarities and comparisons to emerge (Gioia et al., 2013). Quantitative data in the form of Likert and multiple-choice questions was collected to support the qualitative data. The intent was to merge, compare and contrast results from data analyses to add a greater depth of understanding to participant meaning and experiences reported in emerging themes from the qualitative analysis (Creswell & Creswell, 2018).

The data analysis identified themes that characterised the barriers to access experienced by people working to provide community palliative care. The prominent barrier was the role of the home location in accessing resources, including the staff, equipment and medication required to support patients and families. Many healthcare professionals also cited the physical and emotional risks involved in providing care in rural and isolated areas within peri-urban locations, with many stating that they were unable to provide appropriate care to patients and family caregivers. Healthcare professionals also noted that the difficulties accessing required resources and a perceived lack of support from their organisations, with many voicing feelings of stress, exhaustion and frustration.

Emerging themes from family caregiver and patient responses mirrored those from providers, with the home location cited as the underlying factor in all barriers to accessing the services needed or expected, with distance required to travel to services influencing decisions related to care, treatment and relocation. Many spoke about their negative experiences of palliative care resulting from barriers to accessing the services perceived as essential to the caring experience, citing the emotional toll on the family unit.

The key research findings in relation to the research aims and questions, have been summarised in a report, a copy of which is included in this chapter. The report has been directed to Dr Robyn Lawrence, the Chief Executive of the Department for Health and Wellbeing, responsible to the Minister for Health and Wellbeing for the governance, leadership and management of the South Australian health system. The research seeks to create impact in the public health sector, guided by the WHO (1987) public health approach to palliative care, and engage communities in palliative care. The concept of a public health approach to palliative care aims to effectively integrate palliative care into society through appropriate choices, medication availability, education, and implementation of palliative care services at all levels (Kellehear, 1999; Stjernswärd, 2007). These initiatives have the potential to lead to public policies to support dying, death, loss and grief, and reduce vulnerable populations' access barriers to community and hospital-based palliative services.

9.2 Report to Chief Executive Dr Robyn Lawrence

This report summarises the key findings of the research.

JAMES COOK
UNIVERSITY
AUSTRALIA

1 April 2024

Dr Robyn Lawrence
Chief Executive, Department for Health and Wellbeing,
PO Box 287,
Rundle Mall Adelaide SA 5000

Dear Dr Lawrence,

RE: Research titled: 'Access to Australian community palliative care services: The influence of peri-urban location'

This research was undertaken to fulfil requirements for the degree of Doctor of Philosophy at James Cook University. The aim of this research was to explore the challenges of community palliative care provision in peri-urban locations. The researcher welcomes the opportunity to engage with the Department of Health and Wellbeing to provide recommendations to guide future planning and policies in service delivery.

Background

Current research largely focuses on the barriers to accessing healthcare for vulnerable populations and to the geographical location barriers in rural and remote areas of Australia. Few studies have focused on access barriers in outer fringe or peri-urban locations. Peri-urban areas in South Australia are those in close proximity to Adelaide – including Mt Barker, Victor Harbor and Gawler – that are subject to urban sprawl into designated country areas. These areas have a rural model of service delivery, with services jointly planned across both metropolitan and country.

The researcher's lived experience as a specialist palliative care clinical nurse in peri-urban locations guided the initial research. The problem space of existing barriers to access was identified and conceptualised through qualitative analysis of observation and informal discussions with palliative care clinicians who work in South Australian peri-urban locations. To confirm the research gap, an extensive literature review was undertaken to understand the methods of classification and the definition of peri-urban locations to understand the barriers to accessing healthcare services. An online survey was then developed to collect data from clinicians, patients and family caregivers. Data analysis resulted in the development of recommendations for future change to service delivery to enable equitable access to services.

Literature review

A review of the literature provided evidence of the benefits of palliative care provision for people diagnosed with a life-limiting illness and their family caregivers, particularly early in the palliative journey. Person-centred palliative care aims to optimise quality of life by prioritising the needs and values of individuals in every interaction with healthcare services. Peri-urban areas, offer a rural lifestyle in proximity to urban centres and have witnessed a surge in popularity and unprecedented population growth, impacting the provision of healthcare services.

What became clear in the literature is the importance of developing an approach in defining peri-urban areas considering the unique characteristics of that area. The literature highlighted the ambiguity in terminology used to define peri-urban areas, with no clear definition currently being used. Current geographical classification methods to determine locations as urban or non-urban generally use indicators of population density and/or indexes of accessibility based on distance in a straight line. Evidence suggests that the current methods of location classification used to allocate resources and methods of service delivery do not reliably indicate the needs and expectations of the increasing number of the population living in peri-urban locations.

Survey results

A survey was developed to collect open and honest perspectives of experiences related to community palliative care access, from both providers and users. Data collected was not linked to participants and the researcher provided confidentiality by removing any identifiable data in reporting. The survey consisted of a combination of closed-ended questions, including Likert and multiple-choice, open-ended comments and free text boxes.

Quantitative data was sought to support the descriptive data. Participants were divided into three groups within the one survey, following participant identification as either a health professional providing community palliative care in any role, and a person receiving care as either a family caregiver or a person diagnosed with a life-limiting illness. The survey link was distributed by Palliative Care Australia in February 2023 via an e-newsletter, with snowball sampling extending distribution via social media – a method viewed as promoting less risk to participants due to the emotional research subject.

A significant number responded to the survey which closed in April 2023 – 182 clinicians, family caregivers and patients. The majority of completed surveys came from family caregivers (91 or 53%), followed by community palliative healthcare professionals (50 or 29%) and patients (30 or 18%).

The majority (33, or 73%) of participants identifying as health professionals were providing care in peri-urban areas of South Australia. Many voiced concerns about the difficulties accessing equipment, trained staff and medication due to the time and distance associated with location. Travel was viewed as a challenge, with staff voicing an inability to meet daily workload demands without compromising person-centred care or the flexibility to attend to the individual needs of dying patients, thereby compromising place of death. The majority wanted to provide 24/7 contact for support and in-home care options, with a method of delivery that promoted relational continuity of care. A reliance on a digital model of service delivery was a contentious issue; many participants felt strongly about the importance of providing a face-to-face service, due to the emotional environment of palliative care.

Of most concern, was the overwhelming level of emotional distress expressed by clinicians who believed they were unable to provide appropriate care. Words were used such as ‘frustrated’, ‘sad’, ‘overworked’, ‘stressed’ and ‘exhausted’. Clinicians perceived that barriers to access derived from a lack of support from leadership or the organisation for which they worked, which they believed demonstrated a lack of recognition of staff as an asset to be developed, supported and retained. Organisations that equip nursing and other healthcare staff with the necessary resources, including equipment and appropriate staff levels, increase staff satisfaction and decrease the likelihood of adverse medical events, poor patient care and unmet patient needs.

Of the group who identified as family caregivers, 45, or 49%, received care in peri-urban locations, with 30 living in South Australia. Data analysis highlighted a large proportion of responses expressing negative emotions including feelings of dissatisfaction, disappointment and anger, due to perceptions of poor, limited or lack of access to services that caregivers believed were required in the home. Blame was not directly attributed to specific providers; instead, participants provided a generalised view of palliative care services in the health system.

Barriers to access resulting in unmet needs was a common theme, namely removal of choice which influenced decisions regarding treatment, care and place of care. Many reported the need to relocate, particularly at end-of-life, as a direct result of barriers to care in peri-urban locations. The highest unmet needs reported by caregivers were psychological issues, direct patient care and support and these were associated with anxiety, decreased quality of life and complicated grief. Continuity of care with trusted and skilled clinicians is required to develop coping strategies and validate caregiver responses following the death of a loved one; however, many reported difficulties accessing services, including bereavement and grief support in their location.

A small number of patients responded to the survey, with 9, or 30%, receiving care in South Australian peri-urban locations. Their responses were similar to family caregivers', although responses demonstrated that patients were generally more appreciative of the care received. Coping strategies used by those dealing with a life-limiting illness may have influenced their responses however, because this group tends to focus on wellbeing rather than fixing issues (Garg et al., 2018). Distance and time involved in travelling to receive care, attend appointments and receive treatment was voiced by many as likely to influence future decisions regarding treatment, care, place of death and the need to relocate despite their wishes to remain at home.

Key findings

This research suggests that current classifications of location used to determine palliative care service policy, methods of delivery and allocation of resources, fail to consider the heterogeneity and complexities of peri-urban locations. A lack of clear definition of peri-urban areas became evident early in the research. Locations currently viewed as peri-urban are classified as urban or non-urban (rural) depending on the classification used but are considered to have an advantage of over purely rural areas of being relatively close to metropolitan services.

The data analysis refuted this view of proximity providing access and offering an option of sustainable urban growth. Many participants receiving care cited distance, time, financial outlay and discomfort involved in the need to travel for complex symptom management. They also noted a scarcity of local resources and infrastructure which was a significant barrier to access, choice and quality of life. The disappointment at the need to relocate for care, treatment or place of death due to unmet needs and expectations was an emotion reiterated by many participants.

Palliative care clinicians expressed an understanding of the challenges and risks that exist in all community care settings, due to complex care needs and family situations. The potential exists for any home to include domestic violence situations, weapons, domestic and working animals, people with mental health conditions, drug and alcohol addictions and generally unsafe working and living conditions. However, the fact that potential risks are exacerbated in rural and isolated locations within peri-urban areas was clearly voiced. The likelihood of a delayed response by emergency or support services due to location and poor mobile coverage, difficulty accessing resources including staff, medication and equipment was reported by many who cited a lack of confidence, frustration and disappointment in a perceived lack of support from their organisation.

Analysis of responses demonstrated the interrelated and overlapping relationships between peri-urban locations, system-led and organisational policies, procedures, guidelines, funding, leadership, models of care and culture, and the needs and expectations of communities. Overall, the access barriers known to exist in rural areas were reported in South Australian peri-urban locations. The voices of clinicians, family caregivers and patients all focused attention on the need for the health system and organisations providing palliative care, to understand and explore access barriers in peri-urban locations.

Recommendations

The research findings have led to a number of key recommendations concerning policies, practices, guidelines, and effective approaches which need to be evaluated by SA Health to improve access to person-centred palliative care in peri-urban areas. Key recommendations are as follows:

R.1 **Build flexibility into allocation of resources and methods of service delivery.** Explore the method of location classification used to allocate resources and methods of service delivery to meet the needs of the individual communities within peri-urban locations to reduce access barriers and promote person-centred care. A rural model of service delivery and a view that Adelaide is within proximity for access does not optimise quality of life for all.

R.2 **Provide access to equipment.** Access to the equipment and appropriate home modifications are vital to helping people to remain at home for as long as possible, and to optimise quality of life. Access includes the equipment itself, and the resources for providers to appropriately assess, modify, deliver and set up equipment within an appropriate timeframe.

R.3 **Provide 24/7 after-hours telephone support for ongoing education and information.** Develop an after-hours support service for all community palliative care clients that meets community needs and enhances existing relational continuity of care to optimise care and quality of life. Continuity of care helps family caregivers address any concerns or problems, reduces the likelihood of ambulance attendance and transfers to hospital, and supports choice of location for care and death.

R.4 **Support access to essential medication for end-of-life care.** Home-based palliative care at end-of-life requires optimal pharmacological management of symptoms related to the disease process. Detailed protocols and procedures tailored to individual services need to be developed for effective medication management to support end-of-life care in the community in locations where barriers to medication access exist. This includes options for timely delivery of medication to the home for clients unable to collect, clinician access to imprest or emergency medication stock, in addition to 24/7 pharmacist access.

This recommendation excludes any reference to medication for patients who have commenced the voluntary assisted dying process.

R.5 **Increase funding to support choice of location for end-of-life care.** Limited options for place of death are provided for people who prefer to remain within their peri-urban community. Support for home deaths is dependent on the individual situation and is influenced by complex needs and available family supports in the home location, limiting the option for home environment for many. Local hospitals provide private rooms and trained staff as available but is often not a preferred option. There are limited options available within residential aged care facilities and individuals who choose a hospice or who have complex needs are transferred to Adelaide, which can provide challenges for family members at a difficult time.

R.6 **Target strategies to improve physical access to specialist services in peri-urban areas.** The time, distance, financial implications, and physical discomfort related to travelling to specialist services in metropolitan hospitals continues to provide a barrier to access for peri-urban residents and influences home location and decisions about care and treatment. Participants confirmed the usefulness of digital models of service delivery, but they prefer face-to-face visits due to the emotional context of palliative care and poor and unreliable internet and mobile access.

R.7 **Increase workforce capacity.** Increased resources for direct and indirect care workers and clinicians would help people to remain in their own home for longer, enhance continuity of care, provide choice of provider and person-centred care, support face-to-face visits, optimise quality of life for patients and family caregivers, and support choice of place of death.

R.8 **Support access to bereavement and grief support.** Difficulties accessing counselling and grief support in non-urban areas, both anticipatory and following the death of a loved one, was a common complaint. The potential long-term detrimental physical, emotional and financial outcomes for those experiencing complicated grief should be a concern for healthcare providers.

R.9 **Promote a supportive working environment.** Almost all the clinicians cited an inability to voice concerns or provide feedback in a supportive environment with a lack of organisational and leadership support leading to reports of stress, exhaustion, and burnout. The emotional and physical challenges generated by a lack of resources and the distance required to travel, combined with an emotionally challenging environment, cannot be overlooked when considering the prevalence of risks and the need to retain trained, qualified and highly skilled palliative clinicians to optimise quality of life and wellbeing for communities.

The social impacts on health and dying from barriers to accessing quality, person-centred care are substantial and significant. The risk for physical and emotional distress is real for those individuals seeking palliative care but facing accessibility barriers. The removal of personal choice and preferences in care, treatment and locations for care and death has the potential to impede quality of life, wellbeing and the grieving process. The demand and need for community palliative care services is increasing and geographic location should not be a barrier to access. This research is complementary to the long-term investment by the Government in policies to improve access to palliative care. After all, the way we treat our vulnerable, our sick and those who are dying is a measure not only of ourselves, but of the society in which we all live.

Implications from the research

This research has highlighted implications for people living and working in peri-urban areas and their healthcare providers. It is widely accepted that provision of good quality, holistic palliative care in the location of patient choice improves overall wellbeing for patients and their family members, enables choice of place for end-of-life care and death, and facilitates the grieving process for family and friends. The palliative care being provided in peri-urban locations cannot be labelled holistic if barriers to access are ignored, placing increased pressure on the traditional support mechanisms of extended family, friends and neighbours.

Ethically, individuals and communities are entitled to quality, person-centred palliative care in the location of choice to maintain a good quality of life. This research, however, strongly suggests that current models of healthcare service delivery and allocation of the resources required for community palliative care in peri-urban areas requires urgent evaluation. The reliance on proximity to urban centres and an expectation that individuals will be able to travel an acceptable commute distance, have implications for palliative care patients and family caregivers. The findings suggest that the issues related to distance have negative outcomes for quality of life, wellbeing, and decision-making and influence the relocation decisions of families and communities.

A lack of resources results in clinicians having to prioritise and ration resources to meet the needs of the dying. Skilled palliative care staff have developed systems of balancing demands and available resources to the detriment of their own wellbeing, which is unsustainable in the long term. The urgency in palliative care services holds implicit ethical content which requires immediate consideration. Government and healthcare providers are well placed to navigate the challenges of resource allocation through evaluating and developing appropriate policy guidelines and procedures and models of service delivery and care tailored to the contextual needs of peri-urban locations. Future funding is needed to enhance local infrastructure and resources to improve access to community palliative care services in the location of choice and simultaneously support the clinicians providing the care. Evaluation of organisational and leadership culture is also required to retain and expand the experienced palliative care clinicians essential to care provision in peri-urban locations.

Direct contribution to knowledge

The findings from this research contribute to previous research undertaken to understand the barriers to accessing palliative care in rural locations in Australia, but it also confirms that more research needs to take place that focuses specifically on peri-urban locations. The findings indicate that government and healthcare providers rely on proximity to urban centres as an assumed predictor of accessibility to goods and services required. There is no clear or defined appropriate distance to commute for the purpose of work, nor a recognised acceptable distance to expect palliative patients to travel for complex healthcare needs.

Proximity or distance as standalone factors appear to fail to recognise frailty, disease progression, pain and symptoms exacerbated by travel, lack of functional ability, financial status, transport options or support networks available to those individuals requiring palliative treatment or care in urban centres. Peri-urban areas are neither urban nor rural, with policies dictating service delivery and resource allocation falling short for those living in fringe areas. This research demonstrates that peri-urban locations do not represent one issue or challenge for government in Australia – rather, it raises a number of interrelated questions.

Future research

Current research related to healthcare and palliative care needs in the peri-urban environment is limited. Much of the research is directed at rural communities, with the boundaries of peri-urban locations blurred, fitting neatly into neither urban nor rural locations. Future research is needed to provide clear and uniform definitions and classifications of peri-urban. Resource allocation is guided by outdated methods of classifying locations by variations of ‘urbanness’. This research indicates that a rural model of service delivery is no longer applicable to those relocating to peri-urban areas who expect to be able to access the same quality, local services as found in metropolitan centres. Future research into methods of service delivery that currently focus on strengthening the use of digital health to support access need to consider the perspective of peri-urban residents. This research indicates that digital health in these locations is a contentious issue from the view of both clinicians and patients. It is hoped this research provides an opportunity for discussion, debate, and evaluation to ensure that service delivery progresses in the future.

Should you require any further information in relation to the recommendations raised in this report, please contact the researcher.

Shirley Papavasiliou

JCU PhD Candidate

Email: Shirley.papavasiliou@my.jcu.edu.au

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Appendices

Appendix A: Geographical Classification

The ABS uses two definitions of Australia

- Geographic Australia, used for social and demographic statistics, and
- Economic Australia, used for economic statistics (ABS, 2016a).

For ASGC purposes, the ABS uses the definition of Australia as set out in section 17(a) of the Acts Interpretation Act 1901 which currently defines Australia or the Commonwealth as meaning:

"…the Commonwealth of Australia and, when used in a geographical sense, includes the Territory of Christmas Island and the Territory of Cocos (Keeling) Islands, but does not include any other external Territory." (ABS, 2009a).

The ASGC included the Territories of Christmas Island and Cocos (Keeling) Island into geographic Australia from 1 July 1993, following the Territories Law Reform Act, No. 104, 1992 which amended the Acts Interpretation Act 1901 (ABS, 2009a). The treatment of Jervis Bay Territory also changed in the ASGC from July 1993 with other external territories, including Norfolk Island, remaining excluded (ABS, 2009a). For ASGS purposes, the ABS uses the Geographic definition of Australia, as set out in section 2B of the Acts Interpretation Act 1901 and as amended by the Territories Law Reform Act, No. 104, 1992 (ABS, 2016a). The geographic definition of Australia or the Commonwealth is interpreted as meaning:

"…the Commonwealth of Australia and, when used in a geographical sense, includes Norfolk Island, the Territory of Christmas Island and the Territory of Cocos (Keeling) Islands, but does not include any other external Territory." (ABS, 2016a).

Included in this definition of Geographic Australia are the:

- States of New South Wales, Victoria, Queensland, South Australia, Western Australia, and Tasmania
- Northern Territory
- Australian Capital Territory (ACT)
- Territory of Cocos (Keeling) Islands
- Territory of Christmas Island

- Jervis Bay Territory
- Territory of Norfolk Island (ABS, 2016a)

Macquarie Island is excluded although legally part of Tasmania, as it is extremely isolated and with no permanent population (ABS, 2016a). Any population on the Island for Census of Population and Housing is included in the Migratory – Offshore – Shipping Statistical Area Level 2 for Tasmania (ABS, 2016a). Historically, the Territory of Norfolk Island has been excluded from the definition of Geographic Australia however the definition was updated to include the island following Australian Government reforms in 2015 (ABS, 2016a). Subsequently, the 2016 ASGS included the Territory of Norfolk Island within the 'Other Territories' category along with Jervis Bay Territory, the Territory of Cocos (Keeling) Islands and the Territory of Christmas Island (ABS, 2016a). The economic definition of Australia is not used by the ASGC or ASGS (ABS, 2016a).

Australian Standard Geographical Classification (ASGC)

The Australian Standard Geographical Classification (ASGC) was used by the ABS for the collection and dissemination of geographically classified statistics between 1984 and 2011 (ABS, 2021). The geographical areas that had been used by the ABS prior to 1984 were adopted into the ASGC (ABS, 2011a). The ASGC was designed to meet the needs of users for social, demographic and economic statistics by providing a common framework of statistical geography which enabled production of statistics which were comparable and could be spatially integrated (ABS, 2006a, 2023g).

The ASGC was updated and released annually to update Statistical Local Areas (SLA) and to reflect any changes in gazetted Local Government Authorities (LGA) (ABS, 2006a; 2011b). The ASGC classified statistical units such as households and businesses to a geographical area in one of seven hierarchies of geographical areas, as shown in Figure 21 (ABS, 2006a). Each structure was designed for a different statistical purpose and were as follows:

- Main Structure
- LGA Structure
- Statistical District Structure
- Statistical Region Structure
- Urban Centre/Locality Structure
- Section of State Structure
- Remoteness Structure (ABS, 2006a)

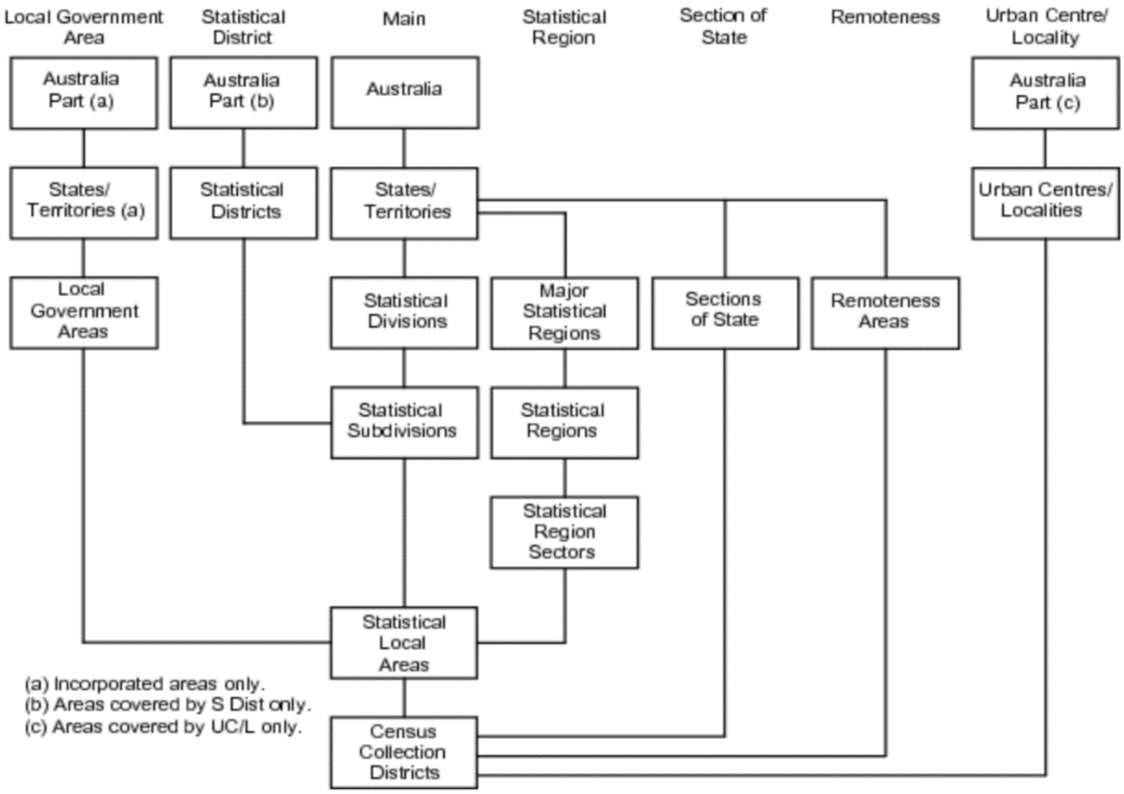
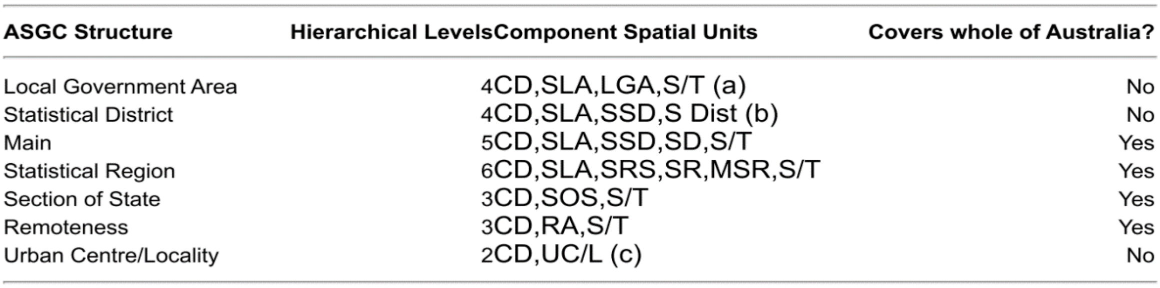


Figure 21 ASGC Structural Chart (ABS, 2009b)

The Main Structure, the Statistical Region Structure, the Section of State Structure, and the Remoteness Structure covered the whole of Australia while the remaining structures covered only parts of Australia (ABS, 2011b). In Census of Population and Housing years all seven structures of the ASGC were defined however, in intercensal years only the first four structures were defined (ABS, 2009a). Classification structures were composed of different numbers of levels, made up of one type of geographical spatial unit (ABS, 2011b). The hierarchy is shown in Figure 22. The spatial units or geographical areas used in ASGC were listed as follows:

- Census Collection District (CD)
- Statistical Local Area (SLA)
- Statistical Subdivision (SSD)
- Statistical Division (SD)
- State and Territory (S/T)
- Statistical District (S Dist.)
- Local Government Area (LGA)
- Statistical Region Sector (SRS)
- Statistical Region (SR)

- Major Statistical Region (MSR)
- Urban Centre/Locality (UC/L)
- Section(s) of State (SOS)
- Remoteness Area (RA) (ABS, 2006a).



ASGC Structure	Hierarchical Levels	Component Spatial Units	Covers whole of Australia?
Local Government Area	4	CD,SLA,LGA,S/T (a)	No
Statistical District	4	CD,SLA,SSD,S Dist (b)	No
Main	5	CD,SLA,SSD,SD,S/T	Yes
Statistical Region	6	CD,SLA,SRS,SR,MSR,S/T	Yes
Section of State	3	CD,SOS,S/T	Yes
Remoteness	3	CD,RA,S/T	Yes
Urban Centre/Locality	2	CD,UC/L (c)	No

Figure 22 Hierarchical Levels ASGC Structure (ABS, 2006a)

In Census of Population and Housing Census years, the smallest spatial unit used to build the classification structures was the Census Collection District (CD) however, in intercensal years the smallest spatial unit was the Statistical Local Area (SLA) (ABS, 2009b). CDs aggregate to form the larger spatial units of SLAs in the Main, Statistical Region, Statistical District and LGAs, SOS in the SOS Structure, Urban Centres and Localities in the Structure and Remoteness Areas in the Remoteness Structure (ABS, 2001a).

The original definition of a CD was an area that one census collector could physically cover, that is deliver and collect census forms, in a period of approximately ten days (ABS, 2001a, 2006b). CDs were created in response to changes within any given area, including significant increase in population or population growth resulting in expansion of locality or urban centre boundary (ABS, 2006b).

Division of CDs into areas of increased population growth to reflect urban growth in Census results is a process referred to as fragmentation (ABS, 2006b). Population in existing CDs which increased to the point that it was not possible for one collector to manage would result in one CD being split into two or more (ABS, 2006b). CDs in urban areas averaged 220 dwellings in 2001 and 225 in 2006 with the number of dwellings per CD declining in rural areas as population densities decreased (ABS, 2001a, 2006b). CD boundaries were designed to not cross SLA or LGA boundaries and adjusted to conform with changes to LGA boundaries (ABS, 2006b). An aggregation of CDs cover the administrative area of a local government entity to enable as much comparability between Censuses as possible (ABS, 2001a, 2006b). CDs are defined for each Census and remain current only at Census time (ABS, 2006b).

ASGC Urban and Rural Classification

Section of State Structure (SOS)

The SOS Structure of the ASGC uses population counts from the Census of Population and Housing to class structures as urban and those that are not urban, as rural (ABS, 2001a). SOS categories of Major Urban and Other Urban are regarded as urban and the categories of Bounded Locality and Rural Balance are regarded as rural (ABS, 2001a). SOS categories are further broken down into different categories called Sections of State Range (SOSR) based on population ranges from the UC/L Structure (ABS, 2009b). The SOS Structure was defined by population data from the Census of Population and Housing, therefore the classification structure was current only at the time of the Census (ABS, 2009b). The SOS categories based on population ranges are:

- Major Urban: provides for three SOSR categories of urban areas
- Other Urban: provides for five SOSR categories of urban areas
- Bounded Locality: provides for two SOSR categories of rural areas
- Rural Balance: equivalent to the SOSR of the remainder of the State/Territory
- Migratory: equivalent to the SOSR of offshore, shipping and migratory (AIHW, 2004; McGrail & Humphreys, 2009)

The following diagram demonstrates the breakdown of SOS categories into SOSR categories.

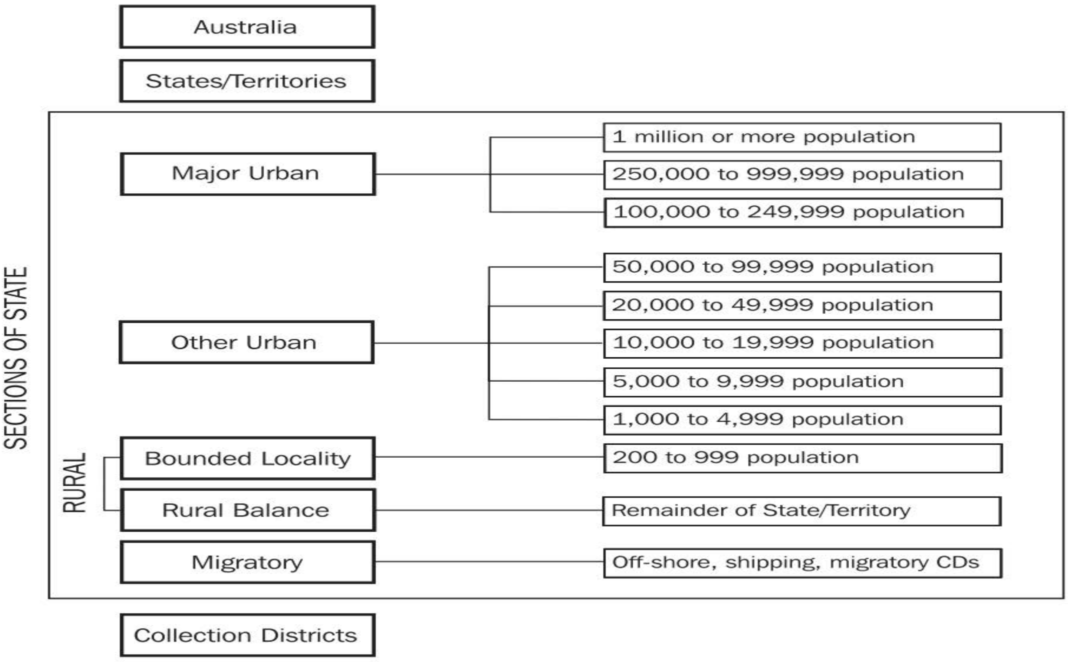


Figure 24 SOSR Categories (ABS, 2001b; 2009b)

Urban Centre/Locality (UC/L)

The UC/L Structure is a separate but interrelated structure to the SOS Structure in the ASGC and aggregates CDs to form areas with similar characteristics by population (ABS, 2001a). The resulting areas formed by one or more contiguous CDs are called Urban Centres or Localities. The areas within the UC/L Structure refer to smaller geographic areas than the broad categories in SOS Structure in the ASGC (ABS, 2001a). People living in urban centres are classified as urban for statistical purposes and generally live in a population centre with a 'core urban population' of 1,000 or more people (ABS, 2001a). People living in localities are classified as rural for statistical purposes and generally live in a population centre of between 200 and 999 people (ABS, 2001a). However, a Locality may contain a population in excess of 1,000 people which would then meet the criteria for an Urban Centre (ABS, 2001a). Urban Centres/Localities are redefined at each Population Census and are comprised of one or more Census Collection Districts (CD) (ABS, 2001a).

Census Collection District (CD)

- CDs classified as urban include the following:
    - All adjoining CDS with a population density of 200 or more persons per square kilometre are classified as urban. State, SD, LGA and other administrative boundaries will not be included in determining if a CD is included within an Urban Centre.
    - A CD with the majority of the land used for factories, airports, small sports areas, cemeteries, hostels, institutions, prisons, military camps or certain research stations is classified as urban if adjoining urban CDs.
    - A CD with most of the land used for large sporting areas, large parks, explosives handling and munitions areas, or holding yards associated with meatworks and abattoirs is classified as urban only if it is bordered on three sides by CDs classified as urban.
    - Any area which is surrounded by urban CDs must be classified as urban.
    - Where an Urban Centre of 20,000 or more population is separated from another urban area by a gap in urban development of less than three kilometres, the gap shall be classified as an urban CD.
    - Large peripheral CDs in growth areas containing at least one hundred persons, may be fragmented and regarded as CDs (ABS, 2001a).

Remoteness Structure

The final structure in the ASGC is the Remoteness Structure which bases remoteness of an area by population and accessibility to goods and services (ABS, 2009a). The Remoteness Structure aggregates all CDs within Australia with common characteristics into broad geographical regions called Remoteness Areas (RAs) (ABS, 2009a). RAs do not align with other spatial units within the ASGC, therefore the Remoteness Structure is maintained as a separate structure in the ASGC (ABS, 2009a). There are three hierarchical levels of the Remoteness Structure; CDs aggregate to RAs which aggregate to S/Ts and six areas within the structure.

- Major Cities of Australia
- Inner Regional Australia
- Outer Regional Australia
- Remote Australia
- Very Remote Australia
- Migratory (ABS, 2006a)

Regional areas of Australia are those areas that are located outside of major cities where geographic distance restricts accessibility to the widest range of goods, services and opportunities for social interaction (AIHW, 2004). Inner Regional Australia and Outer Regional Australia are categories within the ASGC Remoteness Structure and viewed as Regional Australia (ABS, 2006a; AIHW, 2004).

Population data aggregates CDs to RAs and S/Ts, with accessibility to services measured using the Accessibility and Remoteness Index of Australia (ARIA) (ABS, 2006a).

Accessibility/Remoteness Index of Australia (ARIA)

The Accessibility/Remoteness Index of Australia (ARIA) was developed by the National Key Centre for Social Applications of GIS (GISCA) in 1997 (ABS, 2001b; DoHAC, 2001). ARIA was commissioned to measure remoteness in terms of access and the distance using road networks from any locality to one of four categories of service centres (ABS, 2001b; ALSWH, 2003). Actual road distance is calculated rather than the shorter, straight line distance from the populated locality GPO to the GPO of the nearest service centre in each category (Jones, 2000). ARIA Service Centres are ABD defined urban centres grouped into four categories by population size:

Class A: 250,000 or more

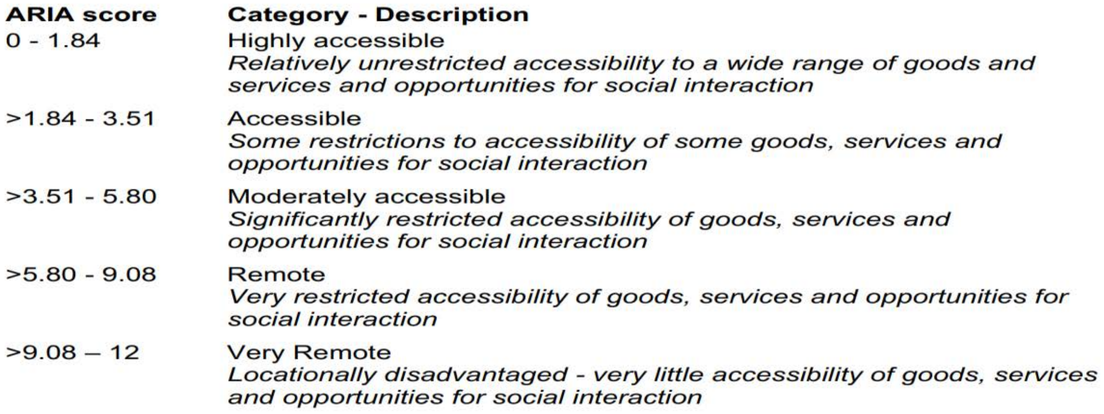
Class B: 48,000 to 249,999

Class C: 18,000 to 47,999

Class D: 5,000 to 17,999 (AIHW, 2004; 2000)

Service Centres are categorised according to a relationship existing between the population size of service centres and the number and range of goods, services and social interaction opportunities accessible (ABS, 2001b). Research during the development of the ARIA, identified that the number, choice and level of services increased with the size of the population at the service centres (ABS, 2001b). However, differences were evident in levels of health services available in service centres of the same category (ABS, 2001b).

The concept of remoteness in the ARIA is the measurement of physical road distance between where people live and the locations where people need to travel to obtain goods, services and social interaction (ABS, 2001b). Socioeconomic factors, time taken to travel and road conditions are not factored into the measurement (ABS, 2001b). The shortest road distance to the mean shortest distance for each category of Service Centre is calculated and capped at three. The five individual values are summed to arrive at a single ARIA Score for the Populated Locality, with the highest total ARIA Score a Populated Locality can have been twelve and the lowest zero as demonstrated in Figure 23.



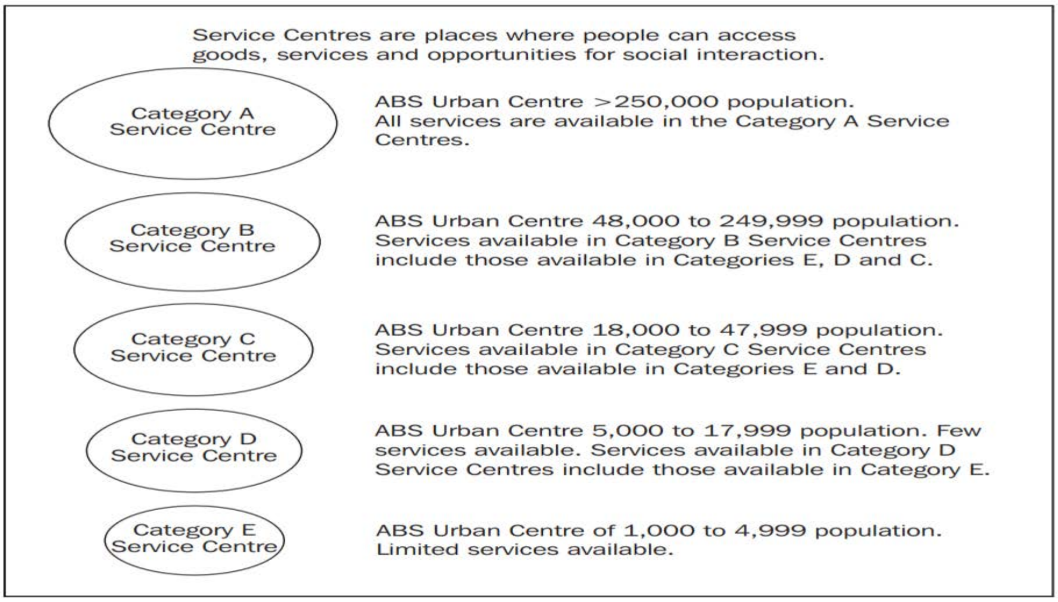
ARIA score	**Category - Description**
0 - 1.84	Highly accessible *Relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction*
>1.84 - 3.51	Accessible *Some restrictions to accessibility of some goods, services and opportunities for social interaction*
>3.51 - 5.80	Moderately accessible *Significantly restricted accessibility of goods, services and opportunities for social interaction*
>5.80 - 9.08	Remote *Very restricted accessibility of goods, services and opportunities for social interaction*
>9.08 – 12	Very Remote *Locationally disadvantaged - very little accessibility of goods, services and opportunities for social interaction*

Figure 23 Five categories of remoteness (AIHW, 2004)

Accessibility/Remoteness Index of Australia (ARIA+)

ARIA is continuously developed and in 2003, GISCA released a new version of the continuous varying index of remoteness called ARIA+. The new version continues to be given geographical areas a score based on road distance from populated localities to the nearest Service Centres in categories based on population size. The major difference between ARIA and ARIA+ is the inclusion of an additional Service Centre category to include all urban centres with populations greater than 1,000 and less than 5,000. This inclusion of a fifth Service Centre category resulted in an index ranging from 0-15 in ARIA+, instead of 0-12 as in ARIA.

There are 5 categories of ARIA+ Service Categories which are detailed in the following figure:



Service Centres are places where people can access goods, services and opportunities for social interaction.

Category A Service Centre	ABS Urban Centre >250,000 population. All services are available in the Category A Service Centres.
Category B Service Centre	ABS Urban Centre 48,000 to 249,999 population. Services available in Category B Service Centres include those available in Categories E, D and C.
Category C Service Centre	ABS Urban Centre 18,000 to 47,999 population. Services available in Category C Service Centres include those available in Categories E and D.
Category D Service Centre	ABS Urban Centre 5,000 to 17,999 population. Few services available. Services available in Category D Service Centres include those available in Category E.
Category E Service Centre	ABS Urban Centre of 1,000 to 4,999 population. Limited services available.

Figure 24 ARIA+ Service Centres by population (ABS, 2001b)

ARIA+ assigns a score between zero and fifteen based on the road distance to service centres. Scores for regions are calculated by averaging scores of 1 km square grid, with index scores classified into various categories. Two of the main categories and their ARIA+ scores are as follows:

Remoteness Areas:

- Major Cities of Australia (ARIA score 0 <=0.20) – relatively unrestricted accessibility to a wide range of goods, services, and opportunities for social interaction,
- Inner Regional Australia (ARIA score 0.20 <=2.40) – some restrictions to accessibility to some goods, services, and opportunities for social interaction,
- Outer Regional Australia (ARIA score 2.40 <=5.92) – significantly restricted accessibility to goods, services, and opportunities for social interaction,
- Remote Australia (ARIA score 5.92 <=10.53) – very restricted accessibility to goods, services, and opportunities for social interaction,

- Very Remote Australia (ARIA score 10.53 <=15) – very little accessibility to goods, services, and opportunities for social interaction.

Remoteness Classes:

- Highly Accessible (ARIA score 0 <=0.20) – relatively unrestricted accessibility to a wide range of goods, services, and opportunities for social interaction,
- Accessible (ARIA score 0.20 <=2.40) – some restrictions to accessibility to some goods, services, and opportunities for social interaction,
- Moderately Accessible (ARIA score 2.40 <=5.92) – significantly restricted accessibility to goods, services, and opportunities for social interaction,
- Remote (ARIA score 5.92 <=10.53) – very restricted accessibility to goods, services, and opportunities for social interaction,
- Very Remote (ARIA score 10.53 <=15) – very little accessibility to goods, services, and opportunities for social interaction.

In ARIA, distance was measured from populated locality GPO to the GPO of the nearest Service Centre. In ARIA+, distance is measured from populated locality to the edge of the built-up area of the nearest service centre per the ABS UC/L boundary. The AIHW believes that this change models accessibility at the urban fringe more effectively as it reduces the distance to the nearest service centre, particularly in major service centres with urban sprawl.

In summary, ARIA, and ARIA+ define remoteness in terms of a measure of relative access to a particular service. This definition uses the average distance of a location from a service centre, which assumes the greater the distance, the more remote the area and the less opportunities for social interaction and supply of goods and services. Figure 25 provides a visual of remoteness areas. Accessibility becomes questionable when the requirement for a service centre is that it contains at least one identified service, usually a government primary school or an Australian Post Office with no requirement for specialist health services. Defining accessibility more broadly would lead to consideration of the dimensions of accessibility being affordability, availability, accommodation, acceptability, and appropriateness and the dimensions of abilities. The abilities of the population are interrelated with dimensions of access and are the ability to perceive, seek, reach, pay and engage with the health services, to realise access.

ARIA and ARIA+ define remoteness on two elements and do not consider the complexities involved in access to services. Complexities include the location of the individual, the infrastructure involved in the distance, the service involved and its affordability and appropriateness in the situation.

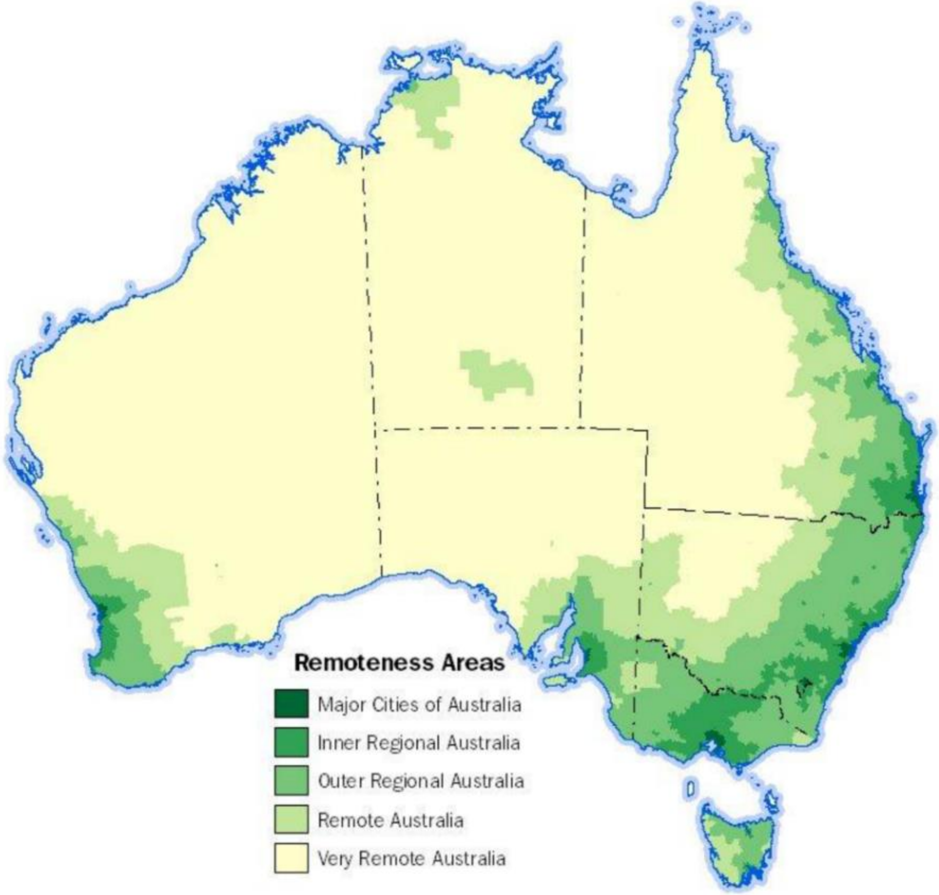
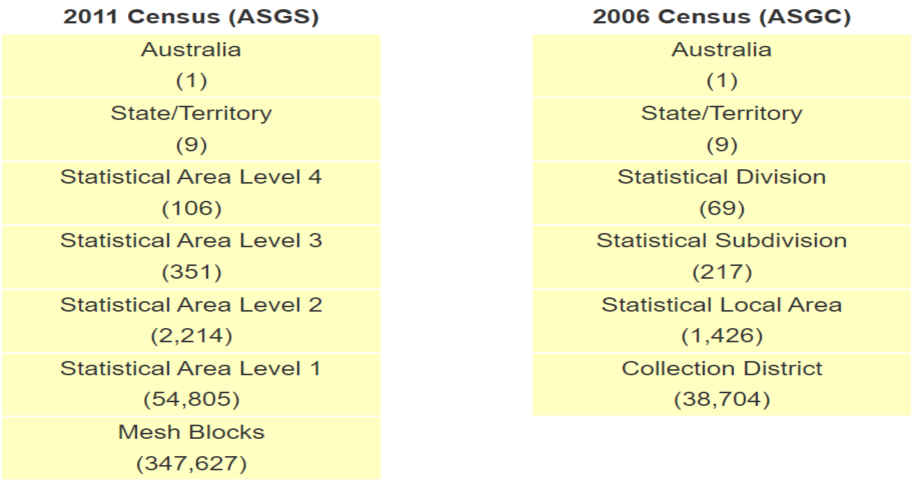


Figure 25 Map of 2016 Remoteness Areas of Australia (ABS, 2017, 2018a)

Australian Statistical Geography Standard (ASGS)

The ASGS is a classification of the whole of Australia into a hierarchical framework of statistical areas. The framework brings all the regions which ABS collects, disseminates and publishes geographically classified statistics, within the one framework (ABS, 2022a). The ASGS is a social geography, reflecting the location of people and communities and updated every five years to account for growth and change (ABS, 2016b). The ASGS replaced the ASGC in 2011 following a review of the ASGC (ABS, 2011a). The aim of the review was to create a new Australian statistical geography framework to both address some of the identified shortcomings of the ASGC and to meet the future needs of users (ABS, 2011a).

Initially adopted for the 2011 Census of Population and Housing and shown in Figure 26, the ASGC and the ASGS both operated in 2011, however the ASGS has been the sole ABS statistical geography framework since 2012 (ABS, 2023a). The ASGS was developed to be a more comprehensive, flexible and consistent way of defining Australia's statistical geography than the previous ASGC framework (ABS, 2011a). It was expected that the new classification framework would lead to improvements in the quality of small area data and enable better comparison of data from the Census and other sources adopting the ASGS (ABS, 2012). The development of a statistical geography to better meet the needs of users resulted in changes including the replacement of spatial units used in the ASGC such as CDs, SLAs and SDs (ABS, 2016d). Due to potential issues with time series comparisons, 2011 Census data was available for both ASGS and SLAs from 2011 ASGC (ABS, 2016d).



2011 Census (ASGS)	2006 Census (ASGC)
Australia (1)	Australia (1)
State/Territory (9)	State/Territory (9)
Statistical Area Level 4 (106)	Statistical Division (69)
Statistical Area Level 3 (351)	Statistical Subdivision (217)
Statistical Area Level 2 (2,214)	Statistical Local Area (1,426)
Statistical Area Level 1 (54,805)	Collection District (38,704)
Mesh Blocks (347,627)	

Figure 26 Comparison main structures by spatial units (ABS, 2012)

In summary, the ASGS took over from the ASGC in the collection and dissemination of geographical statistical data used to classify locations in Australia as urban or non-urban. The ASGS is the common boundary set for analysis, display and recoding of socioeconomic information within the Statistical Framework for Australia, providing a consistent, hierarchical set of geographies (ABS, 2020). The core ASGS boundary hierarchies include approximately equal population numbers within each area to enable comparisons and to aggregate hierarchies to define areas as urban or non-urban (rural). The boundaries range in size from small geographical areas to larger areas, but small areas are designed to ensure a size large enough to provide privacy and confidentiality to residents (ABS, 2020).

The smallest spatial unit used by health services is a SA2 with a population of 3,000 to 25,000 people. Challenges to this size of geographical area becomes evident in peri-urban areas due to the diversity of population and housing density that may be evident within each SA2. Definitions of Other Urban and Bounded Locality as urban or rural are too simplistic for use in peri-urban areas and fail to capture the needs of the community without additional local input.

ABS and Non-ABS Structures

Development of the ASGS involved the inclusion of all regions used by the ABS to output data under the one statistical framework, which is divided into two broad categories, as demonstrated in Figure 27:

- ABS Structures – regions defined and maintained by the ABS
- Non-ABS Structures – regions for which ABS supplies statistical data but defined and maintained by other organisations (ABS, 2016c; 2016d).

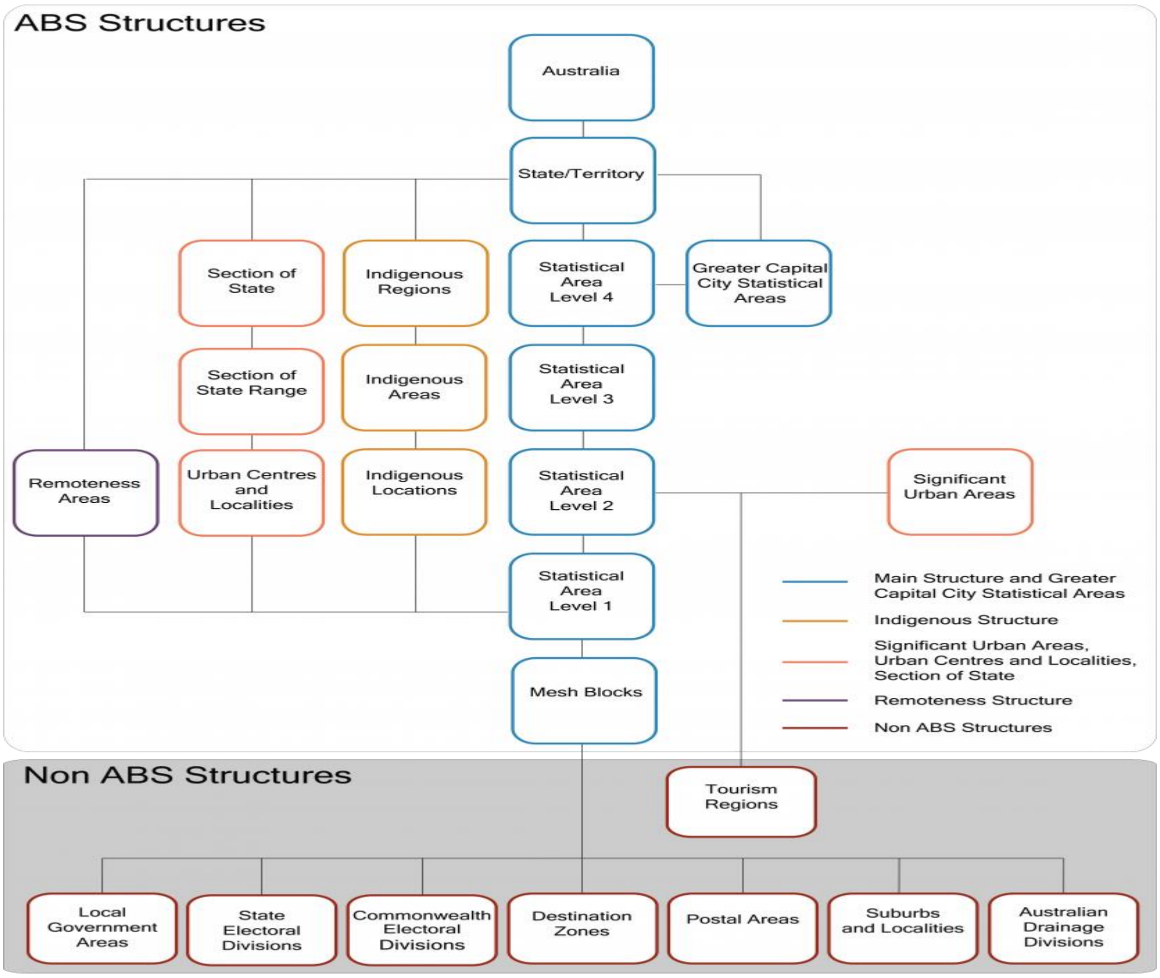


Figure 27 Interrelatedness ABS and Non-ABS Structures (ABS, 2022a)

ABS Structures

ABS Structures comprise six interrelated hierarchies of regions, consistent in population size and designed to remain stable between Censuses (as shown in Figure 28).

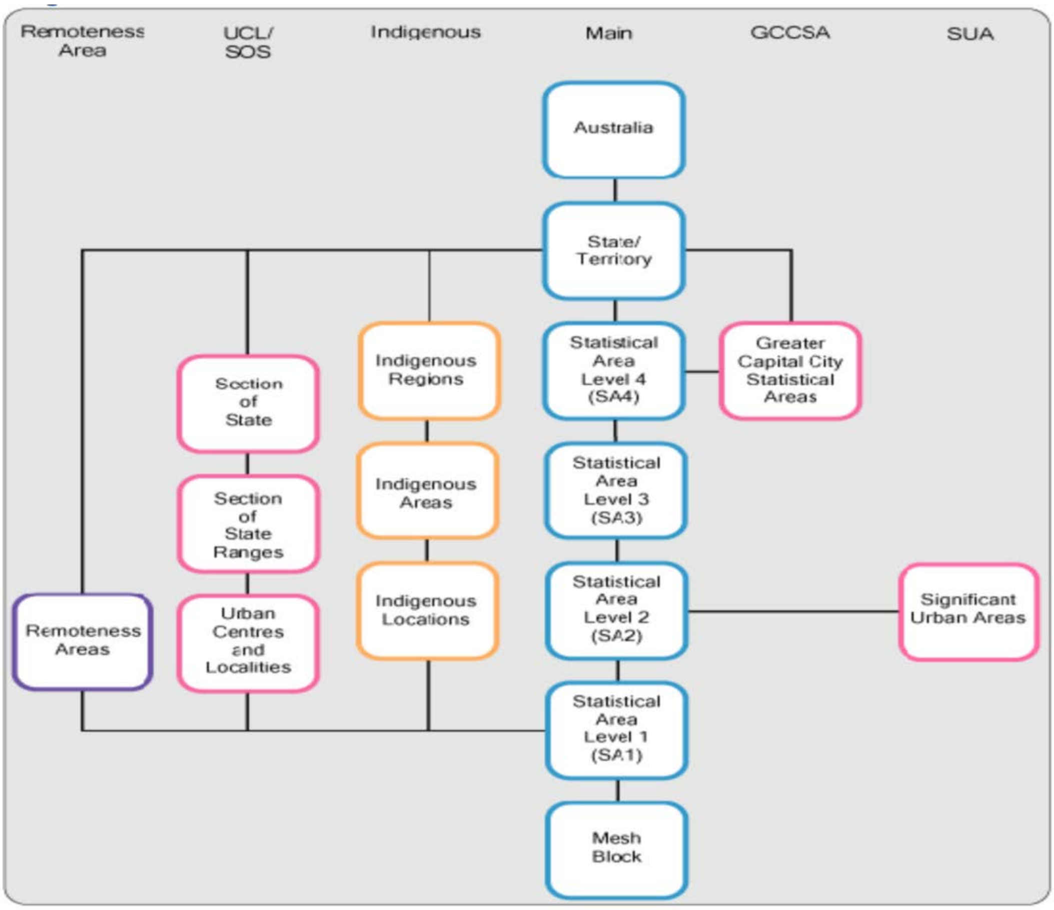


Figure 28 ASGS ABS Structures (ABS, 2016c)

Main Structure

The structure has seven hierarchical levels comprising in ascending order: Mesh Block (MB), Statistical Area Level 1 (SA1), Statistical Area Level 2 (SA2), Statistical Area Level 3 (SA3), Statistical Area Level 4 (SA4), State and Territory (S/T), and Australia (AUS) (ABS, 2016a).

- **Mesh Blocks (MBs)** are the smallest geographical areas defined by the ABS and aggregate to form the building blocks for the larger regions of the ASGS (ABS, 2016c; 2016d). A MB contains an average of thirty dwellings and are both urban and rural in nature (ABS, 2016a; 2023g). The purpose of using Mesh Blocks is to support more accurate statistics for commonly used regions including postcodes and suburbs and to reflect the location of people and communities in Australia (ABS, 2016a).
- **Statistical Areas Level 1 (SA1s)** were adopted in the 2011 Census as the new base unit of output geography with SA1s being smaller than CDS (ABS, 2012). SA1s are the second smallest geographic area defined by the ABS and are composed of aggregates of building block geographical units called a Mesh Block (MB) (ABS,

2016d). SA1s are designed to be consistent in population size and either urban or rural in character, with a population between 200 and 800 persons or an average of 400 persons (ABS, 2016d).

- SA1s replace CDs which consisted of approximately 200 dwellings and were primarily designed to enable one Census collector to deliver and retrieve Census forms (ABS, 2016d). This resulted in geographic areas that were inconsistent in population size and character (ABS, 2016d).
- **Statistical Areas Level 2 (SA2s)** consist of one or more SA1s and are designed to represent functional areas outside of major urban and regional Australia (ABS, 2016d). SA2s are based on gazetted suburbs and localities with an average population 10,000 persons (ABS, 2016d). SA2s are consistent in population and are designed to be stable over several Censuses (ABS, 2016d).
- SA2s replace SLAs which were inconsistent in population size and do not reflect functional areas or settlement patterns (ABS, 2006a). SLAs were subject to change following review of gazetted LGAs as they are contained within LGAs (ABS, 2006a).
- **Statistical Areas Level 3 (SA3s)** represent regions between approximately 15,000 to 150,000 people, built from aggregations of whole SA2s (ABS, 2016d). SA3s represent a combination of informal regions, both rural and urban and fit within SA4 boundaries (ABS, 2016d).
- **Statistical Areas Level 4 (SA4s)** are built from whole SA3s and have large populations over 100,000 people and fit within State/Territory boundaries (ABS, 2016d). In regional areas, SA4s have populations closer to the minimum (100,000 to 300,000 people), in metropolitan areas, the SA4s tend to have larger populations (300,000 to 500,000 people) (ABS, 2016d).
- **States and Territories (S/Ts)** are the largest spatial units in the ASGS Main Structure and have fixed boundaries due to being politically governed entities (ABS, 2016c). S/Ts consist of one or more SA4s and cover Australia without gaps or overlaps (ABS, 2016c).
- **Australia** For ABS Structure purposes, the ABS uses the Geographic Australia definition of Australia as set out in section 2B of the Acts Interpretation Act 1901 and as amended by the Territories Law Reform Act, No. 104, 1992 (ABS, 2016a).
- **Indigenous Structure**
  - **Indigenous Regions (IREGs)** are large geographical units based on Aboriginal and Torres Strait Islander Commission boundaries and consisting of one or more Indigenous Areas (IREAs) (ABS, 2016c). IREGs do not cross state and territory borders and aggregate to S/T level (ABS, 2016c).

  - **Indigenous Areas (IREAs)** are geographical units consisting of one or more Indigenous Locations (ILOCs) and generally have a minimum of 250 Aboriginal and Torres Strait Islander residents (ABS, 2016c).
  - **Indigenous Locations (ILOCs)** aggregate to IAREs and consist of one or more SA1s and identify data on particular Aboriginal and Torres Strait Islander communities with a minimum population of 90 usual residents (ABS, 2016c).

- **Greater Capital City Statistical Area Structure (GCCSAs)** replace the ASGC Capital City Statistical Divisions and provide a stable geographical area to represent each of the eight state and territory capital cities (ABS, 2016a; 2016c). GCCSAs are built up from whole SA4s with the areas not defined as included in the greater capital city, represented by a Rest of State region (ABS, 2016a).

- **Significant Urban Area Structure**
  - **Significant Urban Areas (SUAs)** represent Urban Centres (ABS, 2022a). They are areas based on Urban Centres and Localities (UCLs) and built from Statistical Areas Level 2 (SA2) (ABS, 2022a). SUAs represent an Urban Centre or cluster of Urban Centres that contain the urban population and closely associated populations of major urban concentrations of over 10,000 people (ABS, 2016a). SUAs may contain one or more associated Urban Centre and/or Locality and areas in between as they are designed to include projected growth patterns (ABS, 2016a). SUAs can cross State/Territory boundaries (ABS, 2022a).

    Areas defined as SUAs combine one or more adjacent SA2s based on the following criteria:

    - SA2s containing an Urban Centre of 10,000 persons or more are considered SUAs
    - Other SA2s containing Urban Centres within a five-kilometre distance via sealed road of large Urban Centres may be aggregated into the same SUA
    - SUAs containing Urban Centres of 7,000 persons or more may be considered a SUA if there are other Urban Centres within five-kilometre distance via sealed road and the Urban Centres have a combined population over 10,000
    - SA2s included in an SUA should be within the same Labour Market as defined by GCCSA classification (ABS, 2022a).

- **Urban Centres and Localities/Section of State Structures**

  The 2011 Urban Centres and Localities and Section of State are broadly comparable to ASGC Urban Centres, Bounded Localities and Rural Balance (ABS, 2016d). Section of State Structures and Urban Centres and Localities are built from SA1s in the ASGC rather than Census Collection Districts, used in ASGC (ABS, 2022a).

  - **Urban Centre and Locality (UCL)** classification is aggregated from SA1s which meet population density criteria or contain urban infrastructure (ABS, 2022a). Areas not within Urban Centres or Localities are labelled as Remainder of State/Territory (ABS, 2022a). Urban Centres are areas of concentrated urban populations that are constantly changing by growing, absorbing nearby centres or declining (ABS, 2022a).

  - **Section of State (SOS)** groups the UCLs into four classes of urban areas based on population size, with the remainder considered to be rural (ABS, 2022a). The classes are an aggregation of the more detailed SOSR classification, with SOS regions covering the whole of Australia.

- **Remoteness Area Structure**
  - **Remoteness Areas (RAs)** comprise the six categories identifying a region in Australia used in the ASGC ranging from Major Cities (highly accessible) to Very Remote (very little accessibility) (ABS, 2022a). RAs are built up from SA1s which share a degree of remoteness which is determined using the ARIA or ARIA+ (ABS, 2022a).

    The AGS builds Remoteness Areas from SA1s which share a degree of remoteness rather than Census Collection Districts used in the ASGC (ABS, 2022a).

  - **Section of State Range (SOSR)** provides a more detailed classification than SOS to enable statistical comparison of differently sized Urban Centres and rural areas (ABS, 2022a).

Non-ABS Structures

The Non ABS Structures are hierarchies of regions which are not defined or maintained by the ABS, but for which the ABS provides a range of statistical data (ABS, 2022a) (refer to

Figure 29). The ABS approximates these regions by Mesh Blocks (MBs), Statistical Areas Level 1 (SA1s) or Statistical Areas Level 2 (SA2s) from the main structure of the ASGS (ABS, 2022a). The use of whole geographical units enables the ABS to release data which represents commonly used administrative and environmental units such as Postcode and LGA (ABS, 2016e).

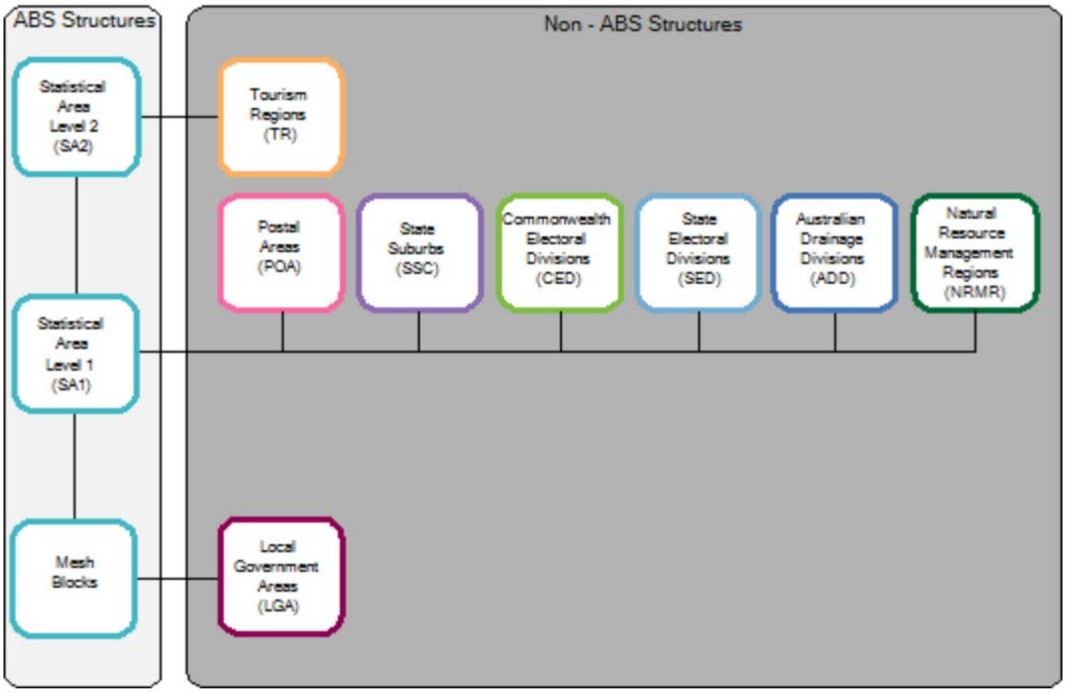


Figure 29 ASGS Non-ABS Structures (ABS, 2016a)

LGAs, Commonwealth Electoral Divisions and State Electoral Divisions are updated annually where redistributions have occurred with the remainder of the structures updated every 5 years (ABS, 2016e).

Defining Urban and Rural Classifications in ASGS

The ASGS defines and classifies areas as urban in several different ways to make a wide range of statistical geographical data available.

Urban Centres and Localities (UCLs)

Urban Centres represent areas of concentrated urban development with populations of 200 people or more. UCLs are defined using Statistical Areas Level 1 (SA1s) that meet the criteria of Urban Character.

UCLs are not official definitions of towns, with small towns less than 200 people and other urban areas represented by State Government Gazetted Localities. To enable comparisons, medium towns are those with populations of 10,000 to 50,000, large towns have populations of 50,000 to 100,000 and major cities are those with populations of 100,000 or more. Census data on these localities are provided through the State Suburbs (SSCs) which are part of the ASGC non-ABS Structures.

For statistical analysis, people living in areas defined as Urban Centres are viewed as urban, areas not defined by Urban Centres or Localities are considered to be 'rural'. UCLs include a category of Rural Balance which ensures that they cover the whole of Australia. Statistical data for Urban Centres are updated every Census and ABS does not provide population projections for Urban Centres, therefore data may be five years out of date.

SA1s are considered as urban using population and dwelling criteria based on 'place of usual residence' from Census of Population and Housing. Mesh Blocks (MBs) are the building blocks of SA1s and an Urban Mesh Block is defined as a MB with a population density of 200 persons or more per square kilometre. Criteria for SA1s to be considered as urban are as follows:

- Have an Urban Mesh Block (MB) population greater or equal to 45% of the total population and a dwelling density greater or equal to 45 dwellings per square kilometre, or
- Have a population density greater or equal to 100 persons per square kilometre and a dwelling density greater or equal to 50 dwellings per square kilometre, or
- Have a population density greater or equal to 200 persons per square kilometre

SA1s adjacent to SA1s classified as 'urban' that contain substantial 'urban infrastructure/ land use' and those located within 500 metres road distance, are also considered to be 'urban' SA1s. A cluster of SA1s classified as urban with a total population of 1,000 persons or more is defined as a separate Urban Centre. Clusters with total populations between 200 and 999 are considered Localities.

Localities

Localities represent configurations of small settlements, including villages, towns, clusters of peri-urban development and areas with significant tourism, with populations between 200 and 1,000 people. Localities are defined by grouping together adjacent SA1s that meet the following 'locality' criteria and for statistical purposes, people living in Localities are viewed as rural.

SA1s are considered to meet the ‘locality’ criteria if:

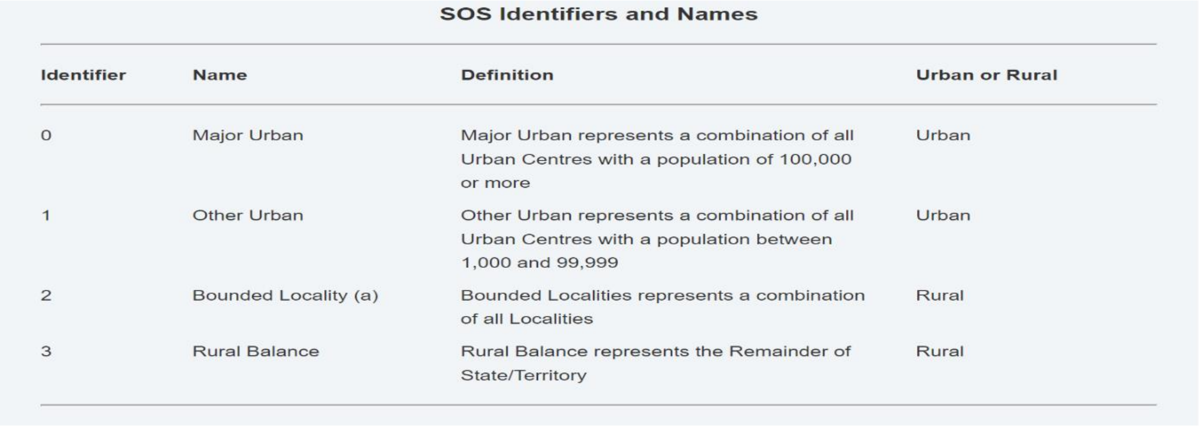
- They are not included in an Urban Centre, and
- Have at least one Urban Mesh Block, and
- Have a population density greater or equal to 200 persons per square kilometre.

Localities can be defined in any one of the following ways:

- One or more adjacent SA1s that meet the urban criteria with a population between 200 and 1,000 people.
- One or more adjacent ‘locality’ SA1s with a total population of at least 200 people.
- One or more adjacent SA1s representing a Discrete Aboriginal and Torres Strait Islander community with a total population between 200 and 999 people.
- One or more adjacent SA1s with a total population of at least 200 people in a concentration of housing and a discernible community centre containing community facilities.
- May contain a population exceeding 999 persons if it contains an ‘urban’ SA1 that does not meet the criteria for an Urban Centre.

Section of State (SOS) and Section of State Range (SOSR)

Section of State (SOS) classifies UCLs into four classes within each State and Territory (S/T) based on population size. The four classes are an aggregation of Section of State Range (SOSR) classifications with the categories being Major Urban, Other Urban, Bounded Locality and Rural Balance (Outlined in Figure 30).

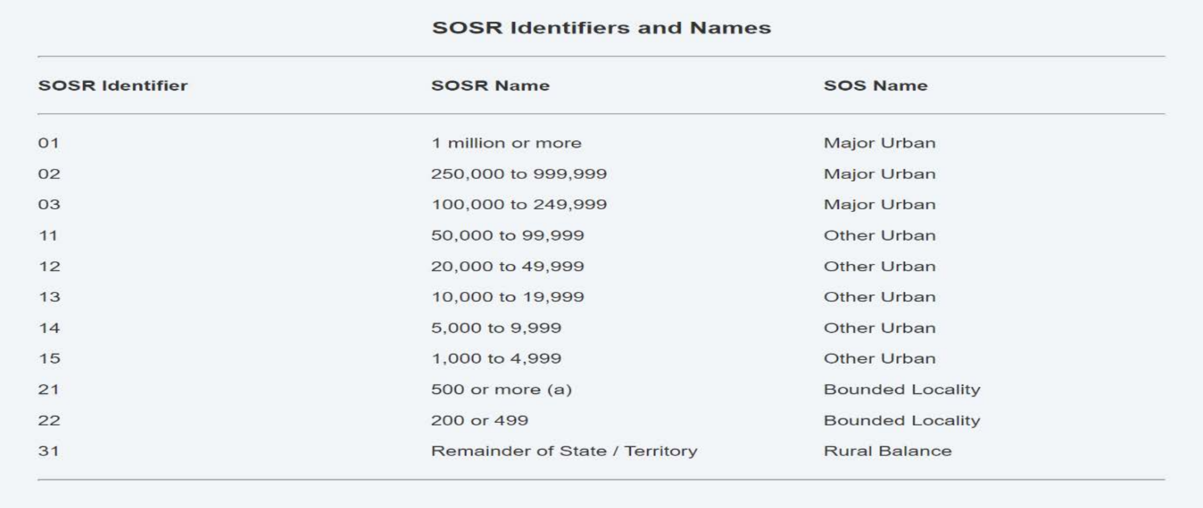


SOS Identifiers and Names

Identifier	Name	Definition	Urban or Rural
0	Major Urban	Major Urban represents a combination of all Urban Centres with a population of 100,000 or more	Urban
1	Other Urban	Other Urban represents a combination of all Urban Centres with a population between 1,000 and 99,999	Urban
2	Bounded Locality (a)	Bounded Localities represents a combination of all Localities	Rural
3	Rural Balance	Rural Balance represents the Remainder of State/Territory	Rural

Figure 30 SOS Classification (ABS, 2017)

Section of State Range (SOSR) are aggregates of UCLs and aggregate to SOS to cover the whole of Australia. SOSR provide more details than SOS which enables statistical comparison of different sized Urban Centres and the remaining rural areas. SOSR classify UCLs into eleven classes within each State and Territory (S/T). Classes are made up of eight population size classes grouping Urban Centres, two population size classes grouping Localities and a Rural Balance (as outlined in Figure 31).



SOSR Identifiers and Names

SOSR Identifier	SOSR Name	SOS Name
01	1 million or more	Major Urban
02	250,000 to 999,999	Major Urban
03	100,000 to 249,999	Major Urban
11	50,000 to 99,999	Other Urban
12	20,000 to 49,999	Other Urban
13	10,000 to 19,999	Other Urban
14	5,000 to 9,999	Other Urban
15	1,000 to 4,999	Other Urban
21	500 or more (a)	Bounded Locality
22	200 or 499	Bounded Locality
31	Remainder of State / Territory	Rural Balance

Figure 31 SOSR Classification (ABS, 2017)

Significant Urban Areas (SUAs) represent significant towns and cities of 10,000 people or more and are classified as urban.

Greater Capital City Statistical Areas (GCCSA) provide the broadest urban extent and represent the functional extent of each of the eight State and Territory capital cities. This classification includes not only the population within the urban city area, but also those who live in rural areas on the fringe of the city and commute. The term urban extent can be measured differently depending on user needs and available data. GCCSA boundaries provide a definition of capital cities and do not align with the built-up edge of the cities. GCCSA are built from SA4s and the area not defined as included in the GCCSA is represented by a Rest of State region.

Rural and remote classifications

Rural, Remote and Metropolitan Area (RRMA)

The Rural, Remote and Metropolitan Area (RRMA) classification is a general purpose tool based on ABS Census of Population and Housing data (as shown in Figure 32) (Department of Primary Industries and Energy and Department of Human Services and Health, 1994). RRMA structure consists of three broad zones, metropolitan, rural, and remote and seven classifications. The RRMA classification allocated each Statistical Local Area (SLA) within capital cities and metropolitan centres (having a population of 100,000 or more) to the

Metropolitan zone. All other SLAs were allocated to either the Rural or Remote zone based on the SLA's score on an 'Index of remoteness'. The index score was calculated by combining a personal distance index (relating to the SLA's population density) and distance indices (relating to the distance of the centroid of an SLA to the nearest urban centres in each of four categories). The SLA was then allocated a class (e.g. 'small rural centres') within the zone, based on the population of the urban centre within the SLA (DPIE & DHSH 1994). RRMA classifies SLAs as metropolitan ('capital cities' or 'other metropolitan areas'), rural ('large rural centres', 'small rural centres' and 'other rural areas'), and remote ('remote centres' and 'other remote areas'). The RRMA measure of remoteness is based on population estimates from the 1991 census (Senate Standing Committee on Community Affairs, 2007).

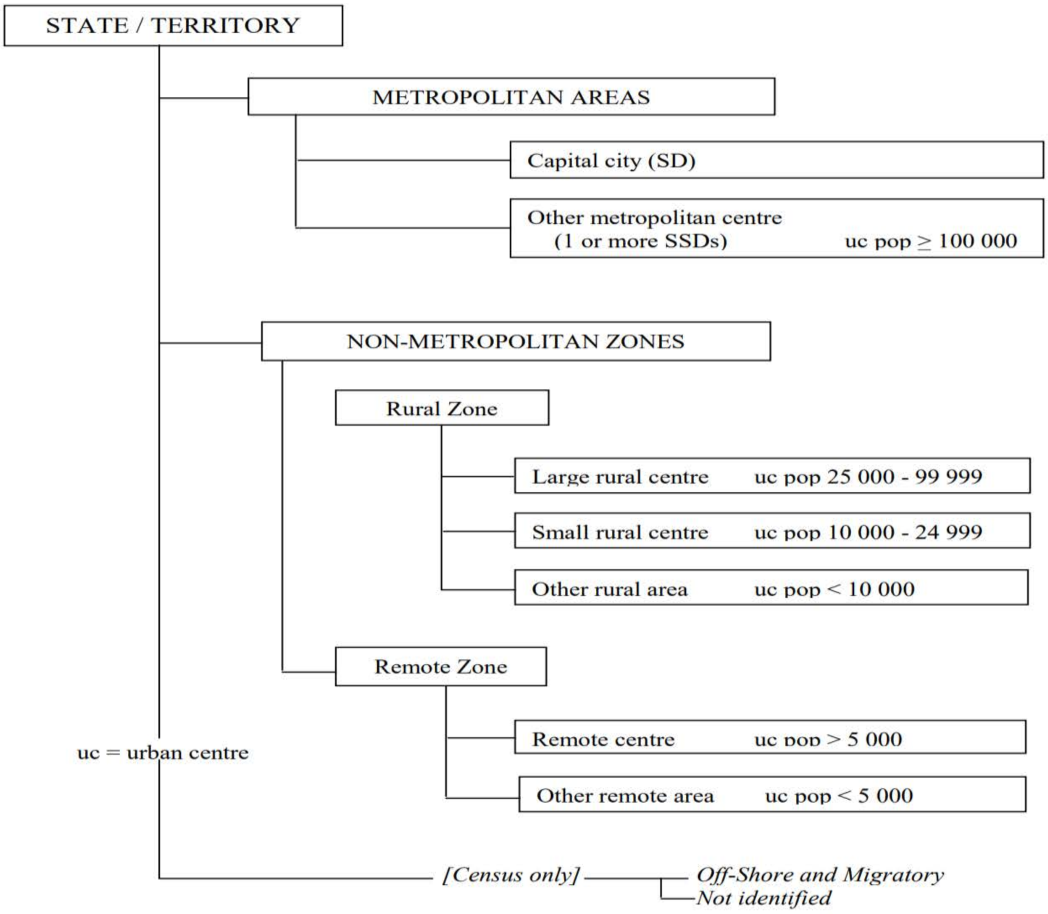


Figure 32 RRMA Structure (Department of Primary Industries and Energy and Department of Human Services and Health, 1994)

In summary the RRMA was a geographical classification of remoteness using Census data to classify areas by population. It has gradually become outdated in health use due to a lack of updates to the population data and is not relevant for use in current classifications of peri-urban locations.

Modified Monash Model (MMM)

The MMM is used by Health providers to define a location as metropolitan, rural, remote or very remote based on the ASGS-RA framework of geographical remoteness and town size (DoHAC, 2021). Transition to the new MMM commenced in 2019 and continues to aid various health workforce programs outside major cities (DoHAC, 2021). Remoteness and population size are measured on a Modified Monash category MM 1 to MM 7.

- MM 1 All areas categorised ASGS-RA1 (major city)
- MM 2 Areas categorised ASGS-RA2 and 3 that are in, or within 20km distance by road of a town with population greater than 50,000
- MM 3 Areas categorised ASGS-RA2 and 3 that are not in MM 2 and are in, or within 15km distance by road of a town with a population between 15,000 and 50,000
- MM 4 Areas categorised ASGS-RA2 and ASGS-RA3 that are not in MM 2 or MM 3 and are in or with 10km distance by road of a town with a population between 5,000 and 15,000
- MM 5 All other areas in ASGS-RA2 and 3
- MM 6 All areas categorised ASGS-RA4 that are not on a populated island that is more than 5km offshore
- MM 7 All other areas (DoHAC, 2021)

In summary, the model is used to determine eligibility for health workforce programs, including rural Bulk Billing and attracting health professionals to work in more remote and smaller communities and is not relevant for peri-urban areas due to proximity to major urban centres.

Other classifications

Primary Health Networks

Australia has 31 PHN areas covering the whole of Australia which replaced the sixty one Medicare Locals in 2015 (AIHW, 2022b). Medical Locals were designed to improve regional primary health care with a focus on General Practitioner services and boundaries closely aligned with LHNs (AIHW, 2016). PHNs are independent organisations funded by the Australian Government with the focus on improving patient outcomes by encouraging primary, community and specialist health sectors to collaborate in their geographical area (Healthdirect, 2022). These networks are managed by a board and clinical committees and work directly with

General Practitioners, allied and community health professionals and hospitals (Healthdirect, 2022). PHNs are designed to work closely with LHNs to integrate care between primary and acute local hospital networks, with boundaries closely aligned with LHN boundaries (Healthdirect, 2022).

ASGS SA3 level data forms the basis for any sub-regions developed by a PHN for demographic analysis. Circumstances may require the use for LHN sub-divisions LGAs. This data is used in conjunction with needs analysis conducted by the PHNs to understand resource allocation in the region. PHN areas are classed into two PHN groups, metropolitan or regional (AIHW, 2022b). PHNs with at least 85% of the population residing in the ASGS-RA classification of Major Cities are classified as metropolitan, with the remainder classified as Regional (AIHW, 2022b).

As an independent primary health care organisation, PHNs were established to meet the needs of the local community. However, the degree that consumer experience and feedback is integrated into healthcare services is subject to the identification and priority placed by the PHN on needs.

Local Health Networks or Local Health Districts (LHDs)

Every public hospital in Australia is part of a local network, known as either networks or districts, depending upon the State or Territory involved (National Health Funding Body, 2022). LHNs comprise a range of sites and services, including services which could be reasonably attributed to a public hospital. These include emergency departments, inpatient and outpatient services including some community based health services and residential aged care services which have a geographical connection (Booth et al., 2016). Each LHN has a governing board and a chief executive officer who reports to the board. Boundaries are set by State and Territory governments who classify LHNs as metropolitan or country.

As local networks, LHNs are like PHNs with a core requirement being to meet the needs of the local community. However, meeting local needs requires input from community members and the priority that the LHN places on the feedback provided.

Population Health Areas (PHA)

Population Health Areas (PHAs) were developed following the introduction of the ASGS when SLAs, the previous dataset used in the ASGC, were phased out. It became evident that the number of cases in some health population datasets would be too small to map in some datasets (AIHW, 2021b). The equivalent area level to SLAs are SA2s which average half the population of the previous SLA units which would increase the difficulty of maintaining confidentiality in datasets. Rather than use the next hierarchical level of SA3, a new Population Health Area (PHA) was constructed, comprised of a combination of whole SA2s and aggregates of SA2s (AIHW, 2021b). In 2016, there were 1,165 PHAs in Australia.

PHAs are used in several health datasets including chronic disease dashboards.

State Suburbs (SSC)

State Suburbs (SSC) are created by allocating one or more MBs to enable the release of ABS data on areas that approximate Gazetted Localities (ABS, 2016b). Gazetted Localities are officially recognised boundaries of suburbs and localities.

Postal Areas (POAs) and Postcodes

Postcodes are four digit numeral codes allocated to geographic areas to assist with processing and delivery of mail to specific addresses (ABS, 2016f). Postcodes are easily accessible and therefore used by many researchers to link data to a geographic area. The ABS provides Postcode Indexes to link postcode data to standard ABS geographic areas including SAs and GCCSAs within the ASGS (ABS, 2016f). Postal Areas (POAs) differ to postcodes being an ABS approximation of postcodes to enable release of data that closely approximates postcodes. POAs are approximated using one or more SA1s from the ASGS and are incorporated as a non-ABS structure (ABS, 2016f). Postcode and POA data have the benefit of providing easily accessible health data to assist with development and implementation of health services that meet the needs of local communities.

Cities, Towns and Villages (CTVs)

CTV geography is designed to assist with analysis of spatial distribution of service access in regional Australia. ABS data is sourced to provide an estimate of population density by square kilometre to identify population centres or clusters where people both live and where services are location. CTV geography identifies population and service centres and includes locations with populations of fewer than 200 persons, thereby removing a limitation of the ASGS. Service centres include health, education, postal, retail and government services (BITRE, 2019). The use of CTVs to represent population centres, has been superseded using GCCS, SUA and UCL, however, none represent the nexus of population and service centre required for service access analysis.

Local Government Areas

The term ‘LGA’ is used by the ABS to refer to local government administrative zones which have several varying designations. LGAs comprise a diverse range of communities and are designated areas for which incorporated local governing bodies have responsibility (ABS, 2022a). LGAs are not defined by the ABS and are therefore identified as non-ABS structures in the ASGS. LGA boundaries are an ABS MB approximation of gazetted local government boundaries as defined by state and territory governments and are used for statistical purposes only (ABS, 2022a). Every LGA in Australia can be assigned to a group based on similar population, population density and the proportion of the population that is classified as urban, as determined by ABS data (ABS, 2016b). These groups are based on the Australian Classification of Local Government (ACLG) framework which was a three step hierarchical framework with twenty two categories and deemed too detailed to enable meaningful comparisons (South Australian Productivity Commission, 2019). Groups of similar LGAs are determined by the States or Territories involved with general groupings being metropolitan, metropolitan fringe, regional city, large rural and rural based on ABS data.

Data provided at a LGA level provides a smaller spatial unit than State or Territory wide, although the area has the potential to cover a diverse range of communities. It can be difficult to define peri-urban areas within LGA boundaries using LGA geography due to the variety of land uses that may exist. Classifying LGAs as peri-urban or metropolitan fringe due to their general proximity to urban centres has the potential to oversimplify challenges to accessing community health services that may exist to some residents within the LGA.

Appendix B: Literature Review summary papers

Author/s	Title	Study Design	Location	Location classification	Theme	Quotes
(Hart et al., 2005)	Rural definitions for health policy and research	Qualitative discussion and comparison rural taxonomies	Rural	Different taxonomies – population size and density, commuting patterns	Definition or rural for health policy	“By treating these diverse types of rural cities and towns and the problems they confront similarly, policy analysts may fail to identify each site’s distinct health care concerns”
(Humphreys, 1998)	Delimiting 'rural': implications of an agreed 'rurality' index for healthcare planning and resource allocation	Qualitative discussion rurality	Rural	Geographical units	Definition of rural for health policy	“rural Australia comprises a complex mosaic”
(Racher et al., 2004)	Conceptualizations of 'rural:' challenges and implications for nursing research	Qualitative discussion re urban/rural	Rural	Population density and size, isolation, census data	Definition of rural for health research	“Defining rural is a complex and multifaceted process that changes, according to the purpose for which the definition is being designed”
(Amirinejad et al., 2018)	Ambiguity at the peri-urban interface in Australia	Qualitative review	Peri-urban	Complex set of land use relationships	Peri-urban definition more than rural-urban dichotomy	“peri-urban area amalgamates urban, rural and natural features in such a way that each feature is influenced by the other two”
(Žlender, 2021)	Developing a spatially explicit method for delineating peri-urban landscape	Qualitative literature review	Peri-urban	Land uses – agriculture, leisure, sealed land, infrastructure, agricultural	Peri-urban definition for planning	‘spatial delineation should be based on variables that reflect peri-urban land use as well as other relevant variables like population density.’
(Kaminski et al., 2021)	Using landscape metrics to characterize towns along an urban-rural gradient	Quantitative cluster analysis	Rural	Distance, population size and density, landscape pattern metrics	Definition of rural for sustainable planning	“Understanding where a town occurs along the urban-rural gradient could aid local decision-makers”
(Çörek Öztaş, 2021)	How to Best Classify Rural in Metropolitan Areas? The Turkish Case	Quantitative analysis	Rural	Population density	Definition of rural for policies and planning	‘developing a clear understanding of what is rural, including a quantifiable and mapable definition, planners will be better prepared to improve strategies’
(Saxena, 2019)	Peri-Urban Areas: Sustainability Dimension	Qualitative review	Peri-urban	Population size and density, employment	Peri-urban definition for planning	“Peri-urban area is no a recognised entity for both studies and research”
(Miller, 2013)	More than "not urban": Seeking a quantifiable definition of rural	Qualitative review	Rural	Census data	Definition of rural for policy and planning	To “best inform policy specific to planning outcomes”
(Smith et al., 2013)	The utility of rural and underserved designations in geospatial assessments of distance traveled to healthcare services: Implications for public health research and practice	Qualitative review	Rural	Geography, population size and density, distance to services	Definition of rural for planning	“discrepancies among conclusions that may be drawn based upon the application of the different definitions of rurality when applied to health data”
(Allen, 2003)	Environmental planning and management of the peri-urban interface: Perspectives on an emerging field	Qualitative review	Peri-urban	Population size and density, infrastructural characteristics, administrative boundaries and economic activities	Peri-urban definition for planning	“construction of an approach that responds to the specific environment, social, economic and institutional aspects of the peri-urban interface”
(Iaquinta & Drescher, 2000)	Defining the peri-urban: Rural-urban linkages and institutional connections	Qualitative review	Peri-urban	Distance to city centres and local culture	Peri-urban definition for food production planning	‘definitions are largely situational and case specific. They provide little basis for a unified understanding of what constitutes periurban.’

(McGrail & Humphreys, 2009)	Geographical classifications to guide rural health policy in Australia	Qualitative debate	Rural	GIS classifications	Definition of rural for health policy	“way in which populations and communities are delimited……has important implications for health care planning and policy”
(Booza et al., 2010)	Incorporating Geographic Information Systems (GIS) into program evaluation: lessons from a rural medicine initiative	Qualitative review	Rural	3 measures: percentage of population, internal level continuous measure and census data	Definition to assist with addressing GP shortage	‘outcome of student placement in rural practices depended on the definition of rural.’
(Nixon et al., 2021)	Developing the geographic classification for health, a rural-urban classification for New Zealand health research and policy: A research protocol	Mixed methods	Rural	Develop existing GIS classification using population and spatial	Definition for rural health policy	‘Rural-urban definitions are most complex and elusive for small towns in rural regions, peri-urban communities in commuter zones and the rural- urban fringe.’
(Williams & Cutchin, 2002)	The rural context of health care provision	Qualitative review	Rural	Land use, population density, demographic structure, environmental characteristics, population characteristics, non-metropolitan areas and community patterns	Definition of rural to address rural health care staff provision	“may provide the basis to best understand the attributes and challenges of rural places”
(Bennett et al., 2019)	What Is Rural? Challenges And Implications Of Definitions That Inadequately Encompass Rural People And Places	Qualitative review	Rural	Population density, travel (distance, roads, geography, availability), resources, socio-economics, local perception, culture and amenities	Definition of rural for health policy and planning	“definition of rural could be operationalized as an index and incorporate measures from a variety of areas”
(Taylor et al., 2021)	General practice access in regional and remote Australia for ageing populations	Quantitative analysis	Rural	Population size and density, spatial and distance to GP clinics	Definition of rural for health policy (GP clinic placement)	‘General practice access in regional and remote Australia for ageing populations’

Appendix C: Ethics Approval

This administrative form
has been removed

Appendix D: Survey questions

Peri-urban survey

Q1.1 Thankyou for participating in this research.

Community based palliative care services aim to optimise quality of life and wellbeing through a person-centred, multidisciplinary approach to home-based care. Palliative care is provided to people diagnosed with a life-limiting illness and their family members. Every person has the right to access all health services including palliative care with barriers to healthcare services from rural and remote locations recognised. Increasing numbers of Australians are relocating from densely populated, urban areas to peri-urban locations offering a rural lifestyle within commuting distance to major cities. This research aims to understand if this counterurbanisation trend to a peri-urban location, is influencing access to healthcare services involved with providing community palliative care.

Access is a complex concept and includes availability of affordable and effective services, provided in a manner which considers diverse perspectives and individual needs. Therefore questions in the following survey will include, how people identify, seek, reach and use the health services required and if the holistic needs of those facing end-of-life care are being fulfilled by the services provided and the method of service delivery. Providing geographic location will enable researcher to identify if peri-urban location influences access to care provision. Health providers views on service availability will provide valuable insights and enable comparison of the views of those receiving care.

Your views may assist in recommendations for future policies.

You are encouraged to read the Grief Supports page and the Participant Information Sheet in full, before consenting to participate in this research.

- o Participant Information Sheet
- o Grief Supports

Q1.4 **I have had the opportunity to read the Participant Information Sheet and ask questions about this research**
I have had the opportunity to read the Grief Supports page
I understand the possible risks to my involvement in this research
I understand that I may not answer questions and/or leave the survey without submitting
I am over 18 years of age and voluntarily consent to this research

- o Yes
- o No

Q1.5 **Please select the statement that best describes you**

- o I am a person receiving community palliative care following a diagnosis of a life-limiting illness
- o I am a family member or care giver of a person diagnosed with a life-limiting illness
- o I am a Health Professional providing community palliative care

Family member or care giver survey questions

Q2.1 **Your age group?**

- o 18 to 34 years
- o 35 – 49 years
- o 50 – 64 years
- o 65 years and over
- o Prefer not to answer

Q2.2 **How long have you been receiving community palliative care?**
Palliative care support and services are provided during the illness period and extends to family members and caregivers after death

- o Less than 1 month

- 1 to 6 months
- 6 months to 1 year
- Over 1 year
- Unsure
- Prefer not to answer

Q2.3 **What is your relationship to the person diagnosed with a life limiting illness?**

- Spouse
- Sibling
- Child
- Extended family member
- Friend
- Other____

Q2.4 **In what State/Territory are services provided?**

If you are receiving in-home care in more than one location, please consider only the main location

- Queensland
- South Australia
- Northern Territory
- New South Wales
- Western Australia
- Victoria
- ACT
- Tasmania
- Outside of Australia

Q2.5 **How would you describe the area where community palliative care is provided?**

- Metropolitan (densely populated, urban centres)
- Peri-urban (fringe areas of major cities, a mix of rural and new residential development, experiencing population growth, often within 150km of major city and commuting distance)
- Rural (predominantly farming land, less densely populated, often over 150km from major city)
- Regional
- Remote
- Unsure
- Other (please describe) ____

Q2.6 **In what local government area (council or shire) is the in-home (community) care being provided?**

To maintain your privacy, please do not provide your full address

Understanding the LGA will provide further detail about the type of location and influence on access

____

Q2.7 The term Health services in this survey refers to all health services/supports that may be needed for those people receiving palliative care and include pharmacy, medical clinic, pathology, radiology, specialist and community services

How much do you agree with the following statements?

	Strongly Disagree	Somewhat Disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Existing health services were considered when selecting the home location	○	○	○	○	○
The location was selected as services were in the development stage	○	○	○	○	○

Consideration was given to accessing services for possible future health needs (eg hospice, aged care facility) when selecting the home location	○	○	○	○	○
There was an expectation that health services were accessible	○	○	○	○	○

Q2.8 **How did you receive/find information about available services?** select all that apply
☐ Health Professional (GP, Specialist, clinic staff)
☐ Referred to Palliative care
☐ Friends/family
☐ Pamphlets/booklets
☐ Online forums
☐ Support groups
☐ Google
☐ Personal knowledge/experience
☐ I was not involved in accessing services
☐ Other ____

Q2.9 **Did you find it difficult to find information about service/s and identify what was needed?**
○ Yes
○ No
○ N/A

Q2.10 **Did you find it difficult to access identified services when required?**
○ Yes
○ No
○ N/A

Q2.11 **Please select all the services that you know are being received or have been received in the home**
☐ Unsure
☐ Specialist Palliative Care
☐ Community Nursing
☐ Personal Care
☐ Transport Assistance
☐ Occupational Therapist
☐ Psychiatrist/Psychologist
☐ Social Worker/Counsellor
☐ Physiotherapy
☐ Dietician/Nutritionist/Speech Pathology
☐ Palliative Care Specialist Physician
☐ Spiritual Support
☐ Volunteers
☐ Complementary Therapies - art, music or massage
☐ Housework/Gardening Assistance
☐ Home maintenance/modifications
☐ Equipment
☐ Assistance with Advance Care Directive
☐ Financial/legal assistance
☐ Regular General Practitioner
☐ End-of-life care
☐ Bereavement support
☐ Family/friends
☐ Other ____

Q2.12 **Do services received meet needs and expectations?**
○ Yes
○ Partially (please provide detail)____
○ No (provide detail) ____
○ Prefer not to answer

Q2.13 **If you are not using all services that are available, why not**? select all that apply
☐ Not required
☐ Family provide

☐ Not happy with the service previously
☐ Not able to access service when I want
☐ Not able to access service as often as I want
☐ Service not available in this location
☐ Local providers do not have the resources to provide the service
☐ Service is too expensive
☐ Using all services we knew about
☐ Personal choice
☐ Have tried to access but unable - unsure why
☐ Other____

Q2.14 **Please select any of the following that apply:**
☐ One or more hospital stays have been extended as services unavailable in-home to support discharge
☐ Needed to attend clinic or hospital outpatients for medication administration as in-home services unavailable
☐ Needed to attend clinic or hospital outpatients for assistance with wound/catheter/stoma care as in-home services unavailable
☐ Needed to call an ambulance for assistance with pain/symptom control as unable to contact community services
☐ Respite in aged care facility was required as in-home services unavailable to support hospital discharge
☐ Will need to transfer to hospital for end-of-life care to remain in local area

Q2.15 **What is the longest distance your family member has needed to travel for healthcare services?**
consider services such as scans, radiotherapy, chemotherapy, dialysis, specialist appointments
○ all services are local and within 10km from home
○ 10 to 50km
○ 50 to 100km
○ 100 to 150km
○ 150km to 250km
○ over 250km
○ Unsure

Q2.16 **What barriers to accessing services do you believe apply in your situation?**
☐ There are no barriers to access
☐ Person requiring services is under 65 years of age
☐ Home location and the distance involved for service providers
☐ Lack of resources by local providers
☐ Time taken for services to commence
☐ Distance and time involved in travelling to some health services not available locally
☐ Cultural or gender diversity
☐ Language
☐ Stigma associated with palliative care
☐ Challenging behaviours
☐ Financial
☐ Personal choice
☐ Care needs beyond scope of existing services
☐ No identified need
☐ Other ____

Q2.17 **Thinking about transport from home to the location of some health services, please select statements that apply to your family**
☐ The time/distance involved has influenced decisions about attending appointments, treatment or tests
☐ The time/distance has influenced the home location of the person requiring care in the home
☐ Travel time/distance is not a problem
☐ Travel any distance is difficult (exhausting, pain, discomfort, etc)
☐ Private transport is difficult due to cost of petrol, parking, lost wages and time involved
☐ Public transport is not an option
☐ Community car is not available/expensive/not an option
☐ All health services are provided in the home
☐ All health services are provided locally
☐ Need to relocate to be closer to services that will provide a higher level of care
☐ Other____

Q2.18 **How much do you agree with the following statements**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
The choice to remain in own home has been supported	○	○	○	○	○
Personal choices, preferences and goals of care have been respected	○	○	○	○	○
All communication and information provided has been respectful and appropriate for our needs	○	○	○	○	○
Access to support is available 24 hours a day 7 days a week	○	○	○	○	○
Quality of life has been improved by community services	○	○	○	○	○
The need for ambulance transport and admission to hospital has been reduced by in-home services	○	○	○	○	○
Family members have been included in all decision-making about care and services	○	○	○	○	○
Physical symptoms are managed in the home	○	○	○	○	○
Support has been provided with advance care planning, completing will and grief counselling	○	○	○	○	○
Financial assistance needed has been provided	○	○	○	○	○
All support and education required by family members to provide safe, quality care, including end-of-life care and/or home death has been provided	○	○	○	○	○
All services have been provided promptly and when needed	○	○	○	○	○
Medication is available locally	○	○	○	○	○
Choices for end-of-life care including hospice, home death and voluntary assisted dying, have been supported and have enabled informed decisions	○	○	○	○	○
Available services are affordable	○	○	○	○	○
Staff providing care have the training, knowledge and expertise to provide the quality of care needed	○	○	○	○	○
Choice of provider and/or staff who attend home visits is provided	○	○	○	○	○
Family/caregiver stress and burnout has been reduced with service provision	○	○	○	○	○
Patient/family have good relationships with health professionals involved in care	○	○	○	○	

Q2.19 Digital health, telehealth, eHealth and telemedicine are broad terms used interchangeably. This survey will use the term digital health to refer to the all the tools and services that are available to diagnose, treat, collect and share health information, including consultations with a healthcare provider that are conducted by phone or video rather than face-to-face.

How are palliative care services provided in your home? select all that apply

☐ Face-to-face
☐ Phone consultation
☐ Video consultation
☐ Email
☐ Text
☐ Apps
☐ Other ____

Q2.20 **Have you experienced any problems with digital health options?** Please select all that apply

☐ No problems using digital health
☐ Lack of computer access/skills
☐ I have not used digital options
☐ poor mobile coverage
☐ Unreliable/non-existent internet access
☐ Digital options not offered by providers
☐ Other____

Q2.21 **How much you agree with the following**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Digital health is an important tool in ensuring regular communication with the palliative care team	○	○	○	○	○
The method palliative care provides support in the home, either face-to-face or digital is appropriate for our needs	○	○	○	○	○
I have the resources and confidence to use digital health effectively	○	○	○	○	○
Digital health consultations are an acceptable alternative to face-to-face consultations with medical professionals	○	○	○	○	○
Digital health means that access to medical support is available that I would not be able to access due to distance	○	○	○	○	○
I feel that the choice of place of care is supported with digital health	○	○	○	○	○
I am comfortable with my family member remaining at home knowing that support can be accessed at any time	○	○	○	○	○

Q2.22 **Overall are you satisfied with the access to community palliative care services in your location?**

○ Yes
○ No
○ Unsure
○ Prefer not to comment

End of Block: Family member or care giver survey

Start of Block: Final questions

Q3.1 **Do you have comments you would like to add?**
Please remember that your opinion is important
o Yes
o No
If = Yes
Q3.2 Please provide details____

Q3.3 Thankyou for participating in this research
Would you like details of the completed research emailed to you.
o Yes
o No

If = Yes

Q3.4 Please provide your email

These details will not be linked to survey responses

Email ____

End of Block: Final questions

Start of Block: Submission

Q4.1 If you experience any upset or distress because of your participation in this research project, please seek assistance from available services in your local area, talk to someone, or

- Call Lifeline on 13 11 14
- 13 Yarn support for Aboriginal and Torres Strait Islander people 13 92 76
- Beyond Blue 1300 224 636
- Lifeline Australia 13 11 14
- or contact your palliative care service for support, GP to discuss the possibility of a Mental Health Care Plan, employer or education institution for available employee assistance or health and wellbeing programs that offer confidential counselling and support.

Do not forget your community support network which includes; friends, family members, church minister or religious leader, a school, university or TAFE counsellor, coach, work colleague, community leaders.
If you or someone near you is in immediate danger: Call Emergency Services on 000; or go to a hospital emergency department

End of Block: Submission

Start of Block: Patient survey

Q5.1 **Your age group?**
o 18 to 34 years
o 35 - 49 years
o 50 - 64 years
o 65 years and over
o Prefer not to answer

Q5.2 **How long have you been receiving community palliative care?**
please consider if you wish to continue with this research if you recently commenced receiving palliative care
o less than 1 month
o 1 to 6 months
o 6 months to 1 year
o over 1 year
o Unsure
o Prefer not to answer

Q5.3 **In what State/Territory do you live? care provision varies by location**
o Queensland
o South Australia
o Northern Territory
o New South Wales
o Western Australia
o Victoria
o ACT
o Tasmania
o Outside of Australia

Q5.4 **How would you describe the area where you live and receive care?**
o Metropolitan (densely populated, urban centres)
o Peri-urban (fringe areas of major cities, a mix of rural and new residential development, experiencing high population growth, often up to 150km from adjoining metropolitan centre)
o Rural (predominantly farming land, less densely populated, often over 150km from metropolitan centre)
o Regional
o Remote
o Unsure

Q5.5 **In what local government area (council or shire) do you receive care?** to maintain your privacy, please do not provide your full address understanding the LGA will provide further detail about the type of location and influence on access

____

Q5.6 The term Health services in this survey, refers to all services/supports that may be required for palliative care and include pharmacy, medical clinic, pathology, radiology, specialist and community services
How strongly do you feel about the following statements?

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I chose this location as health services I need are close by	○	○	○	○	○
I chose this location as services I need/may need, are in the planning or development stage	○	○	○	○	○
I chose this location as health services that provide for increased care needs are close by (eg hospice, aged care facility, specialist care)	○	○	○	○	○
There was an expectation that health services were accessible	○	○	○	○	○

Q5.7 **How did you identify, contact or access services and information?** select all that apply

☐ I was not involved with seeking services or information
☐ Health Professional providing treatment (GP, Specialist, clinic staff)
☐ I was referred to Palliative care
☐ Friends/family
☐ Pamphlets/booklets
☐ Online forums
☐ Support groups
☐ Google
☐ Personal knowledge/experience
☐ Other____

Q5.8 **Did you find it difficult to find information about service/s and identify what was needed?**

○ Yes
○ No
○ n/a

Q5.9 **Did you find it difficult to access identified services when required?**

○ Yes
○ No
○ n/a

Q5.10 **Please select all community services you are using/have used**

☐ Unsure
☐ Specialist Palliative Care
☐ Community nursing
☐ Personal Care
☐ Transport Assistance
☐ Occupational Therapist
☐ Psychiatrist/Psychologist
☐ Social Worker/Counsellor
☐ Physiotherapy
☐ Dietician/Nutritionist/Speech Pathology
☐ Palliative Care Specialist Physician

☐ Spiritual Support
☐ Volunteers
☐ Complementary therapies - art, music or massage
☐ Housework/Gardening assistance
☐ Home maintenance/modifications
☐ Equipment
☐ Assistance with Advance Care Directive
☐ Financial/legal assistance
☐ Regular General Practitioner
☐ Family/friends
☐ Other____

Q5.11 **Do the services you receive meet your needs and expectations?**

○ Yes
○ Partially (please provide detail) ____
○ No (please provide detail) ____
○ Prefer not to answer

Q5.12 **If you are not using all available community services, why not?**

☐ I don't need the service at this time
☐ Family provide
☐ Not happy with the service previously
☐ Not able to access when I want
☐ Not able to access service as often as I want
☐ I am under 65 years of age and unable to access
☐ Service not available in this location
☐ Local providers do not have the resources to provide the service
☐ Too expensive
☐ Didn't know about all the services available
☐ Personal choice
☐ Unsure why unable to access
☐ Other____

Q5.13 **Please select any of the following that apply to you**

☐ I have had one or more hospital stays extended as services were unavailable to support my discharge home
☐ I have needed to attend a clinic or hospital outpatients for medication administration as in-home services were unavailable
☐ I have needed to attend a clinic or hospital outpatients for assistance with wound/catheter/stoma care as in-home services were unavailable
☐ I have needed to call an ambulance for assistance with pain/symptom control as unable to contact local services
☐ Respite in aged care facility has been required as in-home services unavailable to support hospital discharge
☐ Will need to transfer to hospital for end-of-life care to remain in this location

Q5.14 **What is the longest distance you have needed to travel for healthcare services?** consider services such as scans, radiotherapy, chemotherapy, dialysis, specialist appointments

○ all services are local and within 10km from home
○ 10 to 50km
○ 50 to 100km
○ 100 to 150km

○ over 150km
○ unsure

Q5.15 **What barriers to accessing services do you believe apply in your situation?**

☐ There are no barriers to access
☐ I am under 65 years of age
☐ Home location and the distance involved for service providers
☐ Lack of resources by local providers
☐ Time taken for services to commence
☐ Distance and time involved in travelling to some health services not available locally
☐ Cultural or gender diversity
☐ Language
☐ I do not want palliative care
☐ Challenging behaviours related to a family member/caregiver
☐ Financial
☐ Personal choice
☐ Care needs beyond scope of existing services
☐ No identified need
☐ Other ____

Q5.16 **Thinking about distance to health services, please select statements that apply to you**

☐ The distance required to travel to some health services has influenced my decisions about attending appointments, treatments or tests
☐ The distance required to travel to some health services has influenced where I live
☐ Travel any distance to health services is difficult (exhausting, pain, discomfort, etc)
☐ Private transport to some health services is difficult due to cost of petrol, parking, lost wages and time involved for my family
☐ Public transport is not an option in this location
☐ Community car is not available/expensive/not an option
☐ Health services are provided in my home
☐ Health services are provided locally
☐ I will need to relocate to be closer to services that will provide the level of care I need/will need
☐ Other ____

Q5.17 **How much do you agree with the following statements about the services you receive?**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I have been supported in my choice to remain in my own home	○	○	○	○	○
Personal choices, preferences and goals of care are being respected	○	○	○	○	○
All communication and care provided has been culturally and gender inclusive and respectful	○	○	○	○	○
I have access to support 24 hours a day and 7 days a week	○	○	○	○	○
My quality of life has been improved by remaining in my own home	○	○	○	○	○
Access to community services have reduced my need for ambulance transport and hospital admissions	○	○	○	○	○
I have been included in all decision-making about care and services provided	○	○	○	○	○
I am comfortable with the level of symptom management that is available	○	○	○	○	○
I have received support with advance care planning, completing my will and grief counselling	○	○	○	○	○
I have received financial assistance as needed	○	○	○	○	○
I am satisfied that my family and caregivers are receiving the support they need	○	○	○	○	○
All the services I need have been provided promptly	○	○	○	○	○
I am able to access the medication that I need easily	○	○	○	○	○
My personal choices for end-of-life care including hospice, home death and voluntary assisted dying, have been supported and I have been able to make informed decisions	○	○	○	○	○
All services I need are affordable	○	○	○	○	○
I believe the staff providing my care have the training, knowledge and expertise to provide the quality of care I need	○	○	○	○	○
I have choice of provider and/or staff who attend my home	○	○	○	○	○
Family/caregiver stress and burnout has been reduced with service provision	○	○	○	○	○
I have a good relationship with health professionals involved in my care	○	○	○	○	○

Q5.18 Digital health, telehealth, eHealth and telemedicine are broad terms used interchangeably. This survey will use the term digital health to refer to all the tools and services that are available to diagnose, treat, collect and share health information, including those consultations with a healthcare provider that are conducted by phone or video rather than face-to-face.

Digital health options improve access to health services including palliative care. **How do you receive palliative care services in your home?** select all that apply

☐ Face-to-face
☐ Phone consultation
☐ Video consultation
☐ Email
☐ Text
☐ Apps
☐ Other ____

Q5.19 **Have you experienced any problems with digital health options?** Please select all that apply

☐ No problems using digital health
☐ Lack of computer access/skills
☐ I have not used digital options
☐ Poor mobile coverage
☐ Unreliable/non-existent internet access
☐ Digital options not offered by providers
☐ Other ____

Q5.20 **How much you agree with the following**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Digital health is an important tool in ensuring I have regular communication with my palliative care team	○	○	○	○	○
I have the resources and confidence to use digital health effectively	○	○	○	○	○
Digital health consultations are an acceptable alternative to face-to-face consultations with medical professionals	○	○	○	○	○
Digital health means that I can access medical support that I would not be able to access due to distance	○	○	○	○	○
I am comfortable to remain at home knowing that I can access support at any time	○	○	○	○	○

Q5.21 **Overall, are you satisfied with the access to community palliative care services in your location?**

○ Yes
○ No
○ Unsure
○ Prefer not to answer

End of Block: Patient survey

Start of Block: Health Professionals survey

Q6.1 **Your age group?**
o 18 to 34 years
o 35 - 49 years
o 50 - 64 years
o 65 years and over
o Prefer not to answer

Q6.2 **How long have you been providing community palliative care?**
o less than 1 year
o 1 to 5 years
o over 5 years
o prefer not to answer

Q6.3 **What is your current role in providing community palliative care?**
o Nurse Practitioner
o Clinical Nurse
o Registered Nurse
o Enrolled Nurse
o AIN/Personal Care attendant
o Occupational Therapist
o General Practitioner
o Psychiatrist
o Psychologist
o Social Worker
o Physiotherapist
o Dietician
o Speech Therapist
o Palliative Care Physician
o Chaplain
o Pharmacist
o Volunteer
o Other ____

Q6.4 **How would you describe the area where you provide community palliative care?**
If you provide care in more than one location, consider the location where you provide the majority of care
o Metropolitan (densely populated, urban centres)
o Peri-urban (fringe areas of major cities, a mix of rural and new residential development, experiencing population growth, often within 150km of major city)
o Rural (predominantly farming land, less densely populated, often over 150km from major city)
o Regional
o Remote
o Unsure
o Other (please describe)

Q6.5 **In what local government area (council or shire) do you provide community palliative care?**
If multiple areas, please consider the area where you provide majority of care
Understanding the LGA will provider further detail about the type of location and influence on access
____

Q6.6 **In what State/Territory?**
o Queensland
o South Australia

o Northern Territory
o New South Wales
o Western Australia
o Victoria
o ACT
o Tasmania
o Outside of Australia

Q6.7 **In what type of organisation do you provide community palliative care?** If you work in more than one service/organisation, please think about where you work the most hour

o Specialist Palliative Care team

o Generalist Community Health

o Public Hospital

o Private Hospital

o General Practitioner Clinic

o Home Care Provider

o Residential Aged Care Facility

o Other ____

Q6.8 Palliative care teams are multidisciplinary **What health professions are employed to support community palliative care in your organisation?** select all that apply in full or part-time roles
☐ Nurse Practitioner
☐ Clinical Nurse
☐ Registered Nurse
☐ Enrolled Nurse
☐ AIN/Personal Care attendant
☐ Occupational Therapist
☐ General Practitioner
☐ Psychiatry
☐ Psychology
☐ Social Work
☐ Physiotherapy
☐ Dietician
☐ Speech Therapy
☐ Palliative Care Specialist
☐ Chaplain
☐ Pharmacist
☐ Other ____

Q6.9 **If you have a choice, are there any health profession roles you would like added to your team?** consider part-time and full-time roles
o Yes (please detail) ____
o No
o Unsure

Q6.10 Palliative patients often require support services from multiple organisations to remain in their home. **What services are accessible to all homes in the area where you work?** please select all services that you are aware of, whether or not service is provided by your organisation
☐ Specialist palliative care
☐ Occupational Therapist
☐ Physiotherapy
☐ Daily medication administration

☐ Community nursing
☐ Assistance with personal care
☐ Equipment
☐ Home modifications
☐ Advance Care planning
☐ Housekeeping, gardening, home maintenance
☐ Counselling
☐ End-of-life care in the home
☐ Bereavement care
☐ Transport assistance (public transport, community car)
☐ Dietician, speech pathology, nutrition
☐ General Practitioner
☐ Pharmacy
☐ Complementary therapies - art, music, massage
☐ Volunteer support
☐ Pathology
☐ Radiology
☐ Specialist physicians
☐ Other ____

Q6.11 Access is influenced by multiple factors. **What barriers to accessing services do you believe apply in your location?**
☐ No barriers to client access
☐ Clients aged under 65 years
☐ Home location and the distance involved in providing in-home service
☐ Lack of resources/capacity from providers
☐ Time taken for services to commence
☐ Distance and time involved in clients having to travel to services that are not local
☐ Cultural or gender diversity
☐ Language
☐ Client refusing due to stigma associated with palliative care
☐ Challenging behaviours
☐ Financial - services expensive
☐ No identified need
☐ Personal choice
☐ Care needs increase beyond capacity of existing services
☐ Lack of information about available services
☐ Unsure
☐ Other ____

Q6.12 **Thinking about the organisation in which you provide community palliative care, are there any changes you would like to see in your role?**

☐ No changes, service meets the needs of clients
☐ Increase frequency services could be available in the home
☐ Enable choice of provider
☐ Provide choice of day/time of service
☐ Provide 24/7 contact for support
☐ Provide 24/7 in-home care options
☐ Increase in staff numbers to support service availability
☐ Remove restrictions on time allocated to each home visit to ensure needs are met
☐ Increase in available equipment
☐ Reduce cost to consumer

☐ Improve training opportunities for staff
☐ Other____

Q6.13 **Are you aware of any of the following in your area?**
☐ Hospital admissions extended due to in-home services unable/unavailable to support discharge
☐ Clients needing to attend medical clinics or outpatient clinics as no in-home services to provide medication administration
☐ Clients needing to attend medical clinics or outpatient clinics as no/insufficient in-home services available to assist with wound/catheter/stoma care
☐ Ambulance being called for assistance with pain/symptom control as community services unable to be contacted
☐ Respite in aged care facility as no/insufficient services available in-home to support hospital discharge
☐ End-of-life care provided in hospital as appropriate services unable to be provided in the home
☐ People relocating due to services being unable to provide the level of support needed in the home
☐ None apply

Q6.14 **How does your organisation provide information about relevant services to the community?**
☐ rely on staff member to discuss face-to-face
☐ staff member to discuss over phone
☐ pamphlets/booklets
☐ website
☐ advertise in local health and community centres
☐ community events
☐ rely on local community members to discuss
☐ other ____

Q6.15 **Consider the area that you provide community palliative care services to. Select how much you agree with the following statements**

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Existing health services meet the needs and expectations of people in this location	○	○	○	○	○
There is a need for people in this area to travel over 100km distances for some healthcare services	○	○	○	○	○
The need to travel long distances for some healthcare services influences decisions about treatment	○	○	○	○	○
The need to travel long distances for some healthcare services results in people relocating closer to services	○	○	○	○	○
People are supported to remain in their own home	○	○	○	○	○
Home location does not influence access to services	○	○	○	○	○
Communication and care provided is culturally and gender inclusive and respectful	○	○	○	○	○
Personal choices, preferences and goals of care are respected	○	○	○	○	○
Access is available for support 24/7	○	○	○	○	○
Quality of life is improved by remaining in own home	○	○	○	○	○
Ambulance transport and hospital admissions are reduced by community services provided	○	○	○	○	○
Patients and family members are included in all decision-making about care and services	○	○	○	○	○
Physical, emotional, spiritual and social support is provided	○	○	○	○	○
Services are provided promptly and when needed	○	○	○	○	○
Medication required can be accessed easily	○	○	○	○	○
The choice for end-of-life in the home and a home death is supported regardless of the location of the home	○	○	○	○	○
All services are affordable	○	○	○	○	○
Staff providing care have the training, knowledge and expertise to provide quality care	○	○	○	○	○
Choices for end-of-life care including hospice, home death and voluntary assisted dying are supported and clients are able to make informed decisions	○	○	○	○	○
Bereavement care is available as required	○	○	○	○	○
Family/caregiver stress and burnout is reduced with in-home services	○	○	○	○	○

Q6.16 Digital health, telehealth, eHealth and telemedicine are broad terms used interchangeably. This survey will use the term digital health to refer to the all the tools and services that are available to diagnose, treat, collect and share health information, including consultations with a healthcare provider that are conducted by phone or video rather than face-to-face.

How do you provide palliative care in the community? select all that apply

☐ Face-to-face in-home or clinic
☐ phone
☐ video
☐ email
☐ text
☐ other ____

Q6.17 **Why do you use digital health options?** Select all options that apply

☐ To reduce infection risk
☐ Improve support provided to patients/family members
☐ Reduces travel time for clinician
☐ Personal choice of patients/family members
☐ Service provided is not available face-to-face
☐ After hours support
☐ Personal choice of clinician/patient
☐ Face-to-face visit not required
☐ Family are able to be present during consultation
☐ Specialist input required but distance provides a barrier for timely input
☐ Other ____

Q6.18 **Have you experienced any problems with digital health options**? Please select all that apply

☐ No problems using digital health
☐ Lack of computer access/skills by patient/family members
☐ Personal preference of patient/family members for face-to-face service delivery only
☐ Poor mobile coverage in locations where I work
☐ Unreliable/non-existent internet access in locations where I work
☐ Digital options not offered by this organisation/serviced
☐ the service I provide requires a face-to-face visit
☐ Other ____

Q6.19 **How much you agree with the following**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Digital health is an important tool in ensuring regular communication with patients	○	○	○	○	○
I have the resources and confidence to use digital health options effectively	○	○	○	○	○
Telehealth consultations are an acceptable alternative to face-to-face consultations with medical professionals	○	○	○	○	○
Telehealth means that patients can access medical support that would not be readily accessible due to distance	○	○	○	○	○
I feel that patient's choice of place of care is supported with digital health options	○	○	○	○	○
Patients and family members are comfortable to remain at home knowing that they can access support at any time	○	○	○	○	○

Q6.20 **Overall, are you satisfied with the access to community palliative care provided in your location?**

○ Yes
○ No
○ Unsure
○ Prefer not to answer

End of Block: Health Professionals survey

Appendix E: PCA Consent

This administrative form
has been removed

Appendix F: PCA e-newsletter link

Research spotlight

eNewsletter

PalliativeCare
AUSTRALIA

16 February 2023

Yuma from Ngunnawal Country!

Palliative Care Australia (PCA) is delighted to bring you stories, news, events, and resources that support you and the work you do in your community - wherever you are!

● ● ●

PCA is located in Canberra on the land of the Ngunnawal People. PCA wishes to acknowledge the traditional owners of this land, the Ngunnawal People and their Elders past and present. PCA acknowledges and respects their continuing culture and the contribution they make to the life of this city and this region.

● ● ●

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Research spotlight

Participate in palliative care research:

James Cook University PhD Researcher is conducting a study to investigate the influence of counter-urbanisation on access to community palliative care services. Understanding issues to accessibility may contribute to recommendations to future policy. You will be required to complete a short survey which will take approximately 10 minutes to complete. All information collected is anonymous. Take the survey now.

To be eligible to participate you need to be over 18 years of age, a person receiving community palliative care, a family member or caregiver or a health professional providing community palliative care in any location in Australia. JCU HREC approval #H8936

If there are any questions/issues please contact shirley.papavasiliou@my.jcu.edu.au.

JAMES COOK UNIVERSITY
AUSTRALIA

Appendix G: Participant Information Sheet

PROJECT TITLE:

"Access and equity in Australian community palliative care services: the influence of peri-urban location"

You are invited to take part in a research project which aims to understand influences to community palliative care in those areas on the fringe of Australian major cities which are experiencing high population growth, termed peri-urban areas.

What is the research about?

Australians have shown a preference for receiving care in their own home, including end-of-life care and a home death. In home care has been found to improve quality of life for patients and assists family members and friends with the grieving process. In-home or community care includes face-to-face and digital health options. There are known challenges in provision of end-of-life care in a home setting, particularly in a rural area. Recent trends show people moving from metropolitan cities, with high growth evident in those areas within commuting distance to major cities. These peri-urban areas have the potential for increased challenges to accessing services due to location and corresponding influence on service availability and digital access.

Who is doing the research?

The study is being conducted by Principal Investigator Shirley Papavasiliou and will contribute to completion of a PhD by publication at James Cook University.

Who can take part in this research?

Health Professionals, including paid and unpaid, over 18 years of age, in any role which provides palliative care in the community.

Patients, family members and support persons, over 18 years of age, who have received, or are receiving, palliative care in the community.

What do I have to do?

If you agree to be involved in the study, you will be invited to complete an online survey. The survey will take approximately 10-15 minutes to complete.

This survey involves questions about how you access or provide access to community palliative care services.

Accessibility to services is complex and includes identifying palliative care needs, seeking services, reaching, obtaining, using, paying for and engaging with services. Access involves services being appropriate, that is quality services that meet the needs of users, when they are needed, and are culturally and socially acceptable. Services may be face-to-face or virtual.

Do I have to take part in this research?

Taking part in this study is completely voluntary. Any information obtained in connection with this research project will be anonymous. You will not be asked for your name or contact details (unless you request a copy of the survey results).

Any decision about participation in this study will not affect any current or future relationships with any health care professionals or organisations you are involved with as data is anonymous.

By completing the consent form at the start of the online survey, you are consenting to the use of your survey responses in this research. You may select not to answer any question you choose (not including the mandatory questions that ensure your eligibility) and you may withdraw from the survey at any time, without providing a reason, with no risk of repercussion. Please note that once you submit the survey, the researcher will not be able to delete your responses as the survey data is anonymous.

Are there any risks or inconveniences to taking part in this research?

You may find some questions about in-home or community palliative care may trigger an emotional response.

Prior to participating in this survey please remember that grief has no timeline. It can begin long before death arrives. It is not unusual for grief to be felt over an extended period of time, even for many years. Sometimes we may experience feelings of anxiety, dread, sadness, longing, regret, loneliness, thoughts of 'if only' and more.

Grief is not just accepting death, but the losses occurring as an illness progresses. Feelings may spring up unexpectedly or be triggered by an event or a memory. These triggers can re-kindle emotions and be upsetting or bring memories of great joy and gratitude for happier times.

If this survey is likely to trigger feelings that you may find upsetting, then please consider if you wish to continue. Please do not participate if you have a diagnosed mental health condition, are recently bereaved, experiencing chronic grief or are dealing with multiple traumas, due to possible risk of distress from participation.

If you do participate then you may decide to withdraw from the research at any time you choose. If you do not wish to answer a question, you may choose to not answer and go to the next question. You may also stop taking part in the study at any time and not submit, without explanation or prejudice.

If you experience any upset or distress because of your participation in this research project, please seek assistance from available services in your local area, or contact your

- palliative care service for support.
- GP to discuss the possibility of a Mental Health Care Plan.
- employer for available employee assistance programs or health and wellbeing programs that offer confidential counselling and support.
- education institution for available health and wellbeing programs that offer students confidential counselling and support.

Do not forget your community support network which includes; friends, family members, religious leader, coach, work colleague, community leaders.

If you or someone near you is in immediate danger:

- Call Emergency Services on 000; or
- Go to a hospital emergency department

If you are having suicidal thoughts and need someone to talk to:

- Call Lifeline on 13 11 14
- Call 13 Yarn for support for Aboriginal and Torres Strait Islander people at 13 92 76
- Talk to someone

Alternatively, you can contact several free services directly, including

- The Black Dog Institute
  Online resources
  www.blackdoginstitute.org.au/
- Beyond Blue
  1300 224 636
  www.beyondblue.org.au
- Lifeline Australia
  13 11 14
  www.lifeline.org.au/
- Palliative Care Australia (PCA)
  Online resources
  https://palliativecare.org.au/
- Trauma & Grief Network
  Focus on Indigenous support
  https://tgn.anu.edu.au/
- PCA Grief & Loss booklet
  https://palliativecare.org.au//wp-content/uploads/dlm_uploads/2015/05/PCA002_Understanding-Grief_W02.pdf

Are there any benefits to taking part in this research?

The researcher cannot guarantee or promise that you will receive any clear benefits to you personally from participating in this research. There is no payment for taking part in this research. However, a possible benefit may include feeling a sense of value by providing meaningful insights into your journey through palliative care provision which may assist in shaping future palliative care provision for individuals and families. This may or may not directly or indirectly affect health professionals role in palliative care provision.

What happens to the information I provide?

The intention is to publish and report the results of this research project. All information published will done in a way that will not identify any participant.

You have the right to receive feedback about the study results. There will be a question in the survey asking if you wish to receive results at the completion of the survey. Alternatively you could email the researcher and request results at Shirley.papavasiliou@my.jcu.edu.au. You will receive a response once the study is completed and data has been analysed.

Anonymous survey data will be collected and stored electronically on password protected, external hard drive and secure James Cook University (JCU) cloud-based facilities (OneDrive). Data will be retained for 5 years post publication and then permanently deleted from all storage devices.

All research in Australia involving humans is reviewed by a Human Research Ethics Committee (HREC). This research project has been approved by the JCU HREC.

Who do I contact if I have any questions, require further information or wish to provide feedback about this research?

Please contact the following people:

Principal Investigator: Shirley Papavasiliou
College: Business, Law & Governance
James Cook University
Email: Shirley.papavasiliou@my.jcu.edu.au

Supervisor: Associate Professor Carmen Reaiche
College: Business, Law & Governance
James Cook University
Email: carmen.reaiche@jcu.edu.au

Secondary Supervisor: Dr Reza Akbari
College: Business, Law & Governance
James Cook University
Email: reza.akbari@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

Appendix H: Grief Supports

Q1.2

Grief Supports *If the subject or any questions in this survey are likely to trigger feelings that you may find upsetting, then please consider if you wish to continue. Triggers may include some mental health diagnoses, being recently bereaved or receiving bereavement support for an extended period of time, or involved in other recent traumatic events such as bushfires or flooding. If you do participate then you may decide to withdraw from the research at any time you choose. If you do not wish to answer a question, you may choose to not answer and go to the next question. The only mandatory questions are the initial questions used to ensure your eligibility. You may also stop taking part in the study at any time and not submit, without explanation or prejudice.*

Prior to participating in this survey please remember that grief has no timeline. It can begin long before death arrives. It is not unusual for grief to be felt over an extended period of time, even for many years. Sometimes we may experience feelings of anxiety, dread, sadness, longing, regret, loneliness, thoughts of 'if only' and more. Grief is not just accepting death, but the losses occurring as an illness progresses. Feelings may spring up unexpectedly or be triggered by an event or a memory. These triggers can re-kindle emotions and be upsetting or bring memories of great joy and gratitude for happier times.

If you or someone near you is in immediate danger:

- Call Emergency Services on 000; or
- Go to a hospital emergency department If you are having suicidal thoughts and need someone to talk to:
- Call Lifeline on 13 11 14
- Call 13 Yarn for support for Aboriginal and Torres Strait Islander people at 13 92 76
- Talk to someone

If you become upset or distressed because of your participation in this research project, please seek assistance from available services in your local area, or contact your

- palliative care service for support.
- GP to discuss the possibility of a Mental Health Care Plan. This will entitle you to up to 10 Medicare rebated mental health sessions with a mental health professional, or
- employer for available employee assistance programs or health and wellbeing programs that offer confidential counselling and support.
- education institution for available health and wellbeing programs that offer confidential counselling and support.
- do not forget your community support network which includes; friends, family members, church minister or religious leader, coach, work colleague or community leader.

Alternatively, you can contact several free services directly, including

- The Black Dog Institute
- Beyond Blue1300 224 636
- Lifeline Australia 13 11 14
- Palliative Care Australia (PCA)
- Indigenous Trauma and Grief Network
- PCA Grief & Loss booklet

Appendix I: Quantitative Results

Summary survey access

Table 11 Summary Survey Access

Detail	***n***	***n***
Accessed survey link		182
Accessed Participant Information Sheet	21	
Accessed Grief Supports	32	
Declined Informed Consent		6
Opted out during survey		4
Removed when identified as working outside of Australia		1
Total submitted survey for analysis		171

Participants by group

Table 12 Participants by group

Group	**Peri-urban** ***n***	**Rural** ***n***	**Regional** ***n***	**Metropolitan** ***n***	**Total** ***n***
Patient	14	9	4	3	30
Family/caregiver	57	12	7	15	91
Health Professional	35	5	3	7	50
Total	106	26	14	25	171

Data analysis conducted using actual responses received for each question which is reflected in the findings, as:

- survey questions not required to identify participants and gain informal consent, were voluntary,
- responses identified as ‘unsure’ or ‘prefer not to answer’ were not included,
- responses identified as ‘other’ that provided qualitative data, were included in thematic analysis, and
- multiple responses were allowed for some questions.

Family Members/Care-givers group

Table 13 Question 2.1

Q2.1 Family - Your age group?										
Age	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
18-34 years	14.5	5	5.6	1	25.0	1	12.5	2	12.5	9
35-49 years	29.4	10	33.3	6	25.0	1	25.0	4	29.2	21
50-64 years	38.2	13	38.9	7	25.0	1	50.0	8	40.3	29
65+	17.7	6	22.2	4	25.0	1	12.5	2	18.0	13
Total	**47.2**	**34**	**25.0**	**18**	**5.6**	**4**	**22.2**	**16**	**100.0**	**72**

Table 14 Question 2.2

Q2.2 Family - How long have you been receiving community palliative care?										
Receiving care	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
<1 month	25.6	11	9.1	2	14.3	1	6.2	1	17.0	15
1-6 months	48.8	21	59.1	13	28.6	2	50.0	8	50.0	44
6-12 months	18.6	8	22.7	5	14.3	1	25.0	4	12.5	11
>1 years	7.0	3	9.1	2	42.8	3	18.8	3	12.5	11
Total	**48.9**	**43**	**25.0**	**22**	**7.9**	**7**	**18.2**	**16**	**100.0**	**88**

Table 15 Question 2.3

Q2.3 Family - What is your relationship to the person diagnosed with a life-limiting illness?										
Relationship	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Spouse	40.0	18	52.2	12	42.9	3	25.0	4	40.7	37
Child/Step-child	44.4	20	21.7	5	42.8	3	62.5	10	41.8	38
Sibling/extended family/ friend	15.6	7	26.1	6	14.3	1	12.5	2	17.6	16
Total	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**

Table 16 Question 2.4

Q2.4 Family - In what State/Territory are services provided?										
State/Territory	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Queensland	8.9	4	0	0	14.2	1	6.2	1	6.6	6
South Australia	66.7	30	91.3	21	28.6	2	37.5	6	64.8	59
NT and WA	0	0	0	0	0	0	0	0	0	0
ACT	4.4	2	0	0	0	0	0	0	2.2	2
New South Wales	8.9	4	0	0	42.9	3	25.0	4	12.1	11
Victoria	11.1	5	8.7	2	14.3	1	25.0	4	13.2	12
Tasmania	0	0	0	0	0	0	6.3	1	1.1	1
Total	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**

Table 17 Question 2.5

Q2.5 Family - How would you describe the area where community palliative care is provided?		
	%	*n*
Peri-urban	49.4	45
Rural	25.3	23
Regional	7.7	7
Metropolitan	17.6	16
Total	**100.0**	**91**

Table 18 Question 2.7

Q2.7 (Family) How much do you agree with the following statements?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
2.7(1) (Family) Existing health services were considered when selecting the home location										
Strongly disagree	28.9	13	39.1	9	28.6	2	18.7	3	29.6	27
Somewhat disagree	8.9	4	34.8	8	14.3	1	25.0	4	18.7	17
Neither agree/disagree	6.7	3	0	0	0	0	0	0	3.3	3
Somewhat agree	28.9	13	26.1	6	42.8	3	50.0	8	33.0	30
Strongly agree	26.6	12	0	0	4.3	1	6.3	1	15.4	14
Total	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**
2.7(2) (Family) The location was selected as health services were in the planning development stage										
Strongly disagree	60.0	27	60.9	14	42.9	3	75.0	3	61.5	56
Somewhat disagree	15.6	7	21.7	5	28.6	2	18.8	3	18.7	17
Neither agree/disagree	4.4	2	8.7	2	14.3	1	6.2	1	6.6	6
Somewhat agree	17.8	8	8.7	2	14.3	1	0	0	12.1	11
Strongly agree	2.2	1	0	0	0	0	0	0	1.1	1
Total	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**
2.7(3) (Family) Consideration was given to accessing servicers for possible future health needs (eg hospice, aged care facility) when selecting the home location										
Strongly disagree	53.5	24	56.5	13	42.8	3	56.3	9	53.8	49
Somewhat disagree	22.2	10	26.2	6	14.3	1	12.5	2	20.9	19
Neither agree/disagree	0	0	4.3	1	0	0	0	0	1.1	1
Somewhat agree	11.2	5	13.0	3	28.6	2	18.7	3	14.3	13
Strongly agree	13.3	6	0	0	14.3	1	12.5	2	9.9	9
Total	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**
2.7(4) (Family) There was an expectation that health services were accessible										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	0	0	0	0	0	0	0	0	0	0
Neither agree/disagree	0	0	4.3	1	0	0	0	0	1.1	1
Somewhat agree	20.0	9	52.2	12	28.6	2	12.5	2	27.5	25
Strongly agree	80.0	36	43.5	10	71.4	5	87.5	14	71.4	65
Total	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**

Table 19 Question 2.8

Q2.8 Family - How did you receive/find information about available services? Select all that apply.										
Source	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Health Professional	64.4	29	56.5	13	42.9	3	81.3	13	63.7	58
Referral	77.8	35	73.9	17	57.1	4	7.5	12	74.7	68
Friends/family	22.2	10	21.8	5	42.9	3	18.8	3	23.1	21
Pamphlets	4.4	2	0	0	0	0	0	0	2.2	2
Online forums	6.7	3	4.3	1	42.9	3	18.8	3	11.0	10
Support group	15.6	7	4.3	1	28.6	2	43.8	7	18.7	17
Google	15.6	7	8.7	2	0	0	31.2	5	15.4	14
Experience	4.4	2	4.3	1	0	0	0	0	3.3	3
Not involved	0	0	4.3	1	0	0	0	0	1.1	1
Other	26.7	12	17.4	4	28.6	2	12.5	2	22.0	20
Total responses	**50.0**	**107**	**21.0**	**45**	**8.0**	**17**	**21.0**	**45**	**100.0**	**214**

Table 20 Question 2.9

Q2.9 Family - Did you find it difficult to find information about service/s and identify what was needed?

	Peri-urban		Rural		Regional		Metropolitan		Total responses	
	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*
Yes	60.0	27	65.0	13	71.4	5	66.7	10	63.2	55
No	40.0	18	35.0	7	28.6	2	33.3	5	36.8	32
Total	**51.7**	**45**	**23.0**	**20**	**8.0**	**7**	**17.3**	**15**	**100.0**	**87**

Table 21 Question 2.10

Q2.10 Family - Did you find it difficult to access identified services when required?

	Peri-urban		Rural		Regional		Metropolitan		Total responses	
	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*
Yes	72.7	32	80.0	16	71.4	5	60.0	9	72.1	62
No	27.2	12	20.0	4	28.6	2	40.0	6	27.9	24
Total	**51.2**	**44**	**23.3**	**20**	**8.1**	**7**	**17.4**	**15**	**100.0**	**86**

Table 22 Question 2.10

Q2.10 Family - Did you find it difficult to access identified services when required?

	Minimum	Maximum	Mean	Std Deviation	Variance	Count
False	1.00	2.00	1.75	0.43	0.19	4
True	1.00	2.00	1.26	0.44	0.19	82

Table 23 Question 2.11

Q2.11 Family - Please select all the services that you know are being received or have been received in the home. Select all that apply multiple responses allowed

Services	Peri-urban		Rural		Regional		Metropolitan		Total responses	
	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*
Unsure	11.1	5	8.7	2	0	0	0	0	7.7	7
Specialist Palliative Care (SPC)	73.3	33	47.8	11	42.9	3	43.7	7	59.3	54
Community Nursing	24.4	11	39.1	9	28.6	2	43.7	7	31.9	29
Personal care	33.3	15	34.8	8	57.1	4	62.5	10	40.7	37
Transport	8.9	4	0	0	14.3	1	37.5	6	12.1	11
Occupational Therapy	29.9	13	39.1	9	14.3	1	25.0	4	29.7	27
Psychologist	4.4	2	4.3	1	14.3	1	12.5	2	6.6	6
Social Worker	29.3	13	34.8	8	28.6	2	12.5	2	27.5	25
Physiotherapy	4.4	2	21.7	5	14.3	1	6.2	1	9.9	9
Dietician/Speech Pathology	11.1	5	21.7	5	28.6	2	12.5	2	15.4	14
Palliative Care Specialist	8.9	4	21.7	5	0	0	12.5	2	12.1	11
Spiritual	0	0	2.2	1	0	0	6.2	1	2.2	2
Volunteers	6.7	3	0	0	0	0	0	0	3.3	3

Complementary	0	0	0	0	0	0	6.2	1	1.1	1
House/Garden care	37.8	17	17.4	4	57.1	4	56.2	9	37.4	34
Home maintenance	8.9	4	8.7	2	14.3	1	43.7	7	15.4	14
Equipment	42.2	19	47.8	11	42.9	3	56.2	9	46.2	42
ACD assist	13.3	6	17.4	4	0	0	12.5	2	13.2	12
Financial	2.2	1	18.0	3	14.3	1	12.5	2	7.7	7
GP	11.1	5	13.0	3	42.9	3	31.2	5	17.6	16
End-of-life care	11.1	5	17.4	4	0	0	18.7	3	2.7	12
Bereavement	13.3	6	4.3	1	0	0	12.5	2	9.9	9
Family/friends	26.7	12	39.1	9	85.7	6	25.0	4	34.1	31
Other	40.0	18	47.8	11	47.1	4	25.0	4	40.6	37
Total responses	**45.1**	**203**	**25.8**	**116**	**8.7**	**39**	**20.4**	**92**	**100.0**	**450**
Total respondents	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**

Table 24 Question 2.12

Q2.12 Family - Do services received meet needs and expectations?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Yes	24.4	11	21.7	5	28.6	2	18.7	3	23.1	21
Partially	35.6	16	47.8	11	0	0	43.8	7	37.4	34
No	40.0	18	30.4	7	71.4	5	37.5	6	39.5	36
Total	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**

Table 25 Question 2.13

Q2.13 Family - If you are not using all services that are available, why not? **Select all that apply**							**Multiple responses allowed**			
Reasons	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Not required	13.3	6	13.0	3	14.3	1	18.7	3	14.3	13
Family provide	33.3	15	30.0	7	57.1	4	12.5	2	30.8	28
Not happy with services previously	2.2	1	0	0	14.3	1	6.2	1	3.3	3
Not available when I want	42.2	19	26.1	6	28.6	2	31.2	5	35.2	32
Not available as often as I want	40.0	18	30.4	7	42.9	3	25.0	4	35.2	32
Not available home location	22.2	10	60.9	14	42.9	3	0	0	29.7	27
No resources available	22.2	10	39.1	9	42.9	3	0	0	24.2	22
Too expensive	20.0	9	13.0	3	14.3	1	12.5	2	16.5	15
Using all we know about	11.1	5	4.3	1	28.6	2	12.5	2	11.0	10
Personal choice to use/not use	6.7	3	0	0	0	0	0	0	3.3	3
Unsure reason why	26.7	12	17.4	4	28.6	2	18.7	3	23.1	21
Total responses	**52.4**	**108**	**26.2**	**54**	**10.7**	**22**	**10.7**	**22**	**100.0**	**206**
Total respondents	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**

Table 26 Question 2.14

Q2.14 Family - Please select any of the following that apply										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Q2.14(1) (Family) One or more hospital stays have been extended as services unavailable in-home to support discharge	85.7	30	38.9	7	66.7	4	90.9	10	72.9	51
Q2.14(2) (Family) Needed to attend clinic or hospital outpatients for medication administration as in-home services unavailable	17.1	6	11.1	2	33.3	2	0	0	14.3	10
Q2.14(3) (Family) Needed to attend clinic or hospital outpatients for assistance with wound/catheter/ stoma care as in-home services unavailable	17.1	6	22.2	4	16.7	1	9.1	1	17.1	12
Q2.14(4) (Family) Needed to call an ambulance for assistance with pain/symptom control as unable to contact community services	51.4	18	55.6	10	50.0	3	27.3	3	48.6	34
Q2.14(5) (Family) Respite in aged care facility was required as in-home services unavailable to support hospital discharge	20.0	7	11.1	2	0	0	0	0	12.9	9
Q2.14(6) (Family) Will need to transfer to hospital for end-of-life care to remain in local area	51.4	18	77.8	14	100.0	6	27.3	3	58.6	41
Total respondents	**50.0**	**35**	**25.7**	**18**	**8.6**	**6**	**15.7**	**11**	**100.0**	**70**

Table 27 Question 2.15

Q2.15 Family - What is the longest distance your family member has needed to travel for healthcare services?										
Distance	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Services local	0	0	0	0	0	0	37.5	6	6.6	6
10-50 km	11.1	5	4.3	1	28.6	2	56.2	9	18.7	17
50-100 km	71.1	32	34.8	8	0	0	0	0	44.0	40
100-150 km	8.9	4	34.8	8	14.3	1	0	0	14.3	13
150-250 km	2.2	1	26.1	6	0	0	0	0	7.7	7
Over 250 km	6.7	3	0	0	57.1	4	6.3	1	8.8	8
Unsure	0	0	0	0	0	0	0	0	0	0
Total	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**

Table 28 Question 2.16

Q2.16 Family - What barriers to accessing services do you believe apply in your situation?
Select all that apply **Multiple responses allowed**

Barriers	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
No barriers	8.9	4	4.3	1	0	0	25.9	4	9.9	9
Under 65 years	22.2	10	17.4	4	28.6	2	37.5	6	24.2	22
Distance travel to home	33.3	15	82.6	19	57.1	4	0	0	41.8	38
Lack resources	35.5	16	52.2	12	28.6	2	6.2	1	34.1	31
Time taken to start	22.2	10	4.3	1	0	0	0	0	12.1	11
Distance travel from	28.9	13	65.2	15	57.1	4	0	0	35.2	32
Diversity	0	0	0	0	0	0	6.2	1	1.1	1
Language	2.2	1	0	0	0	0	6.2	1	2.2	2
Palliative care stigma	6.7	3	0	0	0	0	6.2	1	4.4	4
Behavioural challenges	11.1	5	0	0	28.6	2	0	0	7.7	7
Financial	8.9	4	21.7	5	0	0	6.2	1	11.0	10
Personal choice	8.9	4	8.7	2	0	0	0	0	6.6	6
Beyond scope of local providers	13.3	6	39.1	9	42.8	3	0	0	19.8	18
No need for services	0	0	0	0	0	0	6.2	1	1.1	1
Total responses	**47.5**	**91**	**35.4**	**68**	**8.8**	**17**	**8.3**	**16**	**1.0**	**192**
Total respondents	**49.4**	**45**	**25.3**	**23**	**7.7**	**7**	**17.6**	**16**	**100.0**	**91**

Table 29 Question 2.17

Q2.17 Family - Thinking about transport from home to the location of some health services, please select all statements that apply to your family. What is your relationship to the person diagnosed with a life-limiting illness?

	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Q2.17(1) Family - The time/distance involved has influenced decisions about attending appointments, treatment or tests	55.8	24	69.6	16	71.4	5	6.3	1	51.7	46
Q2.17(2) Family - The time/distance has influenced the home location of the person requiring care in the home	32.6	14	17.4	4	14.3	1	6.3	1	22.5	20
Q2.17(3) Family - Travel time/distance is not a problem	9.3	4	4.3	1	0	0	18.8	3	9.0	8
Q2.17(4) Family - Travel any distance is difficult (exhausting, pain, discomfort, etc)	79.1	34	82.6	19	100	7	62.5	10	78.7	70
Q2.17(5) Family - Private transport is difficult due to cost of petrol, parking, lost wages and time involved	81.4	35	78.3	18	100	7	43.8	7	75.3	67
Q2.17(6) Family - Public transport is not an option	86.0	37	96.3	21	85.7	6	56.3	9	82.0	73
Q2.17(7) Family - Community car is not available/expensive/not an option	46.5	20	60.9	14	57.1	4	25.0	4	47.2	42

Q2.17(8) Family - All health services are provided in the home	2.3	1	4.3	1	0	0	6.3	1	3.4	3
Q2.17(9) Family - All health services are provided locally	2.3	1	4.3	1	42.9	3	31.3	5	11.2	10
Q2.17(10) Family - Need to relocate to be closer to services that will provide a higher level of care	39.5	17	21.7	5	42.9	3	0	0	28.1	25
Total respondents	**48.3**	**43**	**25.8**	**23**	**7.9**	**7**	**18.0**	**16**	**100.0**	**89**

Table 30 Question 2.18

Q2.18 Family - How much do you agree with the following statements?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
2.18(1) (Family) The choice to remain in own home has been supported										
Strongly disagree	34.1	15	13.0	3	0	0	7.6	1	1.8	19
Somewhat disagree	13.6	6	17.4	4	57.1	4	23.1	3	19.5	17
Neither agree/disagree	11.4	5	8.7	2	0	0	23.1	3	11.5	10
Somewhat agree	9.1	4	21.7	5	42.9	3	23.1	3	17.2	15
Strongly agree	31.8	14	39.1	9	0	0	23.1	3	29.9	26
Total	**50.6**	**44**	**26.4**	**23**	**8.1**	**7**	**14.9**	**13**	**100.0**	**87**
2.18(2) (Family) Personal choices, preferences and goals of care have been respected										
Strongly disagree	23.3	10	13.0	3	0	0	7.7	1	16.3	14
Somewhat disagree	18.6	8	21.7	5	42.9	3	30.8	4	23.3	20
Neither agree/disagree	9.3	4	8.8	2	0	0	15.4	2	9.3	8
Somewhat agree	20.9	9	13.0	3	57.1	4	23.1	3	22.1	19
Strongly agree	27.9	12	43.5	10	0	0	23.0	3	29.0	25
Total	**50.0**	**45**	**26.8**	**23**	**8.1**	**7**	**15.1**	**13**	**100.0**	**86**
2.18(3) (Family) All communication and information provided has been respectful and appropriate for our needs										
Strongly disagree	16.3	7	8.7	2	0	0	0	0	10.6	9
Somewhat disagree	29.3	4	13.0	3	28.6	2	16.7	2	12.9	11
Neither agree/disagree	13.8	6	21.7	5	28.6	2	41.6	5	21.2	18
Somewhat agree	32.6	14	8.7	2	28.6	2	16.7	2	23.5	20
Strongly agree	27.9	12	47.8	11	4.2	1	25.0	3	31.8	27
Total	**50.6**	**43**	**27.1**	**23**	**8.2**	**7**	**14.1**	**12**	**100.0**	**85**
2.18(4) (Family) Access to support is available 24 hours a day 7 days a week										
Strongly disagree	31.8	14	17.4	4	0	0	0	0	20.9	18
Somewhat disagree	36.4	16	34.8	8	71.4	5	33.3	4	38.4	33
Neither agree/disagree	15.9	7	8.7	2	0	0	16.7	2	12.8	11
Somewhat agree	4.5	2	21.7	5	28.6	2	25.0	3	13.9	12
Strongly agree	11.4	5	17.4	4	0	0	25.0	3	14.0	12
Total	**51.2**	**44**	**26.7**	**23**	**8.1**	**7**	**14.0**	**12**	**100.0**	**86**
2.18(5) (Family) Quality of life has been improved by community services										
Strongly disagree	25.0	11	8.7	2	0	0	0	0	14.9	13
Somewhat disagree	13.6	6	17.4	4	42.8	3	23.1	3	18.4	16
Neither agree/disagree	13.6	6	21.7	5	14.3	1	38.5	5	19.6	17
Somewhat agree	25.0	11	17.4	4	42.3	3	15.4	2	23.0	20
Strongly agree	22.7	10	34.8	8	0	0	23.1	3	24.1	21
Total	**50.6**	**44**	**26.4**	**23**	**8.1**	**7**	**14.9**	**13**	**100.0**	**87**
2.18(6) (Family) The need for ambulance transport and admission to hospital has been reduced by in-home services										
Strongly disagree	23.8	10	18.2	4	14.3	1	0	0	18.1	15
Somewhat disagree	31.2	13	36.4	8	42.9	3	41.7	5	34.9	29
Neither agree/disagree	19.0	8	13.6	3	28.6	2	25.0	3	19.3	16

Somewhat agree	9.5	4	18.2	4	14.3	1	8.3	1	12.0	10
Strongly agree	16.7	7	13.6	3	0	0	25.0	3	15.7	13
Total	**50.6**	**42**	**26.5**	**22**	**8.4**	**7**	**14.5**	**12**	**100.0**	**83**
2.18(7) (Family) Family members have been included in all decision-making about care and services										
Strongly disagree	23.8	10	8.7	2	14.3	1	0	0	15.5	13
Somewhat disagree	16.7	7	13.0	3	42.9	3	16.7	2	17.9	15
Neither agree/disagree	11.9	5	26.1	6	14.3	1	41.7	5	20.2	17
Somewhat agree	28.6	12	13.0	3	14.3	1	16.7	2	21.4	18
Strongly agree	19.0	8	39.1	9	14.3	1	25.0	3	25.0	21
Total	**50.0**	**42**	**27.4**	**23**	**8.3**	**7**	**14.3**	**13**	**100.0**	**84**
2.18(8) (Family) Physical symptoms are managed in the home										
Strongly disagree	25.6	11	21.7	5	0	0	16.7	2	21.2	18
Somewhat disagree	30.2	13	17.4	4	57.1	4	25.0	3	28.2	24
Neither agree/disagree	13.9	6	8.7	2	14.3	1	25.0	3	14.1	12
Somewhat agree	13.9	6	39.1	9	14.3	1	0	0	18.8	16
Strongly agree	16.3	7	13.0	3	14.3	1	33.3	4	17.7	15
Total	**50.6**	**43**	**27.1**	**23**	**8.2**	**7**	**14.1**	**12**	**100.0**	**85**
2.18(9) (Family) Support has been provided with advance care planning, completing will and grief counselling										
Strongly disagree	34.9	15	9.1	2	0	0	7.7	1	21.2	18
Somewhat disagree	30.2	13	22.7	5	57.2	4	46.2	6	32.9	28
Neither agree/disagree	6.9	3	9.1	2	14.3	1	15.4	2	9.4	8
Somewhat agree	14.0	6	40.9	9	28.5	2	7.7	1	21.2	18
Strongly agree	14.0	6	18.2	4	0	0	23.0	3	15.3	13
Total	**50.6**	**43**	**25.9**	**22**	**8.2**	**7**	**15.3**	**13**	**100.0**	**85**
2.18(10) (Family) Financial assistance needed has been provided										
Strongly disagree	40.9	18	17.4	4	0	0	16.7	2	27.9	24
Somewhat disagree	27.3	12	17.4	4	71.0	5	50.0	6	31.4	27
Neither agree/disagree	15.9	7	26.1	6	14.3	1	8.3	1	17.4	15
Somewhat agree	6.8	3	34.8	8	14.3	1	0	0	14.0	12
Strongly agree	9.1	4	4.3	1	0	0	25.0	3	9.3	8
Total	**51.2**	**44**	**26.7**	**23**	**8.1**	**7**	**14.0**	**12**	**100.0**	**86**
2.18(11) (Family) All support and education required by family members to provide safe, quality care, including end-of-life care and/or home death has been provided										
Strongly disagree	32.6	14	13.0	3	14.3	1	15.4	2	23.2	20
Somewhat disagree	27.9	12	21.7	5	42.0	3	30.7	4	27.9	24
Neither agree/disagree	4.6	2	17.4	4	28.6	2	23.1	3	12.8	11
Somewhat agree	20.9	9	17.4	4	14.3	1	7.7	1	17.4	15
Strongly agree	14.0	6	30.4	7	0	0	23.1	3	18.6	16
Total	**50.0**	**43**	**26.7**	**23**	**8.1**	**7**	**15.2**	**13**	**100.0**	**86**
2.18(12) (Family) All services have been provided promptly and when needed										
Strongly disagree	38.6	17	18.2	4	14.3	1	16.7	2	28.2	24
Somewhat disagree	27.3	12	31.8	7	42.8	3	33.3	4	30.6	26
Neither agree/disagree	4.5	2	4.5	1	14.3	1	16.7	2	7.1	6
Somewhat agree	11.4	5	27.3	6	28.6	2	8.3	1	16.5	14
Strongly agree	18.2	8	18.2	4	0	0	25.0	3	17.6	15
Total	**51.8**	**44**	**25.9**	**22**	**8.2**	**7**	**14.1**	**12**	**100.0**	**85**
2.18(13) (Family) Medication is available locally										
Strongly disagree	2.4	1	8.7	2	0	0	0	0	3.5	3
Somewhat disagree	0	0	30.4	7	14.3	1	7.7	1	10.6	9
Neither agree/disagree	16.7	7	17.4	4	0	0	0	0	12.9	11
Somewhat agree	57.1	24	17.4	8	85.7	6	38.5	5	50.6	43
Strongly agree	23.8	10	8.7	2	0	0	53.8	7	22.4	19
Total	**49.4**	**42**	**27.1**	**23**	**8.2**	**7**	**15.3**	**13**	**100.0**	**85**
2.18(14) (Family) Choices for end-of-life care including hospice, home death and voluntary assisted dying, have been supported and have enabled informed decisions										
Strongly disagree	34.1	15	17.4	4	14.3	1	23.1	3	26.4	23
Somewhat disagree	25.0	11	34.8	8	71.4	5	46.1	6	34.5	30

Neither agree/disagree	4.6	2	8.7	2	0	0	0	0	4.6	4
Somewhat agree	13.6	6	17.4	4	14.3	1	7.7	1	13.8	12
Strongly agree	22.7	10	21.8	5	0	0	23.1	3	20.7	18
Total	**50.6**	**44**	**26.4**	**23**	**8.1**	**7**	**14.9**	**13**	**100.0**	**87**
2.18(15) (Family) Available services are affordable										
Strongly disagree	11.9	5	9.1	2	0	0	8.3	1	9.7	8
Somewhat disagree	16.7	7	27.3	6	42.9	3	8.3	1	20.5	17
Neither agree/disagree	40.5	17	36.4	8	28.6	2	41.7	5	38.5	32
Somewhat agree	19.0	8	9.1	2	28.6	2	16.7	2	16.9	14
Strongly agree	1.9	5	18.2	4	0	0	25.0	3	14.4	12
Total	**50.6**	**42**	**26.5**	**22**	**8.4**	**7**	**14.5**	**12**	**100.0**	**83**
2.18(16) (Family) Staff providing care have the training, knowledge and expertise to provide quality of care needed										
Strongly disagree	9.5	4	13.6	3	0	0	0	0	8.4	7
Somewhat disagree	4.8	2	18.2	4	14.3	1	8.3	1	9.6	8
Neither agree/disagree	23.8	10	13.6	3	28.6	2	41.7	5	24.1	20
Somewhat agree	40.5	17	22.7	5	42.9	3	25.0	3	33.8	28
Strongly agree	21.4	9	31.8	7	14.3	1	25.0	3	24.1	20
Total	**50.6**	**42**	**26.5**	**22**	**8.4**	**7**	**14.5**	**12**	**100.0**	**83**
2.18(17) (Family) Choice of provider and/or staff who attend home visits is provided										
Strongly disagree	19.0	8	27.3	6	14.3	1	8.3	1	19.3	16
Somewhat disagree	33.3	14	31.8	7	57.1	4	50.0	6	37.4	31
Neither agree/disagree	31.0	13	22.7	5	0	0	16.7	2	24.1	20
Somewhat agree	4.8	2	18.2	4	28.6	2	0	0	9.6	8
Strongly agree	11.9	5	0	0	0	0	25.0	3	9.6	8
Total	**50.6**	**42**	**26.5**	**22**	**8.4**	**7**	**14.5**	**12**	**100.0**	**83**
2.18(18) (Family) Family/caregiver stress and burnout has been reduced with service provision										
Strongly disagree	29.5	13	18.2	4	14.3	1	23.1	3	24.4	21
Somewhat1 disagree	31.8	14	22.7	5	57.1	4	38.5	5	32.6	28
Neither agree/disagree	6.8	3	9.1	2	0	0	15.4	2	8.1	7
Somewhat agree	6.8	3	18.2	4	28.6	2	0	0	10.5	9
Strongly agree	25.0	11	31.8	7	0	0	23.1	3	24.4	21
Total	**51.2**	**44**	**25.6**	**22**	**8.1**	**7**	**15.1**	**13**	**100.0**	**86**
2.18(19) (Family) Patient/family have good relationships with health professionals involved in care										
Strongly disagree	14.0	6	9.1	2	0	0	0	0	9.4	8
Somewhat disagree	9.3	4	13.6	3	0	0	15.4	2	10.6	9
Neither agree/disagree	14.0	6	18.2	4	28.6	2	30.8	4	18.8	16
Somewhat agree	30.2	13	9.1	2	42.9	3	15.4	2	23.6	20
Strongly agree	32.5	14	50.0	11	28.6	2	38.5	5	37.6	32
Total	**50.6**	**43**	**25.9**	**22**	**8.2**	**7**	**15.3**	**13**	**100.0**	**85**

Table 31 Question 2.18 (Descriptive Statistics)

Q2.18 Family - How much do you agree with the following statements?

	n	**min**	**max**	**mean**	**SD**	**Variance**	**Confidence Interval**
2.18(1) (Family) The choice to remain in own home has been supported							
Peri-Urban	44	1	5	2.9	1.7	2.8	0.25
Rural	23	1	5	3.6	1.5	2.1	0.30
Regional	7	2	4	2.8	1.0	1.0	0.40
Metro	13	1	5	3.3	1.3	1.6	0.40
Total	87	1	5	3.2	1.4	1.9	0.40
2.18(2) (Family) Personal choices, preferences and goals of care have been respected							
Peri-Urban	45	1	5	3.1	1.6	2.4	0.23
Rural	23	1	5	3.5	1.5	2.3	0.31
Regional	7	2	4	3.1	1.0	1.0	0.40
Metro	13	1	5	3.2	1.3	1.3	0.40
Total	86	1	5	3.2	1.4	1.8	0.30

2.18(3) (Family) All communication and information provided has been respectful and appropriate for our needs							
Peri-Urban	43	1	5	3.5	1.4	2.0	0.20
Rural	23	1	5	3.7	1.4	1.9	0.30
Regional	7	2	5	3.2	1.0	1.1	0.40
Metro	12	2	5	3.5	1.0	1.1	0.30
Total	85	1	5	3.5	1.2	1.5	0.30
2.18(4) (Family) Access to support is available 24 hours a day 7 days a week							
Peri-Urban	44	1	5	2.3	1.3	1.6	0.20
Rural	23	1	5	2.9	1.4	1.9	0.30
Regional	7	2	4	3.3	1.0	1.1	0.40
Metro	12	2	5	3.5	1.1	1.0	0.30
Total	86	1	5	3.0	1.2	1.4	0.30
2.18(5) (Family) Quality of life has been improved by community services							
Peri-Urban	44	1	5	3.1	1.5	2.3	0.20
Rural	23	1	5	3.5	1.3	1.8	0.30
Regional	7	2	4	3.1	0.9	0.9	0.30
Metro	13	2	5	3.5	1.1	1.3	0.30
Total	87	1	5	3.3	1.2	1.6	0.30
2.18(6) (Family) The need for ambulance transport and admission to hospital has been reduced by in-home services							
Peri-Urban	42	1	5	2.6	1.4	1.9	0.20
Rural	22	1	5	2.5	1.2	1.4	0.30
Regional	7	1	4	2.7	1.3	1.6	0.50
Metro	12	2	5	3.5	1	1.1	0.30
Total	83	1	5	2.8	1.2	1.5	0.30
2.18(7) (Family) Family members have been included in all decision-making about care and services							
Peri-Urban	42	1	5	3.0	1.5	2.2	0.20
Rural	23	1	5	3.6	1.3	1.8	0.30
Regional	7	1	5	2.7	1.3	1.6	0.50
Metro	13	2	5	3.5	1	1.4	0.30
Total	84	1	5	3.2	1.3	1.8	0.30
2.18(8) (Family) Physical symptoms are managed in the home							
Peri-Urban	43	1	5	2.7	1.4	2.0	0.20
Rural	23	1	5	3.0	1.4	2.0	0.30
Regional	7	2	5	2.9	1.1	1.2	0.40
Metro	12	1	5	3.1	1.4	1.9	0.40
Total	85	1	5	2.9	1.3	1.8	0.30
2.18(9) (Family) Support has been provided with advance care planning, completing will and grief counselling							
Peri-Urban	43	1	5	2.4	1.4	2.0	0.20
Rural	22	1	5	3.4	1.3	1.6	0.30
Regional	7	2	5	2.7	0.9	0.8	0.30
Metro	13	1	5	2.9	1.3	1.8	0.40
Total	85	1	5	2.8	1.2	1.6	0.30
2.18(10) (Family) Financial assistance needed has been provided							
Peri-Urban	44	1	5	2.2	1.3	1.6	0.20
Rural	23	1	5	2.9	1.2	1.4	0.20
Regional	7	2	4	2.4	0.7	0.5	0.30
Metro	12	1	5	2.7	1.4	2.0	0.40
Total	86	1	5	2.6	1.2	1.4	0.30
2.18(11) (Family) All support and education required by family members to provide safe, quality care, including end-of-life care and/or home death has been provided							
Peri-Urban	43	1	5	2.6	1.5	2.2	0.20
Rural	23	1	5	3.3	1.4	2.0	0.30
Regional	7	1	4	2.4	0.9	0.8	0.30
Metro	13	1	5	2.9	1.4	1.9	0.40
Total	86	1	5	2.8	1.3	1.7	0.30
2.18(12) (Family) All services have been provided promptly and when needed							
Peri-Urban	44	1	5	2.4	1.5	2.3	1.50
Rural	22	1	5	2.9	1.3	1.5	0.20
Regional	7	1	4	2.4	0.9	0.8	0.30
Metro	12	1	5	2.9	1.4	2.0	0.40

Total	85	1	5	2.7	1.3	1.7	0.60
2.18(13) (Family) Medication is available locally							
Peri-Urban	42	1	5	4.0	0.8	0.6	0.10
Rural	23	1	5	3.0	1.2	1.3	0.20
Regional	7	1	4	3.7	0.7	0.5	0.30
Metro	13	1	5	4.4	0.8	0.7	0.20
Total	85	1	5	3.8	0.9	0.8	0.20
2.18(14) (Family) Choices for end-of-life care including hospice, home death and voluntary assisted dying, have been supported and have enabled informed decisions							
Peri-Urban	44	1	5	2.7	1.6	2.5	0.20
Rural	23	1	5	2.9	1.4	2.1	0.30
Regional	7	1	4	2.1	0.8	0.7	0.30
Metro	12	1	5	3.4	1.2	1.4	0.30
Total	83	1	5	2.8	1.3	1.7	0.30
2.18(15) (Family) Available services are affordable							
Peri-Urban	42	1	5	3.0	1.1	1.3	0.20
Rural	22	1	5	3.0	1.2	1.5	0.30
Regional	7	2	4	2.9	0.8	0.7	0.30
Metro	12	1	5	3.4	1.2	1.4	0.30
Total	83	1	5	3.1	1.1	1.2	0.30
2.18(16) (Family) Staff providing care have the training, knowledge and expertise to provide quality of care needed							
Peri-Urban	42	1	5	3.6	1.2	1.3	0.20
Rural	22	1	5	3.4	1.4	2.0	0.30
Regional	7	2	5	3.6	0.9	0.3	0.90
Metro	12	2	5	3.7	0.9	0.9	0.30
Total	83	1	5	3.6	1.1	1.2	0.40
2.18(17) (Family) Choice of provider and/or staff who attend home visits is provided							
Peri-Urban	42	1	5	2.6	1.2	1.4	0.20
Rural	22	1	4	2.3	1.1	1.1	0.30
Regional	7	1	4	2.4	1	1.1	0.40
Metro	12	1	4	3.7	0.9	0.9	0.30
Total	83	1	5	2.8	1.1	1.1	0.30
2.18(18) (Family) Family/caregiver stress and burnout has been reduced with service provision							
Peri-Urban	44	1	5	2.7	1.6	2.5	0.20
Rural	22	1	5	2.3	1.1	1.1	0.20
Regional	7	1	4	2.4	1	1.1	0.40
Metro	13	1	5	2.6	1.4	2.0	0.40
Total	86	1	5	2.5	1.3	1.7	0.30
2.18(19) (Family) Patient/family have good relationships with health professionals involved in care							
Peri-Urban	43	1	5	3.6	1.4	1.9	0.20
Rural	22	1	5	3.8	1.4	2.0	0.30
Regional	7	3	5	4.0	0.8	0.6	0.30
Metro	13	2	5	3.8	1.1	1.2	0.30
Total	85	1	5	3.8	1.2	1.4	0.30

Table 32 Question 2.19

Q2.19 Family - How are palliative care services provided in your home? Select all that apply							**Multiple responses allowed**			
Methods	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***N***	**%**	***n***	**%**	***n***
Face-to-face	86.0	37	78.3	18	85.7	6	68.7	11	80.9	72
Phone	60.5	26	78.3	18	71.4	5	26.1	6	61.8	55
Video	18.6	8	43.5	10	42.9	3	18.8	3	27.0	24
Email	0	0	4.3	1	0	0	0	0	1.1	1
Text	11.6	5	17.4	4	0	0	12.5	2	12.3	11
Apps	0	0	4.3	1	0	0	0	0	1.1	1
Total respondents	**48.3**	**43**	**25.8**	**23**	**7.9**	**7**	**18.0**	**16**	**100.0**	**89**
Total responses	**46.3**	**76**	**31.8**	**23**	**7.9**	**7**	**18.0**	**16**	**100.0**	**164**

Table 33 Question 2.20

Q2.20 Family - Have you experienced any problems with digital health options? **Select all that apply**							**Multiple responses allowed**			
Methods	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
No problems	44.2	19	17.4	4	57.1	4	68.8	11	42.7	38
No access/skill	11.6	5	8.7	2	0	0	0	0	7.9	7
Do not use	9.3	4	8.7	2	0	0	6.2	1	7.9	7
Poor mobile	11.6	5	60.9	14	0	0	0	0	21.3	19
Poor internet	9.3	4	47.8	11	0	0	0	0	16.9	15
Digital not offered	23.3	10	13.0	3	14.3	1	18.8	3	19.1	17
Total respondents	**48.3**	**43**	**25.8**	**23**	**7.9**	**7**	**18.0**	**16**	**100.0**	**89**
Total responses	**45.6**	**47**	**34.9**	**36**	**4.9**	**5**	**14.6**	**15**	**100.0**	**103**

Table 34 Question 2.21

Q2.21 Family - How much do you agree with the following statements?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
2.21(1) (Family) Digital health is an important tool in ensuring regular communication with the palliative care team										
Strongly disagree	2.7	1	5.0	1	0	0	0	0	2.7	2
Somewhat disagree	5.4	2	10.0	2	16.7	1	0	0	6.7	5
Neither agree/disagree	54.1	20	30.0	6	33.3	2	50.0	6	45.3	34
Somewhat agree	18.9	7	40.0	8	50.0	3	33.3	4	29.3	22
Strongly agree	18.9	7	15.0	3	0	0	16.7	2	16.0	12
Total	**49.3**	**37**	**26.7**	**20**	**8.0**	**6**	**16.0**	**12**	**100.0**	**75**
2.21(2) (Family) The method palliative care provides support in the home, either face-to-face or digital is appropriate for our needs										
Strongly disagree	8.3	3	10.0	2	0	0	0	0	6.7	5
Somewhat disagree	5.6	2	5.0	1	16.7	1	0	0	5.4	4
Neither agree/disagree	36.1	13	20.0	4	33.3	2	33.4	4	31.1	23
Somewhat agree	22.2	8	35.0	7	16.7	1	33.3	4	27.1	20
Strongly agree	27.8	10	30.0	6	33.3	2	33.3	4	29.7	22
Total	**48.6**	**36**	**27.1**	**20**	**8.1**	**6**	**16.2**	**12**	**100.0**	**74**
2.21(3) (Family) I have the resources and confidence to use digital health effectively										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	5.4	2	0	0	0	0	0	0	2.7	2
Neither agree/disagree	16.2	6	10.0	2	16.7	1	8.4	1	13.3	10
Somewhat agree	21.6	8	55.0	11	66.6	4	33.3	4	36.0	26
Strongly agree	56.8	21	35.0	7	16.7	1	58.3	7	48.0	36
Total	**49.3**	**37**	**26.7**	**20**	**8.0**	**6**	**16.0**	**12**	**100.0**	**75**
2.21(4) (Family) Digital health consultations are an acceptable alternative to face-to-face consultations with medical professionals										
Strongly disagree	2.6	1	5.0	1	0	0	0	0	2.6	2
Somewhat disagree	10.5	4	5.0	1	50.0	3	8.4	1	11.8	9
Neither agree/disagree	36.8	14	30.0	6	16.7	1	33.3	4	33.0	25
Somewhat agree	39.5	15	55.0	11	33.3	2	50.0	6	44.7	34
Strongly agree	10.5	4	5.0	1	0	0	8.3	1	7.9	6
Total	**50.0**	**38**	**26.3**	**20**	**7.9**	**6**	**15.8**	**12**	**100.0**	**76**
2.21(5) (Family) Digital health means that access to medical support is available that I would not be able to access due to distance										
Strongly disagree	2.7	1	0	0	0	0	0	0	1.3	1
Somewhat disagree	5.4	2	10.5	2	16.7	1	25.0	3	10.8	8
Neither agree/disagree	40.6	15	21.1	4	33.3	2	50.0	6	36.5	27
Somewhat agree	43.2	16	47.4	9	50.0	3	8.3	1	39.2	29

Strongly agree	8.1	3	21.0	4	0	0	16.7	2	12.2	9
Total	**50.0**	**37**	**25.7**	**19**	**8.1**	**6**	**16.2**	**12**	**100.0**	**74**
2.21(6) (Family) I feel that the choice of place of care is supported with digital health										
Strongly disagree	8.3	3	5.0	1	0	0	0	0	5.4	4
Somewhat disagree	13.9	5	15.0	3	16.7	1	16.7	2	14.9	11
Neither agree/disagree	41.7	15	30.0	6	50.0	3	50.0	6	40.6	30
Somewhat agree	27.8	10	35.0	7	33.3	2	16.6	2	28.3	21
Strongly agree	8.3	3	15.0	3	0	0	16.7	2	10.8	8
Total	**48.7**	**36**	**27.1**	**20**	**8.1**	**6**	**16.2**	**12**	**100.0**	**74**
2.21(7) (Family) I am comfortable with my family member remaining at home knowing that support can be accessed at any time										
Strongly disagree	12.1	4	10.0	2	0	0	8.3	1	9.9	7
Somewhat disagree	21.2	7	20.0	4	66.7	4	41.7	5	28.2	20
Neither agree/disagree	30.3	10	40.0	8	33.3	2	25.0	3	32.4	23
Somewhat agree	21.2	7	20.0	4	0	0	8.3	1	16.9	12
Strongly agree	15.2	5	10.0	2	0	0	16.7	2	12.6	9
Total	**46.5**	**33**	**28.1**	**20**	**8.5**	**6**	**16.9**	**12**	**100.0**	**71**

Table 35 Question 2.21 (Descriptive Statistics)

Q2.21 Family - How much do you agree with the following statements?							
	n	**min**	**max**	**mean**	**SD**	**Variance**	**Confidence Interval**
2.21(1) (Family) Digital health is an important tool in ensuring regular communication with the palliative care team							
Peri-Urban	37	1	5	3.5	0.9	0.9	0.20
Rural	20	1	5	3.5	1.0	1.1	0.20
Regional	6	2	4	3.3	0.7	0.6	0.30
Metro	12	3	5	3.7	0.7	0.6	0.20
Total	75	1	5	3.5	0.8	0.8	0.20
2.21(2) (Family) The method palliative care provides support in the home, either face-to-face or digital is appropriate for our needs							
Peri-Urban	36	1	5	3.6	1.2	1.4	0.20
Rural	20	1	5	3.7	1.2	1.5	0.30
Regional	6	2	4	3.7	1.1	1.2	0.40
Metro	12	2	4	4.0	0.8	0.7	0.20
Total	74	1	5	3.8	1.1	1.2	0.30
2.21(3) (Family) I have the resources and confidence to use digital health effectively							
Peri-Urban	36	1	5	4.3	0.9	0.9	0.20
Rural	20	1	5	4.2	0.6	0.4	0.10
Regional	6	2	5	4.0	0.6	0.3	0.20
Metro	12	2	5	4.5	0.6	0.4	0.20
Total	74	1	5	4.3	0.7	0.5	0.20
2.21(4) (Family) Digital health consultations are an acceptable alternative to face-to-face consultations with medical professionals							
Peri-Urban	38	1	5	3.4	0.9	0.8	0.15
Rural	20	1	5	3.5	0.9	0.8	0.20
Regional	6	2	4	2.8	0.9	0.8	0.40
Metro	12	2	5	3.6	0.8	0.6	0.20
Total	76	1	5	3.3	0.9	0.8	0.20
2.21(5) (Family) Digital health means that access to medical support is available that I would not be able to access due to distance							
Peri-Urban	37	1	5	3.5	0.8	0.7	0.10
Rural	19	2	5	3.8	0.9	0.8	0.20
Regional	6	2	4	3.3	0.7	0.6	0.30
Metro	12	2	5	3.2	1.0	1.0	0.30
Total	74	1	5	3.5	0.9	0.8	0.20
2.21(6) (Family) I feel that the choice of place of care is supported with digital health							

Peri-Urban	36	1	5	3.1	1.0	1.1	0.20
Rural	20	1	5	3.4	1.1	1.1	0.20
Regional	6	2	4	3.2	0.7	0.5	0.30
Metro	12	2	5	3.3	0.9	0.9	0.30
Total	74	1	5	3.3	0.9	0.9	0.30
2.21(7) (Family) I am comfortable with my family member remaining at home knowing that support can be accessed at any time							
Peri-Urban	33	1	5	3.1	1.2	1.5	0.20
Rural	20	1	5	3.0	1.2	1.2	0.20
Regional	6	2	3	2.3	0.5	0.2	0.20
Metro	12	1	5	2.8	1.2	1.5	0.40
Total	71	1	5	2.8	1.0	1.1	0.30

Table 36 Question 2.22

Q2.22 Family - Overall are you satisfied with the access to community palliative care services in your location?										
Opinion	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Yes	36.4	12	57.1	8	25.0	1	37.5	3	40.7	24
No	63.6	21	42.9	6	75.0	3	62.5	5	59.3	35
Total	**55.9**	**33**	**23.7**	**14**	**6.8**	**4**	**13.6**	**8**	**100.0**	**59**

Health Care Professionals

Table 37 Question 6.1

Q6.1 Professional - Your age group?										
Age	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
18-34 years	9.1	2	33.3	1	0	0	33.3	2	14.7	5
35-49 years	40.9	9	33.3	1	66.7	2	33.3	2	41.2	14
50-64 years	50.0	22	33.4	1	33.3	1	33.4	2	44.1	15
65+	0	0	0	0	0	0	0	0	0	0
Total	**64.7**	**22**	**8.8**	**3**	**8.8**	**3**	**17.7**	**6**	**100.0**	**34**

Table 38 Question 6.2

Q6.2 Professional - How long have you been providing community palliative care?										
Providing care	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
<1 year	5.7	2	16.7	1	0	0	14.3	1	7.8	4
1-5 years	34.3	12	16.7	1	0	0	57.1	4	33.3	17
>5 years	60.0	21	66.7	4	100	3	28.6	2	58.8	30
Total	**68.6**	**35**	**11.8**	**6**	**5.9**	**3**	**13.7**	**7**	**100.0**	**51**

Table 39 Question 6.3

Q6.3 Professionals - What is your current role in providing community palliative care?										
Role	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Nurse Practitioner	2.8	1	0	0	0	0	14.3	1	4.0	2
Clinical Nurse	20.0	7	20.0	1	33.3	1	0	0	18.0	9
Registered Nurse	22.8	8	20.0	1	0	0	71.4	5	28.0	14
AIN/PCA	14.3	5	20.0	1	0	0	0	0	12.0	6
OT/Physiotherapist	5.8	2	0	0	0	0	14.3	1	6.0	3
GP	2.8	1	0	0	0	0	0	0	2.0	1
Psychologist	2.8	1	0	0	33.3	1	0	0	4.0	2
Social Worker	2.8	1	20.0	1	0	0	0	0	4.0	2
Volunteer	8.6	3	0	0	0	0	0	0	6.0	3
Nurse Navigator	5.8	2	20.0	1	33.4	1	0	0	8.0	4
Equipment/Transport	5.7	2	0	0	0	0	0	0	4.0	2
Admin/Referral	5.8	2	0	0	0	0	0	0	4.0	2
Total	**67.3**	**35**	**13.5**	**5**	**5.7**	**3**	**13.5**	**7**	**100.0**	**50**

Table 40 Question 6.4

Q6.4 Professionals - How would you describe the area where community palliative care is provided?		
	%	*n*
Peri-urban	67.3	35
Rural	13.5	7
Regional	5.7	3
Metropolitan	13.5	7
Total	**100.0**	**52**

Table 41 Question 6.6

Q6.6 Professionals - In what State/Territory are services provided?										
State/Territory	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Queensland	5.7	2	20.0	1	66.7	2	14.3	1	12.0	6
South Australia	94.3	33	80.0	4	33.3	1	57.1	4	84.0	42
NT, WA and ACT	0	0	0	0	0	0	0	0	0	0
New South Wales	0	0	0	0	0	0	28.6	2	4.0	2
Victoria and Tasmania	0	0	0	0	0	0	0	0	0	0
Total	**70.0**	**35**	**10.0**	**5**	**6.0**	**3**	**14.0**	**7**	**100.0**	**30**

Table 42 Question 6.7

Q6.7 (Professionals) In what type of organisation do you provide community palliative care?										
Organisation	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Specialist palliative care team (SPC)	31.4	11	40.0	2	66.7	2	14.3	1	32.0	16
Public Hospital	8.6	3	20.0	1	33.3	1	0	0	10.0	5
Private Hospital	0	0	0	0	0	0	14.4	1	2.0	1
GP clinic	2.9	1	0	0	0	0	0	0	2.0	1

Home Care Provider	20.0	7	0	0	0	0	42.9	3	20.0	10
RACF Community	2.8	1	20.0	1	0	0	14.4	1	6.0	3
Community Health	22.9	8	20.0	1	0	0	0	0	18.0	9
Mental Health	2.8	1	0	0	0	0	0	0	2.0	1
Retired	2.9	1	0	0	0	0	0	0	2.0	1
Palliative Care Unit	2.8	1	0	0	0	0	14.4	1	4.0	2
Cancer charity	2.9	1	0	0	0	0	0	0	2.0	1
Total	**70.0**	**35**	**10.0**	**5**	**6.0**	**3**	**14.0**	**7**	**100.0**	**50**

Table 43 Question 6.8

Q6.8 If answered yes to SPC team - What health professions are employed to support community palliative care in your organisation? Select all that apply										
Role	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Nurse Practitioner	18.2	2	0	0	11.1	1	12.5	1	25.0	4
Clinical Nurse	90.9	10	25.0	1	22.2	2	0	0	81.2	13
Registered Nurse	27.3	3	0	0	0	0	12.5	1	25.0	4
AIN/PCA	9.1	1	0	0	0	0	0	0	6.2	1
OT	72.7	8	0	0	0	0	12.5	1	56.2	9
GP	0	0	0	0	11.1	1	0	0	6.2	1
Psychologist	0	0	0	0	11.2	1	0	0	6.2	1
Social Worker	54.5	6	25.0	1	22.2	2	12.5	1	62.5	10
Physiotherapist	18.2	2	0	0	0	0	12.5	1	18.7	3
Palliative Care Specialist	27.3	3	25.0	1	22.2	2	12.5	1	43.8	7
Chaplain	0	0	0	0	0	0	12.5	1	6.2	1
Pharmacist	0	0	0	0	0	0	12.5	1	6.2	1
Bereavement Coordinator	9.1	1	0	0	0	0	0	0	6.2	1
Nurse Navigator	0	0	25.0	1	0	0	0	0	6.2	1
Total responses	**63.2**	**36**	**7.0**	**4**	**15.8**	**9**	**14.0**	**8**	**100.0**	**57**
Total respondents	**68.8**	**11**	**12.5**	**2**	**12.5**	**2**	**6.2**	**1**	**100.0**	**16**

Table 44 Question 6.9

Q6.9 If yes as member of SPC team- If you have a choice, are there any health profession roles you would like added to your team?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Yes	100.0	11	50.0	1	100.0	2	100.0	1	93.8	15
No	0	0	50.0	1	0	0	0	0	6.2	1
Total	**68.7**	**11**	**12.5**	**2**	**12.5**	**2**	**6.3**	**1**	**100.0**	**16**

Table 45 Question 6.9

Q6.9 If yes - please provide detail							**Multiple responses allowed**			
Role	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Nurse Practitioner	0	0	0	0	50.0	1	0	0	6.7	1
Clinical Nurse	18.2	2	0	0	0	0	0	0	13.3	2
Registered Nurse	0	0	100.0	1	0	0	0	0	100.0	1
Enrolled Nurse	54.5	6	0	0	50.0	1	0	0	46.7	7
AIN/PCA	72.7	8	0	0	0	0	0	0	53.8	8
OT	18.2	2	100.0	1	100	2	0	0	33.3	5
GP	18.2	2	100.0	1	50.0	1	0	0	26.7	4
Psychologist	27.2	3	0	0	0	0	0	0	20.0	3

Social Worker	54.5	6	0	0	0	0	0	0	40.0	6
Physiotherapist	45.4	5	0	0	50.0	1	0	0	40.0	6
Palliative Care Specialist	9.1	1	0	0	50.0	1	0	0	13.3	2
Chaplain/Spiritual	9.1	1	0	0	0	0	0	0	6.7	1
Pharmacist	9.1	1	100.0	1	0	0	0	0	13.3	2
Grief/Bereavement support	45.4	5	0	0	50.0	1	0	0	40.0	6
Speech Pathologist	18.2	2	0	0	0	0	0	0	13.3	2
Equipment support	36.3	4	0	0	0	0	0	0	26.7	4
Dietician	9.1	1	0	0	0	0	100	1	13.3	2
Volunteer	9.1	1	0	0	0	0	0	0	6.7	1
Handyman	9.1	1	0	0	0	0	0	0	6.7	1
Total responses	**79.7**	**51**	**6.2**	**4**	**12.5**	**8**	**1.6**	**1**	**100.0**	**64**
Total respondents	**73.3**	**11**	**6.7**	**1**	**13.3**	**2**	**6.7**	**1**	**100.0**	**15**

Table 46 Question 6.10

Q6.10 – Professionals - Please select all the services that are accessible to all homes in the area where you work. Select all that apply multiple responses allowed										
Services	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Unsure	5.7	2	0	0	0	0	0	0	4.0	2
Specialist Palliative Care Team (SPC)	77.1	27	80.0	4	100.0	3	85.7	6	80.0	40
Community Nursing	85.7	30	60.0	3	100.0	3	71.4	5	82.0	41
Personal care	88.6	31	40.0	2	100.0	3	85.7	6	84.0	42
Transport Assistance	80.0	28	40.0	2	100.0	3	71.4	5	34.0	38
Occupational Therapy	80.0	28	60.0	3	100.0	3	100	7	82.0	41
Psychologist	0	0	0	0	0	0	0	0	0	0
Social Worker	25.7	9	20.0	1	66.7	2	71.4	5	34.0	17
Physiotherapy	65.7	23	40.0	2	100.0	3	85.7	6	68.0	34
Dietician/Speech Therapy	65.7	23	80.0	4	66.7	2	71.4	5	68.0	34
Palliative Care Specialist	25.7	9	20.0	1	33.3	1	85.7	6	34.0	17
Spiritual	0	0	20.0	1	0	0	28.6	2	6.0	3
Volunteers	20.0	7	20.0	1	33.3	1	57.1	4	26.0	13
Complementary	14.3	5	0	0	33.3	1	71.4	5	22.0	11
House/Garden maintenance	82.8	29	40.0	2	100.0	3	71.4	5	78.0	39
Home modification	77.1	27	40.0	2	100.0	3	71.4	5	74.0	37
Equipment	80.0	28	100	5	100.0	3	85.7	6	84.0	42
Advance Care Directive assistance	37.1	13	40.0	2	66.7	2	85.7	6	78.0	23
Financial	0	0	0	0	0	0	0	0	0	0
GP	65.7	23	40.0	2	100.0	3	100	7	70.0	35
End-of-life care	88.6	31	80.0	4	100.0	3	85.7	6	88.0	44
Bereavement	28.6	10	40.0	2	66.7	2	85.7	6	40.0	20
Family/friends	0	0	0	0	0	0	0	0	0	0
Daily medication assistance	25.7	9	0	0	100.0	3	71.4	5	34.0	17
Pharmacy	54.3	19	60.0	3	66.7	2	85.7	6	60.0	30
Pathology	62.8	22	40.0	2	33.3	1	100	7	64.0	32
Radiology	42.8	15	40.0	2	66.7	2	85.7	6	50.0	25
Wigs	2.8	1	0	0	0	0	0	0	2.0	1
Meal Delivery	0	0	0	0	0	0	14.3	1	2.0	1
Overnight respite	0	0	0	0	0	0	14.3	1	2.0	1
Doula	2.8	1	0	0	0	0	0	0	2.0	1

Anything that helps	5.7	2	0	0	0	0	0	0	4.0	2
Depends on location	8.6	3	0	0	0	0	14.3	1	6.0	4
Other	22.8	8	0	0	6.7	2	42.9	3	26.0	13
Total responses	**66.1**	**463**	**7.1**	**50**	**7.8**	**54**	**19.0**	**133**	**100.0**	**700**
Total respondents	**70.0**	**35**	**10.0**	**5**	**6.0**	**3**	**14.0**	**7**	**100.0**	**700**

Table 47 Question 6.11

Q6.11 Professionals - What barriers to accessing services do you believe apply in your location? Select all that apply										
Barriers	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
No barriers to access	2.9	1	0	0	0	0	28.6	2	6.0	3
Clients under 65 yrs	82.9	29	60.0	3	100.0	3	28.6	2	74.0	37
Distance for providers	88.6	31	60.0	3	100.0	3	0	0	74.0	37
Providers lack resources	94.3	33	60.0	3	100.0	3	28.6	2	82.0	41
Time taken to start	80.0	28	60.0	3	33.3	1	28.6	2	68.0	34
Distance travel to	82.9	29	60.0	3	66.7	2	0	0	68.0	34
Diversity	31.4	11	0	0	0	0	14.3	1	24.0	12
Language	40.0	14	40.0	2	33.3	1	14.3	1	36.0	18
Palliative care stigma	60.0	21	60.0	3	100.0	3	28.6	2	58.0	29
Behaviours	25.7	9	20.0	1	33.3	1	0	0	22.0	11
Financial	57.1	20	40.0	2	66.7	2	42.9	3	54.0	27
Personal choice	45.7	16	20.0	1	0	0	28.6	2	38.0	19
Care needs exceed scope	85.7	30	60.0	3	66.7	2	28.6	2	74.0	37
No need identified	11.4	4	0	0	0	0	0	0	8.0	4
Lack of information	57.1	20	0	0	66.7	2	42.9	3	50.0	25
Total respondents	**70.0**	**35**	**10.0**	**5**	**6.0**	**3**	**14.0**	**7**	**100.0**	**50**

Table 48 Question 6.12

Q6.12 Professionals – Are there any changes you would like to see in your role? Select all that apply										
Reason	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
No changes	0	0	20.0	1	0	0	14.3	1	4.0	2
Increase frequency	85.7	30	80.0	4	33.3	1	28.6	2	74.0	37
Enable choice provider	31.4	11	40.0	2	33.3	1	0	0	28.0	14
Enable choice day/time	71.4	25	60.0	3	33.3	1	28.6	2	62.0	31
Provide 24/7 contact	77.1	27	80.0	4	66.7	2	28.6	2	70.0	35
24/7 in-home care	82.8	29	80.0	4	33.3	1	42.9	3	74.0	37
Increase staff	100	35	80.0	4	66.7	2	57.1	4	88.0	44
Remove time restriction	74.3	26	60.0	3	33.3	1	42.9	3	66.0	33
Increase avail equip	62.9	22	60.0	3	33.3	1	28.6	2	36.0	28
Reduce service cost	51.4	18	40.0	2	33.3	1	42.9	3	48.0	25
Improve staff training	51.4	18	60.0	3	0	0	42.9	3	48.0	24
Total respondents	**70.0**	**35**	**10.0**	**5**	**6.0**	**3**	**14.0**	**7**	**100.0**	**50**
Total responses	**77.7**	**241**	**10.6**	**33**	**3.6**	**11**	**8.1**	**25**	**100.0**	**310**

Table 49 Question 6.13

Q6.13 Professionals - Please select any of the following that apply										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Q6.13(1) (Professionals) Hospital admissions extended due to in-home services unable/ unavailable to support discharge	85.7	30	57.1	4	100.0	3	28.6	2	78.0	39
Q6.13(2) (Professionals) Clients needing to attend medical clinics or outpatient clinics as no in-home services to provide medication administration	65.7	23	57.1	4	0	0	28.6	2	58.0	29
Q6.13(3) (Professionals) Clients needing to attend medical clinics or outpatient clinics as no/ insufficient in-home services available to assist with wound/ catheter/stoma care	71.4	25	28.6	2	33.3	1	42.9	3	62.0	31
Q6.13(4) (Professionals) Ambulance being called for assistance with pain/symptom control as community services unable to be contacted	82.9	29	42.9	3	66.7	2	57.1	4	76.0	38
Q6.13(5) (Professionals) Respite in aged care facility as no/insufficient services available in-home to support hospital discharge	80.0	28	42.9	3	66.7	2	57.1	4	74.0	37
Q6.13(6) (Professionals) End-of-life care provided in hospital as appropriate services unable to be provided in the house	88.6	31	57.1	4	33.3	1	57.1	4	76.0	38
Q6.13(7) (Professionals) None apply	5.7	2	0	0	0	0	42.8	3	10.0	5
Total responses	**70.0**	**35**	**10.0**	**5**	**6.0**	**3**	**14.0**	**7**	**100.0**	**50**

Table 50 Question 6.14

Q6.14 Professionals - How does your organisation provide information about relevant services to the community? Select all that apply										
Information source	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Rely staff face-to-face	29.4	10	20.0	1	100	3	28.6	2	32.6	16
Referral process	47.0	16	40.0	2	0	0	57.1	4	44.9	22
Pamphlets/booklets	26.5	9	40.0	2	33.3	1	57.1	4	32.6	16
Website	38.2	13	40.0	2	0	0	57.1	4	38.8	19
Advertise locally	23.5	8	0	0	0	0	28.6	2	20.4	10
Community events	14.7	5	0	0	0	0	28.6	2	14.3	7
Rely community talk	23.5	8	0	0	33.3	1	42.9	3	24.0	12
Staff over phone	20.6	34	60.0	3	100	3	42.9	3	32.6	16
Total respondents	**69.3**	**34**	**10.2**	**5**	**6.1**	**3**	**14.4**	**7**	**100.0**	**49**
Total responses	**64.4**	**76**	**8.5**	**10**	**6.8**	**8**	**20.3**	**24**	**100.0**	**118**

Table 51 Question 6.15

Q6.15 (Professionals) How much do you agree with the following statements?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
6.15(1) (Professionals) Existing health services meet the needs and expectations of people in this location										
Strongly disagree	8.6	3	0	0	33.3	1	14.3	1	10.2	5
Disagree	37.1	13	50.0	2	0	0	14.3	1	32.6	16
Neither agree/disagree	17.1	6	25.0	1	0	0	0	0	14.3	7
Agree	34.3	12	25.0	1	66.7	2	14.3	1	32.7	16
Strongly agree	2.9	1	0	0	0	0	57.1	4	10.2	5
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(2) (Professionals) There is a need for people in this area to travel over 100km distances for some healthcare services										
Strongly disagree	2.9	1	0	0	0	0	14.3	1	4.1	2
Disagree	8.6	3	0	0	0	0	57.1	4	14.3	7
Neither agree/disagree	8.6	3	0	0	0	0	0	0	6.1	3
Agree	37.1	13	25.0	1	66.7	2	14.3	1	34.7	17
Strongly agree	42.8	15	75.0	3	33.3	1	14.3	1	40.8	20
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(3) (Professionals) The need to travel long distances for some healthcare services influences decisions about treatment										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	0	0	0	0	0	0	28.6	2	4.1	2
Neither agree/disagree	14.3	5	0	0	0	0	28.6	2	14.3	7
Agree	57.1	20	50.0	2	66.7	2	28.5	2	53.1	26
Strongly agree	28.6	10	50.0	2	33.3	1	14.3	1	28.5	14
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(4) (Professionals) The need to travel long distances for some healthcare services results in people relocating closer to services										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	0	0	0	0	0	0	14.3	1	2.0	1
Neither agree/disagree	5.7	2	25.0	1	0	0	28.5	2	10.2	5
Agree	54.3	19	25.0	1	66.7	2	28.6	2	49.0	25
Strongly agree	40.0	14	50.0	2	33.3	1	28.6	2	38.8	19
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(5) (Professionals) People are supported to remain in their own home										
Strongly disagree	0	0	0	0	0	0	14.3	1	2.0	1
Disagree	14.3	5	25.0	1	33.3	1	14.3	1	16.3	8
Neither agree/disagree	2.9	1	0	0	0	0	0	0	2.0	1
Agree	68.6	5	25.0	1	0	0	57.1	4	20.5	10
Strongly agree	14.2	5	25.0	1	0	0	57.1	4	20.5	10
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(6) (Professionals) Home location does not influence access to services										
Strongly disagree	51.4	18	50.0	2	33.3	1	42.8	3	49.0	24
Disagree	28.6	10	0	0	66.7	2	14.3	1	26.5	13
Neither agree/disagree	14.3	5	50.0	2	0	0	0	0	14.3	7
Agree	5.7	2	0	0	0	0	28.6	2	8.2	4
Strongly agree	0	0	0	0	0	0	14.3	1	2.0	1
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(7) (Professionals) Communication and care provided is culturally and gender inclusive and respectful										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	8.6	3	0	0	0	0	0	0	6.1	3
Neither agree/disagree	11.4	4	0	0	0	0	14.3	1	10.2	5
Agree	51.4	18	50.0	2	66.7	2	42.9	3	51.0	25

Strongly agree	28.6	10	50.0	2	33.3	1	42.8	3	32.7	16
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15 (8) (Professionals) Personal choices, preferences and goals of care are respected										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	5.9	2	0	0	0	0	0	0	4.2	2
Neither agree/disagree	8.8	3	25.0	1	0	0	57.1	4	8.3	4
Agree	55.9	19	25.0	1	66.7	2	42.9	3	54.2	26
Strongly agree	29.4	10	50.0	2	33.3	1	14.6	7	33.3	16
Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.6**	**7**	**100.0**	**48**
6.15(9) (Professionals) Access is available for support 24/7										
Strongly disagree	11.8	4	25.0	1	66.7	2	14.2	1	16.7	8
Disagree	61.8	21	50.0	2	33.3	1	0	0	50.0	24
Neither agree/disagree	14.7	5	25.0	1	0	0	0	0	12.5	6
Agree	11.7	4	0	0	0	0	42.9	3	14.6	7
Strongly agree	0	0	0	0	0	0	42.9	3	6.2	3
Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.6**	**7**	**100.0**	**48**
6.15(10) (Professionals) Quality of life is improved by remaining in own home										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	0	0	0	0	0	0	0	0	0	0
Neither agree/disagree	2.9	1	0	0	66.7	2	14.3	1	8.2	4
Agree	37.1	13	25.0	1	0	0	14.3	1	30.6	15
Strongly agree	60.0	21	75.0	3	33.3	1	71.4	5	61.2	30
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(11) (Professionals) Ambulance transport and hospital admissions are reduced by community service provided										
Strongly disagree	0	0	0	0	33.3	1	0	0	2.1	1
Disagree	14.7	5	0	0	0	0	0	0	10.4	5
Neither agree/disagree	32.3	11	50.0	2	0	0	28.6	2	31.2	15
Agree	41.2	14	50.0	2	33.4	1	14.3	1	37.5	18
Strongly agree	11.8	4	0	0	33.3	1	57.1	4	18.8	9
Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.6**	**7**	**100.0**	**48**
6.15(12) (Professionals) Patients and family members are included in all decision-making about care and services										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	2.9	1	0	0	0	0	14.2	1	4.2	2
Neither agree/disagree	14.8	5	25.0	1	0	0	14.3	1	14.6	7
Agree	52.9	18	25.0	1	66.7	2	28.6	2	47.9	23
Strongly agree	29.4	10	50.0	2	33.3	1	57.1	3	33.3	16
Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.6**	**7**	**100.0**	**48**
6.15(13) (Professionals) Physical, emotional, spiritual and social support is provided										
Strongly disagree	29.0	1	0	0	0	0	14.2	1	4.2	2
Disagree	29.4	10	50.0	2	33.3	1	0	0	27.1	13
Neither agree/disagree	14.8	5	0	0	0	0	14.2	1	12.5	6
Agree	35.3	12	25.0	1	33.4	1	28.6	2	33.3	16
Strongly agree	17.6	6	25.0	1	33.3	1	42.9	3	22.9	11
Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.6**	**7**	**100.0**	**48**
6.15(14) (Professionals) Services are provided promptly and when needed										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	31.4	11	50.0	2	66.7	2	28.6	2	34.7	17
Neither agree/disagree	31.4	11	0	0	0	0	0	0	22.4	11
Agree	34.3	12	50.0	2	33.3	1	28.6	2	34.7	17
Strongly agree	2.9	1	0	0	0	0	42.8	3	8.2	4
Total	**71.4**	**35**	**6.1**	**4**	**6.3**	**3**	**14.3**	**7**	**100.0**	**48**
6.15(15) (Professionals) Medication required can be accessed easily										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	35.3	12	100	4	66.7	2	28.6	2	33.3	16
Neither agree/disagree	41.2	14	0	0	0	0	0	0	27.5	18
Agree	23.5	8	0	0	33.3	1	28.6	2	22.9	11
Strongly agree	0	0	0	0	0	0	42.8	3	6.3	3

Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.3**	**7**	**100.0**	**48**
6.15(16) (Professionals) The choice for end-of-life in the home and a home death is supported regardless of the location of the home										
Strongly disagree	0	0	25.0	1	0	0	0	0	2.1	1
Disagree	35.3	12	25.0	1	33.3	1	28.6	2	33.3	16
Neither agree/disagree	23.5	8	0	0	0	0	0	0	16.7	8
Agree	35.3	12	25.0	1	66.7	2	28.6	2	35.4	17
Strongly agree	5.9	2	25.0	1	0	0	42.8	3	12.5	6
Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.6**	**7**	**100.0**	**48**
6.15(17) (Professionals) All services are affordable										
Strongly disagree	5.9	2	0	0	0	0	14.3	1	6.3	3
Disagree	47.1	16	25.0	1	33.3	1	42.8	3	43.7	21
Neither agree/disagree	26.5	9	25.0	1	0	0	0	0	20.8	10
Agree	17.6	6	50.0	2	66.7	2	14.3	1	22.9	11
Strongly agree	2.9	1	0	0	0	0	28.6	2	6.3	3
Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.6**	**7**	**100.0**	**48**
6.15(18) (Professionals) Staff providing care have the training, knowledge and expertise to provide quality care										
Strongly disagree	5.7	2	0	0	33.3	1	0	0	6.1	3
Disagree	11.4	4	50.0	2	0	0	28.6	2	16.3	8
Neither agree/disagree	25.8	9	25.0	1	0	0	14.3	1	22.5	11
Agree	45.7	16	25.0	1	33.4	1	14.3	1	38.8	19
Strongly agree	11.4	4	0	0	33.3	1	42.8	3	16.3	8
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(19) (Professionals) Choices for end-of-life care including hospice, home death and voluntary assisted dying are supported and clients are able to make informed decisions										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	26.5	9	50.0	2	0	0	28.6	2	27.1	13
Neither agree/disagree	32.3	11	50.0	2	33.4	1	0	0	29.2	14
Agree	35.3	12	0	0	33.3	1	57.1	4	35.4	17
Strongly agree	5.9	2	0	0	33.3	1	14.3	1	8.3	4
Total	**70.8**	**34**	**8.3**	**4**	**6.3**	**3**	**14.6**	**7**	**100.0**	**48**
6.15(20) (Professionals) Bereavement care is available as required										
Strongly disagree	12.1	4	0	0	66.7	2	0	0	12.8	6
Disagree	27.3	9	50.0	2	0	0	0	0	23.4	11
Neither agree/disagree	42.4	14	50.0	2	0	0	0	0	34.0	16
Agree	15.2	5	0	0	0	0	71.4	5	21.3	10
Strongly agree	3.0	1	0	0	33.3	1	28.6	2	8.5	4
Total	**70.2**	**33**	**8.5**	**4**	**6.4**	**3**	**14.9**	**7**	**100.0**	**47**
6.15(21) (Professionals) Family/caregiver stress and burnout is reduced with in-home services										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	11.4	4	25.0	1	0	0	0	0	10.2	5
Neither agree/disagree	20.0	7	0	0	33.3	1	14.3	1	18.4	9
Agree	54.3	19	50.0	2	66.7	2	57.1	4	55.1	27
Strongly agree	14.3	5	25.0	1	0	0	28.6	2	16.3	8
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
6.15(22) (Professionals) Staff maintain good relationships with patients/family members receiving care										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Disagree	0	0	0	0	0	0	0	0	0	0
Neither agree/disagree	8.6	3	0	0	0	0	0	0	6.1	3
Agree	57.1	20	25.0	1	66.7	2	57.1	4	55.1	27
Strongly agree	34.3	12	75.0	3	33.3	1	42.9	3	38.8	19
Total	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**

Table 52 Questions 6.15 (Descriptive Statistics)

Q6.15 (Professionals) How much do you agree with the following statements?

Statement	*n*	min	max	mean	SD	Variance	Confidence Interval
6.15(1) (Professionals) Existing health services meet the needs and expectations of people in this location	49	1	5	3.0	1.2	1.5	0.20
6.15(2) (Professionals) There is a need for people in this area to travel over 100km distances for some healthcare services	49	1	5	3.9	1.2	1.4	0.16
6.15(3) (Professionals) The need to travel long distances for some healthcare services influences decisions about treatment	49	2	5	4.2	0.7	0.5	0.10
6.15(4) (Professionals) The need to travel long distances for some healthcare services results in people relocating closer to services	49	1	5	3.8	1.0	1.0	0.14
6.15(5) (Professionals) People are supported to remain in their own home	49	1	5	1.9	1.0	1.1	0.15
6.15(6) (Professionals) Home location does not influence access to services	49	1	5	4.1	0.8	0.7	0.11
6.15(7) (Professionals) Communication and care provided is culturally and gender inclusive and respectful	48	2	5	4.2	0.7	0.5	0.10
6.15(8) (Professionals) Personal Choices, Preferences and goals of care are respected	48	2	5	2.4	1.1	1.2	0.16
6.15(9) (Professionals) Access is available for support 24/7	48	1	5	4.5	0.6	0.4	0.09
6.15(10) (Professionals) Quality of life is improved by remaining in own home	49	2	5	3.6	1.0	1.0	0.14
6.15(11) (Professionals) Ambulance transport and hospital admissions are reduced by community services provided	48	1	5	4.1	0.8	0.6	0.11
6.15(12) (Professionals) Patients and family members are included in all decision-making about care and services	48	2	5	3.4	1.2	1.5	0.20
6.15(13) (Professionals) Physical, emotional, spiritual and social support is provided	48	1	5	1.2	1.0	1.0	0.10
6.15(14) (Professionals) Services are provided promptly and when needed	49	2	5	3.0	0.9	0.8	0.10
6.15(15) (Professionals) Medication required can be accessed readily	48	2	5	3	0.9	0.8	0.10
6.15(16) (Professionals) The choice for end-of-life in the home and a home death is supported regardless of the location of the home	48	1	5	3.3	1.0	1.1	0.15
6.15(17) (Professionals) All services are affordable	48	1	5	2.9	1.1	1.3	0.20
6.15(18) (Professionals) Staff providing care have the training, knowledge and expertise to provide quality care	49	1	5	3.4	1.1	1.3	0.20
6.15(19) (Professionals) Choices for end-of-life care including hospice,							

home death and voluntary assisted dying are supported and clients are able to make informed decisions	48	2	5	3.2	1.0	0.9	0.10
6.15(20) (Professionals) Bereavement care is available as required	47	2	5	3.2	1.0	1.3	0.20
6.15(21) (Professionals) Family/caregiver stress and burnout is reduced with in-home services	49	2	5	3.8	0.8	0.6	0.11
6.15(22) (Professionals) Staff maintain good relationships with patients/family members receiving care	49	3	5	4.3	0.6	0.9	0.10

Table 53 Question 6.16

Q6.16 Professionals – How do you provide palliative care in the community? Select all that apply										
Methods	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Face-to-face	100.0	35	100.0	4	100.0	3	100.0	7	100.0	49
Phone	51.4	18	75.0	3	100.0	3	85.7	6	61.2	30
Video	28.6	10	0	0	100.0	3	28.6	2	30.6	15
Email	8.6	3	25.0	1	100.0	3	0	0	14.3	7
Text	22.9	8	50.0	2	100.0	3	14.3	1	28.6	14
Apps	0	0	0	0	0	0	0	0	0	0
Role does not contact	2.9	1	0	0	0	0	0	0	2.0	1
Total respondents	**71.4**	**35**	**8.2**	**4**	**6.1**	**3**	**14.3**	**7**	**100.0**	**49**
Total responses	**64.6**	**75**	**8.7**	**10**	**12.9**	**15**	**13.8**	**16**	**100.0**	**116**

Table 54 Question 6.17

Q6.17 Professional – Why do you use digital health options? Select all that apply										
Reasons	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Reduce infection	38.7	12	0	0	0	0	50.0	3	34.9	15
Improve support	29.0	9	66.7	2	66.7	2	83.3	5	41.9	18
Reduce travel time for clinician	29.0	9	66.7	2	66.7	2	50.0	3	37.2	16
Patient/family choice	25.8	8	0	0	33.3	1	66.7	4	30.2	13
Face-to-face not required	9.7	2	33.3	1	66.7	2	0	0	13.9	6
After hours support	16.1	5	0	0	0	0	66.7	4	20.9	9
Professional choice	41.9	13	66.7	2	33.3	1	66.7	4	46.5	20
Home visit not required	29.0	9	33.3	1	0	0	83.3	5	34.9	15
Family present	12.9	4	0	0	66.7	2	33.3	2	18.6	8
Specialist input needed	32.2	10	33.3	1	100.0	3	33.3	2	37.2	16
Total respondents	**72.1**	**31**	**7.0**	**3**	**7.0**	**3**	**13.9**	**6**	**100.0**	**43**
Total responses	**60.3**	**82**	**6.6**	**9**	**9.6**	**13**	**23.5**	**32**	**100.0**	**136**

Table 55 Question 6.18

Q6.18 Professionals - Have you experienced any problems with digital health options? Select all that apply										
Problems	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
No problems using	15.1	5	0	0	0	0	50.0	3	17.0	8
Patient lack access/skill	30.3	10	0	0	100.0	3	50.0	3	34.0	16
Choice patient/family	24.2	8	20.0	1	33.3	1	33.3	2	25.5	12
Poor mobile coverage	42.4	14	60.0	3	100.0	3	16.7	1	44.7	21
Unreliable/no internet	33.3	11	60.0	3	100.0	3	0	0	36.2	17
No digital option offered	6.1	2	0	0	0	0	16.7	1	6.4	3
Face-to-face required	45.4	15	40.0	2	0	0	50.0	3	42.6	20
Patient does not answer phone	9.1	3	0	0	0	0	0	0	6.4	3
Hearing/language barrier	3.0	1	0	0	0	0	0	0	2.1	1
Sometimes/not used	6.1	2	0	0	0	0	0	0	4.2	2
Total respondents	**70.2**	**33**	**10.6**	**5**	**6.4**	**3**	**12.8**	**6**	**100.0**	**47**
Total responses	**68.9**	**71**	**8.8**	**9**	**9.7**	**10**	**12.6**	**13**	**100.0**	**103**

Table 56 Question 6.19

Q6.19 Professionals - How much do you agree with the following statements?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
6.19(1) (Professional) Digital health is an important tool in ensuring regular communication with patients										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	9.4	3	0	0	33.3	1	0	0	8.7	4
Neither agree/disagree	28.1	9	25.0	1	0	0	14.3	1	23.9	11
Somewhat agree	50.0	16	25.0	1	66.7	2	42.8	3	47.8	22
Strongly agree	12.5	4	50.0	2	0	0	42.9	3	19.6	9
Total	**69.6**	**32**	**8.7**	**4**	**6.5**	**3**	**15.2**	**7**	**100.0**	**46**
6.19(2) (Professional) I have the resources and confidence to use digital health options effectively										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	9.1	3	0	0	33.3	1	28.6	2	12.8	6
Neither agree/disagree	9.1	3	25.0	1	0	0	0	0	8.5	4
Somewhat agree	48.0	16	25.0	1	33.4	1	28.6	2	42.5	20
Strongly agree	33.3	11	50.0	2	33.3	1	42.8	3	36.2	17
Total	**70.2**	**33**	**8.5**	**4**	**6.4**	**3**	**14.9**	**7**	**100.0**	**47**
6.19(3) (Professional) Telehealth consultations are an acceptable alternative to face-to-face consultations with medical professionals										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	18.7	6	50.0	2	33.3	1	14.3	1	21.7	10
Neither agree/disagree	28.1	9	25.0	1	0	0	28.6	2	26.1	12
Somewhat agree	46.9	15	25.0	1	66.7	2	42.9	3	45.6	21
Strongly agree	6.3	2	0	0	0	0	14.2	1	6.6	3
Total	**69.6**	**32**	**8.7**	**4**	**6.5**	**3**	**15.2**	**7**	**100.0**	**46**
6.19(4) (Professional) Telehealth means that patients can access medical support that would not be readily accessible due to distance										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	0	0	0	0	0	0	0	0	0	0
Neither agree/disagree	24.2	8	50.0	2	0	0	28.6	2	25.5	12
Somewhat agree	54.6	18	25.0	1	66.7	2	14.3	1	46.8	22
Strongly agree	21.2	7	25.0	1	33.3	1	57.1	4	27.7	13
Total	**70.2**	**33**	**8.5**	**4**	**6.4**	**3**	**14.9**	**7**	**100.0**	**47**

6.19(5) (Professional) I feel that patient's choice of place of care is supported with digital health options										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	6.1	2	0	0	0	0	14.3	3	6.4	3
Neither agree/disagree	30.3	10	50.0	2	0	0	42.9	1	31.9	15
Somewhat agree	45.4	15	50.0	2	100.0	3	0	0	42.6	20
Strongly agree	18.2	6	0	0	0	0	42.8	3	19.1	9
Total	**70.2**	**33**	**8.5**	**4**	**6.4**	**3**	**14.9**	**7**	**100.0**	**47**
6.19(6) (Professional) Patients and family members are comfortable to remain at home knowing that they can access support at any time										
Strongly disagree	3.0	1	0	0	0	0	0	0	2.1	1
Somewhat disagree	12.1	4	25.0	1	0	0	0	0	10.6	5
Neither agree/disagree	45.5	15	75.0	3	0	0	28.6	2	42.6	20
Somewhat agree	24.2	8	0	0	100.0	3	42.8	3	29.8	14
Strongly agree	15.2	5	0	0	0	0	28.6	2	14.9	7
Total	**70.2**	**33**	**8.5**	**4**	**6.4**	**3**	**14.9**	**7**	**100.0**	**47**

Table 57 Question 6.20

Q6.20 Professionals - Overall are you satisfied with the access to community palliative care services provided in your location?										
Opinion	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Yes	30.8	8	0	0	66.7	2	85.7	6	42.1	16
No	69.2	18	100.0	2	33.3	1	14.3	1	57.9	22
Total	**68.4**	**26**	**5.3**	**2**	**7.9**	**3**	**18.4**	**7**	**100.0**	**38**

People diagnosed with a life-limiting illness (Patient)

Table 58 Question 5.1

Q5.1 Patient - Your age group?										
Age	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
18-34 years	8.3	1	0	0	25.0	1	33.3	1	11.1	3
35-49 years	25.0	3	12.5	1	0	0	0	0	14.8	4
50-64 years	41.7	5	37.5	3	25.0	1	66.7	2	40.7	11
65+	25.0	3	50.0	4	50.0	2	0	0	33.3	9
Total	**44.4**	**12**	**29.7**	**8**	**14.8**	**4**	**11.1**	**3**	**100.0**	**27**

Table 59 Question 5.2

Q5.2 Patient - How long have you been receiving community palliative care?										
Receiving care	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
<1 month	30.8	4	0	0	0	0	33.3	1	17.8	5
1-6 months	38.5	5	62.5	5	75.0	3	33.3	1	50.6	14
6-12 months	7.7	1	12.5	1	0	0	0	0	7.1	2
>1 year	23.0	3	28.6	2	25.0	1	33.4	1	25.0	7
Total	**46.4**	**13**	**28.6**	**8**	**14.3**	**4**	**10.7**	**3**	**100.0**	**28**

Table 60 Question 5.3

Q5.3 Patient - In what State/Territory do you live?										
State/Territory	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Queensland	3.3	2	12.5	1	25.0	1	0	0	13.3	4
South Australia	60.0	9	87.5	7	25.0	1	100.0	3	66.7	20
NT, WA and ACT	0	0	0	0	0	0	0	0	0	0
New South Wales	6.7	1	0	0	25.0	1	0	0	6.7	2
Victoria	13.3	2	0	0	25.0	1	0	0	10.0	3
Tasmania	6.7	1	0	0	0	0	0	0	3.3	1
Total	**50.0**	**15**	**26.7**	**8**	**13.3**	**4**	**10.0**	**3**	**100.0**	**30**

Table 61 Question 5.4

Q5.4 Patient – How would you describe the area where you live and receive care?		
	%	*n*
Peri-urban	46.2	12
Rural	30.8	8
Regional	11.5	3
Metropolitan	11.5	3
Total	**100.0**	**26**

Table 62 Question 5.6

Q5.6 (Patient) How strongly do you feel about the following statements?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
5.6(1) (Patient) I chose this location as health services I need are close by										
Strongly disagree	28.6	4	77.8	7	0	0	33.3	1	40.0	12
Somewhat disagree	35.7	5	11.1	1	25.0	1	33.3	1	26.7	8
Neither agree/disagree	0	0	0	0	25.0	1	0	0	3.3	1
Somewhat agree	21.4	3	11.1	1	50.0	2	33.3	1	23.3	7
Strongly agree	14.3	2	0	0	0	0	0	0	6.7	2
Total	**46.7**	**14**	**30.0**	**9**	**13.3**	**4**	**10.0**	**3**	**100.0**	**30**
5.6(2) (Patient) I chose this location as services I need/may need, are in the planning or development stage										
Strongly disagree	64.3	9	66.7	6	50.0	2	66.7	2	63.3	19
Somewhat disagree	7.1	1	22.2	2	25.0	1	0	0	13.4	4
Neither agree/disagree	0	0	0	0	0	0	0	0	0	0
Somewhat agree	21.4	3	11.1	1	25.0	1	33.3	1	20.0	6
Strongly agree	7.2	1	0	0	0	0	0	0	3.3	1
Total	**46.7**	**14**	**30.0**	**9**	**13.3**	**4**	**10.0**	**3**	**100.0**	**30**
5.6(3) (Patient) I chose this location as health services that provide for increased care needs are close by (eg hospice, aged care facility, specialist care)										
Strongly disagree	71.4	10	77.8	7	50.0	2	66.7	2	70.0	21
Somewhat disagree	7.1	1	11.1	1	25.0	1	0	0	10.0	3
Neither agree/disagree	7.2	1	0	0	0	0	0	0	3.3	1
Somewhat agree	14.3	2	11.1	1	25.0	1	33.3	1	16.7	5
Strongly agree	0	0	0	0	0	0	0	0	0	0
Total	**46.7**	**14**	**30.0**	**9**	**13.3**	**4**	**10.0**	**3**	**100.0**	**30**
5.6(4) (Patient) There was an expectation that health services were accessible										

Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	7.2	1	11.1	1	0	0	0	0	6.7	2
Neither agree/disagree	0	0	0	0	0	0	0	0	0	0
Somewhat agree	21.4	3	44.4	4	25.0	1	0	0	26.7	8
Strongly agree	71.4	10	44.4	4	75.0	3	100	3	66.6	20
Total	**46.7**	**14**	**30.0**	**9**	**13.3**	**4**	**10.0**	**3**	**100.0**	**30**

Table 63 Question 5.7

Q5.7 Patient - How did you identify, contact or access services and information? Select all that apply										
Find information	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Not involved in access	0	0	33.3	3	0	0	0	0	10.0	3
Health Professional	71.4	10	44.4	4	75.0	3	100.0	3	66.7	20
Referred	78.6	11	66.7	6	100	4	66.7	2	76.7	23
Friends/family	0	0	11.1	1	25.0	1	33.3	1	10.0	3
Pamphlets/booklets	0	0	0	0	0	0	0	0	0	0
Online forums	14.3	2	0	0	0	0	0	0	6.7	2
Support groups	14.3	2	11.1	1	25.0	1	0	0	13.3	4
Google	7.1	1	11.1	1	0	0	0	0	6.7	2
Knowledge/experience	0	0	0	0	0	0	0	0	0	0
Total responses	**45.6**	**26**	**28.1**	**16**	**15.8**	**9**	**10.5**	**6**	**100.0**	**57**
Total respondents	**46.7**	**14**	**30.0**	**9**	**13.3**	**4**	**10.0**	**3**	**100.0**	**30**

Table 64 Question 5.8

Q5.8 Patient - Did you find it difficult to find information about service/s and identify what was needed?										
Yes/no	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Yes	46.2	6	50.0	3	75.0	3	33.3	1	50.0	3
No	53.8	7	50.0	3	25.0	1	66.7	2	50.0	13
Total	**50.0**	**13**	**23.1**	**6**	**15.4**	**4**	**11.5**	**3**	**100.0**	**26**

Table 65 Question 5.9

Q5.9 Patient - Did you find it difficult to access identified services when required?										
Yes/no	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Yes	38.5	5	85.7	6	33.3	1	100	1	54.2	13
No	61.5	8	14.3	1	66.7	2	0	0	45.8	11
Total	**54.2**	**13**	**29.1**	**7**	**12.5**	**3**	**4.2**	**1**	**100.0**	**24**

Table 66 Question 5.10

Q5.10 Patient - Please select all community services you are using/have used. Select all that apply										
Services	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Unsure	0	0	11.1	1	25.0	1	0	0	6.7	2
Specialist Palliative Care (SPC)	71.4	10	44.4	4	50.0	2	33.3	1	56.7	17
Community Nursing	7.1	1	44.4	4	25.0	1	0	0	20.0	6

Personal Care	14.3	2	22.2	2	25.0	1	0	0	16.7	5
Transport Assistance	0	0	22.2	2	0	0	0	0	6.7	2
Occupational Therapy	14.3	2	33.3	3	25.0	1	0	0	20.0	6
Psychiatrist/ Psychologist	14.3	2	0	0	0	0	33.3	1	10.0	3
Social Worker	35.7	5	22.2	2	50.0	2	33.3	1	33.3	10
Physiotherapy	14.3	2	11.1	1	0	0	0	0	10.0	3
Dietician/Speech Pathology	7.1	1	0	0	0	0	0	0	3.3	3
Palliative Care Specialist	21.4	3	0	0	0	0	0	0	3.3	3
Spiritual support	0	0	0	0	0	0	0	0	0	0
Volunteers	0	0	0	0	0	0	0	0	0	0
Complementary therapy	7.1	1	0	0	0	0	0	0	3.3	1
Housework/Garden maintenance	21.4	3	11.1	1	25.0	1	0	0	16.7	5
Home maintenance/ modification	7.1	1	11.1	1	0	0	0	0	6.7	2
Equipment	28.6	4	44.4	4	0	0	0	0	26.7	8
Advance care directive assistance	14.3	2	0	0	0	0	0	0	6.7	2
Financial/legal assistance	14.3	2	0	0	25.0	1	0	0	10.0	3
Regular GP	35.7	5	11.1	1	50.0	2	0	0	26.7	8
Family/friends	28.6	4	22.2	2	75.0	3	33.3	1	33.3	10
MND Association	7.1	1	0	0	0	0	0	0	3.3	1
Breast cancer nurse	7.1	1	0	0	0	0	0	0	3.3	1
My Aged Care	0	0	11.1	1	0	0	0	0	3.3	1
Home Oxygen	7.1	1	0	0	0	0	0	0	3.3	1
None	7.1	1	22.2	2	0	0	33.3	1	13.3	4
Total responses	**51.4**	**54**	**29.5**	**31**	**14.3**	**15**	**4.8**	**5**	**100.0**	**105**
Total respondents	**46.7**	**14**	**30.0**	**9**	**13.3**	**4**	**10.0**	**3**	**100.0**	**30**

Table 67 Question 5.11

Q5.11 Patient - Do the services you receive meet your needs and expectations?										
Yes/no	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Yes	53.8	7	44.4	4	25.0	1	66.7	2	48.3	14
Partially	23.1	3	33.3	3	50.0	2	0	0	27.6	8
No	23.1	3	22.2	2	25.0	1	33.3	1	24.1	7
Total	**44.8**	**13**	**31.0**	**9**	**13.8**	**4**	**10.4**	**3**	**100.0**	**29**

Table 68 Question 5.12

5.12 Patient - If you are not using all services that are available, why not? Select all that apply										
Reasons	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Not needed now	61.5	8	44.4	4	50.0	2	66.7	2	55.2	16
Family provide	23.1	3	11.1	1	25.0	1	0	0	17.2	5
Not happy with service previously	0	0	0	0	0	0	0	0	0	0
Not when I want	0	0	11.1	1	0	0	0	0	3.4	1
Not available as often as I want	0	0	22.2	2	0	0	0	0	6.9	2
I am under 65 years	53.8	7	44.4	4	25.0	1	33.3	1	44.8	13

Not available in this location	23.1	3	55.6	5	25.0	1	0	0	31.0	9
Local providers lack resources	15.4	2	44.4	4	0	0	0	0	20.7	6
Too expensive	30.8	4	22.2	2	0	0	0	0	24.1	7
Using all I knew about	0	0	0	0	0	0	0	0	0	0
Personal choice	15.4	2	22.2	2	25.0	1	0	0	13.8	4
Unsure why no access	7.7	1	22.2	2	25.0	1	0	0	13.8	4
Total responses	**44.8**	**30**	**40.3**	**27**	**10.4**	**7**	**4.5**	**3**	**100.0**	**67**
Total respondents	**44.9**	**13**	**31.0**	**9**	**13.8**	**4**	**10.3**	**3**	**100.0**	**29**

Table 69 Question 5.13

Q5.13 Patient - Please select any of the following that apply										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Q5.13(1) (Patient) I have had one or more hospital stays extended as services unavailable to support my discharge home	80.8	8	57.1	4	0	0	100.0	1	61.9	13
Q5.13(2) (Patient) I have needed to attend a clinic or hospital out-patients for medication administration as in-home services unavailable	30.0	3	14.3	1	33.3	1	100.0	1	28.6	6
Q5.13(3) (Patient) I have needed to attend a clinic or hospital out-patients for assistance with wound/catheter/stoma care as in-home services unavailable	30.0	3	14.3	1	0	0	0	0	19.0	4
Q5.13(4) (Patient) I have needed to call an ambulance for assistance with pain/symptom control as unable to contact local services	20.0	2	28.6	2	0	0	0	0	19.0	4
Q5.13(5) (Patient) Respite in aged care facility has been required as in-home services unavailable to support hospital discharge	0	0	14.3	1	0	0	0	0	4.8	1
Q5.13(6) (Patient) Will need to transfer to hospital for end-of-life care to remain in this location	20.0	2	85.7	6	66.7	2	0	0	47.8	10
Total responses	**47.6**	**10**	**33.3**	**7**	**14.3**	**3**	**4.8**	**1**	**100.0**	**21**

Table 70 Question 5.14

Q5.14 Patient - What is the longest distance you have needed to travel for healthcare services?										
Distance	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Services local	0	0	0	0	0	0	0	0	0	0
10-50 km	7.1	1	0	0	25.0	1	100.0	2	13.8	4
50-100 km	64.3	9	0	0	0	0	0	0	31.0	9
100-150 km	28.6	4	44.4	4	0	0	0	0	27.6	8
150-250 km	0	0	55.6	5	75.0	3	0	0	27.6	8
Unsure	0	0	0	0	0	0	0	0	0	0
Total responses	**48.3**	**14**	**31.0**	**9**	**13.8**	**4**	**6.9**	**2**	**100.0**	**29**

Table 71 Question 5.15

Q5.15 Patient - What barriers to accessing services do you believe apply in your situation? Select all that apply										
Barriers	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
No barriers to access	21.4	3	0	0	0	0	0	0	10.3	3
I am under 65 years	57.1	8	66.7	6	25.0	1	100	2	58.6	17
Distance for providers	28.6	4	100	9	25.0	1	0	0	48.3	14
Providers lack resources	21.4	3	44.4	4	0	0	0	0	24.1	7
Time taken to start	7.1	1	33.3	3	0	0	0	0	13.8	4
Travel from	92.8	13	65.2	15	57.1	4	0	0	16.7	32
Distance to travel to	21.4	3	77.8	7	25.0	1	0	0	37.9	11
Diversity	0	0	11.1	1	0	0	0	0	3.4	1
Language	0	0	11.1	1	0	0	0	0	3.4	1
I do not want palliative care	7.1	1	33.3	3	0	0	0	0	13.8	4
Challenging behaviours	0	0	11.1	1	0	0	0	0	3.4	1
Financial	7.1	1	11.1	1	0	0	0	0	6.9	2
Personal choice	7.1	1	0	0	0	0	0	0	3.4	1
Care needs exceed local provider scope	14.3	2	44.4	4	25.0	1	0	0	24.1	7
No need identified	21.4	3	0	0	25.0	1	50.0	1	17.2	5
Total responses	**39.1**	**43**	**50.0**	**55**	**8.2**	**9**	**2.7**	**3**	**100.0**	**110**
Total respondents	**48.3**	**14**	**31.0**	**9**	**13.8**	**4**	**6.9**	**2**	**100.0**	**29**

Table 72 Question 5.16

Q5.16 Patient - Thinking about distance to health services, please select all statements that apply to you.										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Q5.16(1) Patient - The distance required to travel to some health services has influenced my decisions about attending appointments, treatment or tests	42.8	6	44.4	4	50.0	2	50.0	1	44.8	13
Q5.16(2) Patient – The distance required to travel to some health	50.0	7	11.1	1	25.0	1	0	0	3.0	9

services has influenced where I live										
Q5.16(3) Patient - Travel any distance to health services is difficult (exhausting, pain, discomfort, etc)	85.7	12	77.8	7	25.0	1	50.0	1	72.4	21
Q5.16(4) Patient – Private transport to some health services is difficult due to cost of petrol, parking, lost wages and time involved for my family	85.7	12	88.9	8	50.0	2	100	2	82.7	24
Q5.16(5) Patient – Public transport is not an option in this location	92.3	12	72.8	7	75.0	3	50.0	1	79.3	23
Q5.16(6) Patient – Community car is not available/expensive/not an option	64.3	9	44,4	4	50.0	2	66.7	2	58.6	17
Q5.16(7) Patient – Health services are provided in my home	7.1	1	11.1	1	25.0	1	0	0	10.3	3
Q5.16(8) Patient – Health services are provided locally	0	0	11.1	1	25.0	1	0	0	6.9	2
Q5.16(9) Patient – I will need to relocate to be closer to services that will provide the level of care I need/will need	78.6	11	100.0	9	50.0	2	0	0	79.3	23
Total respondents	**48.3**	**14**	**31.0**	**9**	**13.8**	**4**	**6.9**	**2**	**100.0**	**29**

Table 73 Question 5.17

Q5.17 Patient - How much do you agree with the following statements?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
5.17(1) (Patient) I have been supported in my choice to remain in own home										
Strongly disagree	8.3	1	22.2	2	25.0	1	0	0	14.8	4
Somewhat disagree	0	0	0	0	0	0	0	0	0	0
Neither agree/disagree	16.7	2	11.1	1	0	0	100.0	2	18.5	5
Somewhat agree	25.0	3	44.4	4	0	0	0	0	25.9	7
Strongly agree	50.0	6	22.2	2	75.0	3	0	0	40.8	11
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(2) (Patient) Personal choices, preferences and goals of care are being respected										
Strongly disagree	16.7	2	22.2	2	25.0	1	0	0	18.5	5
Somewhat disagree	0	0	0	0	0	0	0	0	0	0
Neither agree/disagree	16.7	2	11.1	1	0	0	50.0	1	14.8	4
Somewhat agree	16.7	2	44.4	4	0	0	50.0	1	25.9	7
Strongly agree	50.0	6	22.2	2	75.0	3	0	0	40.8	11
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(3) (Patient) All communication and care provided has been culturally and gender inclusive and respectful										
Strongly disagree	8.3	1	0	0	25.0	1	0	0	7.7	2
Somewhat disagree	0	0	0	0	25.0	1	0	0	3.8	1
Neither agree/disagree	8.3	1	12.5	1	0	0	0	0	7.7	2
Somewhat agree	33.3	4	37.5	3	0	0	50.0	1	30.8	8
Strongly agree	50.0	6	50.0	4	50.0	2	50.0	1	50.0	13
Total	**46.1**	**12**	**39.8**	**8**	**15.4**	**4**	**7.7**	**2**	**100.0**	**26**
5.17(4) (Patient) I have access to support 24 hours a day and 7 days a week										
Strongly disagree	8.3	1	44.4	4	0	0	0	0	18.5	5
Somewhat disagree	25.0	3	33.3	3	50.0	2	0	0	29.6	8
Neither agree/disagree	8.3	1	0	0	0	0	0	0	3.8	1
Somewhat agree	16.7	2	22.2	2	25.0	1	100.0	2	25.9	7

Strongly agree	41.7	5	0	0	25.0	1	0	0	22.2	6
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(5) (Patient) My quality of life has been improved by remaining in my own home										
Strongly disagree	8.3	1	0	0	0	0	0	0	3.7	1
Somewhat disagree	0	0	0	0	0	0	0	0	0	0
Neither agree/disagree	16.7	2	33.3	3	0	0	0	0	18.5	5
Somewhat agree	8.3	1	11.1	1	0	0	0	0	7.4	2
Strongly agree	66.7	8	55.5	5	100.0	4	100.0	2	70.4	19
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(6) (Patient) Access to community services have reduced my need for ambulance transport and hospital admissions										
Strongly disagree	8.3	1	33.3	3	25.0	1	50.0	1	22.2	6
Somewhat disagree	16.7	2	22.2	2	0	0	0	0	14.8	4
Neither agree/disagree	33.3	4	11.1	1	0	0	50.0	1	22.3	6
Somewhat agree	16.7	2	22.2	2	75.0	3	0	0	25.9	7
Strongly agree	25.0	3	11.1	1	0	0	0	0	25.9	4
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(7) (Patient) I have been included in all decision-making about care and services provided										
Strongly disagree	8.3	1	0	0	0	0	0	0	3.8	1
Somewhat disagree	0	0	33.3	3	25.0	1	0	0	14.8	4
Neither agree/disagree	0	0	33.3	3	0	0	0	0	11.1	3
Somewhat agree	41.7	5	11.1	1	25.0	1	0	0	25.9	7
Strongly agree	50.0	6	22.2	2	50.0	2	100	2	44.4	12
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(8) (Patient) I am comfortable with the level of symptom management that is available										
Strongly disagree	16.7	2	22.2	2	0	0	0	0	7.4	2
Somewhat disagree	0	0	11.1	1	25.0	1	0	0	14.8	4
Neither agree/disagree	8.3	1	22.2	2	25.0	1	0	0	14.9	4
Somewhat agree	33.3	4	44.4	4	0	0	50.0	1	33.3	9
Strongly agree	41.7	5	0	0	50.0	2	50.0	1	29.6	8
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(9) (Patient) I have received support with advance care planning, completing my will and grief counselling										
Strongly disagree	16.7	2	22.2	2	0	0	0	0	14.8	4
Somewhat disagree	11.1	1	0	0	25.0	1	0	0	7.4	2
Neither agree/disagree	8.3	1	22.2	2	25.0	1	0	0	14.9	4
Somewhat agree	33.3	4	44.4	4	50.0	2	100	2	44.4	12
Strongly agree	41.7	5	0	0	0	0	0	0	18.5	5
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(10) (Patient) I have received assistance as needed										
Strongly disagree	8.3	1	55.6	5	25.0	1	0	0	25.9	7
Somewhat disagree	8.3	1	0	0	0	0	50.0	1	7.4	2
Neither agree/disagree	41.7	5	22.2	2	25.0	1	0	0	29.7	8
Somewhat agree	16.7	2	22.2	2	25.0	1	50.0	1	22.2	6
Strongly agree	25.0	3	0	0	25.0	1	0	0	14.8	4
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(11) (Patient) I am satisfied that my family and caregivers are receiving the support they need										
Strongly disagree	8.3	1	0	0	0	0	0	0	3.7	1
Somewhat disagree	8.3	1	22.2	2	0	0	50.0	1	14.8	4
Neither agree/disagree	16.7	2	55.6	5	25.0	1	0	0	29.7	8
Somewhat agree	16.7	2	22.2	2	75.0	3	50.0	1	29.6	8
Strongly agree	50.0	6	0	0	0	0	0	0	22.2	6
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(12) (Patient) All the services I need have been provided promptly										
Strongly disagree	8.3	1	33.3	3	0	0	0	0	14.8	4
Somewhat disagree	33.3	4	22.2	2	25.0	1	50.0	1	29.6	8
Neither agree/disagree	8.3	1	11.1	1	50.0	2	0	0	14.9	4
Somewhat agree	8.3	1	33.3	3	25.0	1	50.0	1	22.2	6
Strongly agree	41.7	5	0	0	0	0	0	0	18.5	5

Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(13) (Patient) I am able to access the medication that I need easily										
Strongly disagree	16.7	2	22.2	2	0	0	0	0	14.8	4
Somewhat disagree	16.7	2	33.3	3	50.0	2	0	0	25.9	7
Neither agree/disagree	8.3	1	22.2	2	0	0	0	0	11.2	3
Somewhat agree	16.7	2	22.2	2	50.0	2	100.0	2	29.6	8
Strongly agree	41.7	5	0	0	0	0	0	0	18.5	5
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(14) (Patient) My personal choices for end-of-life care including hospice, home death and voluntary assisted dying, have been supported and I have been able to make informed decisions										
Strongly disagree	8.3	1	37.5	3	0	0	0	0	15.4	4
Somewhat disagree	16.7	2	25.0	2	25.0	1	0	0	19.2	5
Neither agree/disagree	41.7	5	25.0	2	50.0	2	100.0	2	42.4	11
Somewhat agree	8.3	1	12.5	1	25.0	1	0	0	11.5	3
Strongly agree	25.0	3	0	0	0	0	0	0	11.5	3
Total	**46.1**	**12**	**39.8**	**8**	**15.4**	**4**	**7.7**	**2**	**100.0**	**26**
5.17(15) (Patient) All services I need are affordable										
Strongly disagree	8.3	1	55.5	5	25.0	1	0	0	25.9	7
Somewhat disagree	41.7	5	11.1	1	25.0	1	0	0	25.9	7
Neither agree/disagree	16.7	2	0	0	0	0	50.0	1	11.2	3
Somewhat agree	8.3	1	33.3	3	50.0	2	50.0	1	25.9	7
Strongly agree	25.0	3	0	0	0	0	0	0	11.1	3
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(16) (Patient) I believe the staff providing my care have the training, knowledge and expertise to provide the quality of care I need										
Strongly disagree	8.3	1	0	0	0	0	0	0	3.7	1
Somewhat disagree	0	0	0	0	25.0	1	0	0	3.7	1
Neither agree/disagree	8.3	1	44.4	4	0	0	0	0	18.6	5
Somewhat agree	25.0	3	33.3	3	50.0	2	0	0	29.6	8
Strongly agree	58.3	7	22.2	2	25.0	1	100	2	44.4	12
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(17) (Patient) I have choice of provider and/or staff who attend my home										
Strongly disagree	16.7	2	44.4	4	0	0	0	0	22.2	6
Somewhat disagree	22.2	2	0	0	25.0	1	50.0	1	14.8	4
Neither agree/disagree	41.7	5	11.1	1	50.0	2	50.0	1	33.4	9
Somewhat agree	8.3	1	22.2	2	25.0	1	0	0	14.8	4
Strongly agree	33.3	4	0	0	0	0	0	0	14.8	4
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(18) (Patient) Family/caregiver stress and burnout has been reduced with service provision										
Strongly disagree	8.3	1	22.2	2	0	0	0	0	11.1	3
Somewhat disagree	8.3	1	0	0	25.0	1	50.0	1	11.1	3
Neither agree/disagree	16.7	2	55.5	5	25.0	1	0	0	29.7	8
Somewhat agree	16.7	2	22.2	2	50.0	2	50.0	1	25.9	7
Strongly agree	50.0	6	0	0	0	0	0	0	22.2	6
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.17(19) (Patient) I have a good relationship with health professionals involved in my care										
Strongly disagree	8.3	1	0	0	0	0	0	0	3.7	1
Somewhat disagree	0	0	0	0	25.0	1	0	0	3.7	1
Neither agree/disagree	0	0	22.2	2	0	0	0	0	7.4	2
Somewhat agree	25.0	3	55.6	5	0	0	0	0	29.6	8
Strongly agree	66.7	8	22.2	2	75.0	3	100.0	2	55.6	15
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**

Table 74 Question 5.17 (Descriptive Statistics)

Q5.17 Patient - How much do you agree with the following statements?

Statement	n	min	max	mean	SD	Variance	Confidence Interval
5.17(1) (Patient) I have been supported in my choice to remain in own home	27	1	5	3.8	1.4	1.9	0.3
5.17(2) (Patient) Personal choices, preferences and goals of care are being respected	27	1	5	3.7	1.5	2.1	0.3
5.17(3) (Patient) All communication and care provided has been culturally and gender inclusive and respectful	26	1	5	4.1	1.2	1.4	0.2
5.17(4) (Patient) I have access to support 24 hours a day and 7 days a week	27	1	5	3.0	1.5	2.2	0.3
5.17(5) (Patient) My quality of life has been improved by remaining in my own home	27	1	5	4.4	1.0	1	0.2
5.17(6) (Patient) Access to community services have reduced my need for ambulance transport and hospital admissions	27	1	5	2.9	1.9	1.4	0.3
5.17(7) (Patient) I have been included in all decision-making about care and services provided	27	1	5	3.9	1.2	1.5	0.2
5.17(8) (Patient) I am comfortable with the level of symptom management that is available	27	1	5	3.6	1.3	1.6	0.2
5.17(9) (Patient) I have received support with advance care planning, completing my will and grief counselling	27	1	5	3.4	1.3	1.7	0.2
5.17(10) (Patient) I have received assistance as needed	27	1	5	2.9	1.4	1.9	0.3
5.17(11) (Patient) I am satisfied that my family and caregivers are receiving the support they need	27	1	5	3.5	1.1	1.2	0.2
5.17(12) (Patient) All the services I need have been provided promptly	27	1	5	3.0	1.4	1.9	0.3
5.17(13) (Patient) I am able to access the medication that I need easily	27	1	5	3.1	1.4	1.9	0.3
5.17(14) (Patient) My personal choices for end-of-life care including hospice, home death and voluntary assisted dying, have been supported and I have been able to make informed decisions	26	1	5	2.8	1.2	1.4	0.3
5.17(15) (Patient) All services I need are affordable	27	1	5	2.7	1.4	1.9	0.3
5.17(16) (Patient) I believe the staff providing my care have the training, knowledge and expertise to provide the quality of care I need	27	1	5	4.1	1.1	1.1	0.2
5.17(17) (Patient) I have choice of provider and/or staff who attend my home	27	1	5	2.9	1.3	1.8	0.3
5.17(18) (Patient) Family/caregiver stress and burnout has been reduced with service provision	27	1	5	3.4	1.3	1.6	0.2
5.17(19) (Patient) I have a good relationship with health professionals involved in my care	27	1	5	4.3	1.0	1.0	0.2

Table 75 Question 5.18

Q5.18 Patient - How do you receive palliative care services in your home? Select all that apply										
Methods	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
Face-to-face	91.7	11	66.7	6	75.0	3	100.0	2	81.5	22
Phone	83.3	10	77.8	7	75.0	3	0	0	74.1	20
Video	8.3	1	0	0	25.0	1	0	0	7.4	2
Email	8.3	1	0	0	0	0	0	0	3.7	1
Text	8.3	1	0	0	0	0	50.0	1	7.4	2
Apps	8.3	1	0	0	0	0	0	0	3.7	1
Hospital/clinic	8.3	1	11.1	1	0	0	0	0	7.4	2
Total respondents	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
Total responses	**52.0**	**26**	**28.0**	**14**	**14.0**	**7**	**6.0**	**3**	**100.0**	**50**

Table 76 Question 5.19

Q5.19 Patient - Have you experienced any problems with digital health options? Select all that apply										
Problems	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
No problems	66.7	8	0	0	50.0	2	50.0	1	40.7	11
Lack access/skill	16.7	2	33.3	3	50.0	2	0	0	25.9	7
Not used digital options	0	0	55.5	5	0	0	0	0	18.5	5
Poor mobile coverage	8.3	1	77.8	7	0	0	0	0	29.6	8
Unreliable/no internet	8.3	1	66.7	6	25.0	1	0	0	29.6	8
Not offered digital option	8.3	1	11.1	1	0	0	50.0	1	11.1	3
Total	**44.4**	**12**	**33.3**	**9**	**14.8**	**4**	**7.5**	**2**	**100.0**	**27**

Table 77 Question 5.20

Q5.20 Patient - How much do you agree with the following statements?										
	Peri-urban		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***
5.20(1) (Patient) Digital health is an important tool in ensuring I have regular communication with my palliative care team										
Strongly disagree	8.3	1	0	0	0	0	0	0	3.7	1
Somewhat disagree	0	0	0	0	0	0	0	0	0	0
Neither agree/disagree	41.7	5	55.6	5	50.0	2	50.0	1	48.1	13
Somewhat agree	25.0	3	33.3	3	25.0	1	50.0	1	29.6	8
Strongly agree	25.0	3	11.1	1	25.0	1	0	0	18.6	5
Total	**44.5**	**12**	**33.3**	**9**	**14.8**	**4**	**7.4**	**2**	**100.0**	**27**
5.20(2) (Patient) I have the resources and confidence to use digital health effectively										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	0	0	33.3	3	50.0	2	0	0	18.5	5
Neither agree/disagree	16.7	2	0	0	0	0	50.0	1	11.1	3
Somewhat agree	25.0	3	55.6	5	25.0	1	0	0	33.3	9
Strongly agree	58.3	7	11.1	1	25.0	1	50.0	1	37.1	10
Total	**44.4**	**12**	**33.3**	**9**	**14.8**	**4**	**7.5**	**2**	**100.0**	**27**
5.20(3) (Patient) Digital health consultations are an acceptable alternative to face-to-face consultations with medical professionals										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	16.7	2	0	0	25.0	1	0	0	11.5	3
Neither agree/disagree	16.6	2	62.5	5	25.0	1	50.0	1	34.7	9
Somewhat agree	50.0	6	25.0	2	50.0	2	50.0	1	42.3	11

Strongly agree	16.7	2	12.5	1	0	0	0	0	11.5	3
Total	**46.1**	**12**	**30.8**	**8**	**15.4**	**4**	**7.7**	**2**	**100.0**	**26**
5.20(4) (Patient) Digital health means that I can access medical support that I would not be able to access due to distance										
Strongly disagree	0	0	0	0	0	0	0	0	0	0
Somewhat disagree	8.3	1	0	0	25.0	1	0	0	7.7	2
Neither agree/disagree	8.3	1	25.0	2	0	0	0	0	11.6	3
Somewhat agree	66.7	8	62.5	5	25.0	1	100.0	2	61.5	16
Strongly agree	16.7	2	12.5	1	50.0	2	0	0	19.2	5
Total	**46.1**	**12**	**30.8**	**8**	**15.4**	**4**	**7.7**	**2**	**100.0**	**26**
5.20(5) (Patient) I am comfortable to remain at home knowing that I can access support at any time										
Strongly disagree	7.7	1	0	0	0	0	0	0	3.8	1
Somewhat disagree	23.1	3	0	0	25.0	1	0	0	15.4	4
Neither agree/disagree	7.7	1	57.1	4	25.0	1	0	0	23.1	6
Somewhat agree	23.1	3	42.9	3	25.0	1	100.0	2	34.6	9
Strongly agree	38.4	5	0	0	25.0	1	0	0	23.1	6
Total	**50.0**	**13**	**26.9**	**7**	**15.4**	**4**	**7.7**	**2**	**100.0**	**26**

Table 78 Question 5.21

Q5.21 Patients - Overall are you satisfied with the access to community palliative care services in your location?										
Opinion	**Peri-urban**		**Rural**		**Regional**		**Metropolitan**		**Total responses**	
	%	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Yes	66.7	8	50.0	3	75.0	3	0	0	60.9	14
No	33.3	4	50.0	3	25.0	1	33.3	1	39.1	9
Total	**52.2**	**12**	**26.1**	**6**	**17.4**	**4**	**4.3**	**1**	**100.0**	**23**