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Australian Capital Territory

**Palliative Care Service Function Review
Final Report**

June 2023

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Acronyms and Abbreviations

Abt	Abt Associates
ACT	Australian Capital Territory
ACTHD	Australian Capital Territory Health Directorate
AIHW	Australian Institute of Health and Welfare
ALOS	Average length of stay
CASP	Community Assistance and Support Program
CHH	Clare Holland House
CHS	Canberra Health Service
DVA	Department of Veterans' Affairs
ELDAC	End of Life Direction for Aged Care C
FTE	Full-time equivalent
HCCA	Health Care Consumers' Association
MBS	Medicare Benefit Scheme
MND	Motor Neurone Disease
NDIS	National Disability Insurance Scheme
NSW	New South Wales
NT	Northern Territory
PBS	Pharmaceutical Benefit Scheme
PCA	Palliative Care Australia
PHN	Primary Health Network
Qld	Queensland
QoL	Quality of Life
SA	South Australia
TAS	Tasmania
VAD	Voluntary Assisted Dying
Vic	Victoria
WA	Western Australia

Executive Summary

Background

Abt Associates were engaged by the Australian Capital Territory (ACT) Government to undertake a palliative care service function review in response to a range of recent initiatives and inquiries into palliative and end-of-life care. This report outlines the analysis and findings of the review.

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through early identification, correct assessment and appropriate treatment. Palliative care supports a range of critical functions including managing physical symptoms such as pain, provision of emotional, spiritual and psychological support, referrals to respite care, activities of daily life, and counselling and grief support. An important part of palliative care is 'End-of-life care'. End-of-life care is the health care that people receive in the last months and/or weeks of their lives and focuses on bringing together a range of health professionals, family and carers to plan for and support a person to live out their life as comfortably as possible. Palliative care and end-of-life care services can be provided at home, hospital, hospice, or in a residential aged care facility. As the services involve active clinical treatments through to providing bereavement support after a loved one's death, a person-centred care approach requires services to work together efficiently and effectively via integrated multidisciplinary teams.

The ACT Government are committed to improving palliative and end-of-life care for individuals and their families across the ACT. In 2016, the ACT Government funded the 'The Communio Model of Care'. It was envisaged that the Model, and the accompanying 'Road Map for Implementation' (Roadmap), would serve as a guide to drive local system enhancement in the ACT. Based on the recommendations from the Communio Report, the 'Territory Wide Palliative Care Service Project' (the Project) was established in 2018, which coincided with the implementation of the National Palliative Care Strategy (2018). The objective of the Project was to provide palliative care services through a network of providers, that was patient and family centric and underpinned by the vision and goals outlined in the Communio Model. Deliverables of the Project were directly linked to the key priorities of the National Palliative Care Strategy – implementation Plan.

Alongside this work, in 2016, a separate inquiry into end-of-life care was established in the ACT that recommended the ACT Government investigate the various clinical and non-clinical service options available to individuals and determine whether these options would meet the increasing demand for such services. The findings from the Aged Care Royal Commission, 2020 include recommendations on improving palliative care nationally as part of the aged care reforms. With the demand for palliative care increasing over time due to an aging population and extending human life, in a resource limited sector, it has become more critical to ensure the system is structured and resourced to provide the right services by the right healthcare provider in a timely fashion.

The review was conducted between January and June 2023. Since that time, management of Calvary Public Hospital Bruce and Clare Holland House has transitioned to Canberra Health Services.

For the purposes of this report, the names of these facilities remain as they were in January - June 2023.

This service function review of Palliative Care in the ACT aims to identify and understand the unmet need, referral pathways, demand for services, service cost, barriers to care and demographics of patients and carers.

Methodology

This service review used a comprehensive methodology for mapping services and identifying gaps and unmet need including the following:

- ***Development of the review framework*** to generate key themes as focal areas for the review and to ensure information is gathered comprehensively. The findings of this review are arranged under these key themes.

- **Six key informant interviews were** held early in the project to gain a broad understanding of the context of palliative care service provision in the ACT and further identify or confirm review themes, and to ensure the proposed review methodology was appropriate.
- **Literature and document review** to ensure critical contextual information was gathered and to inform the development of the stakeholder consultation guides.
- **Quantitative data** on service utilisation, cost of services, demographics and workforce was gathered from publicly available data sources mainly Australian Institute of Health and Welfare (AIHW) data, as well as from the Policy, Partnerships and Programs Division in the ACT Health Directorate
- **Service mapping** was conducted using a desktop audit along with development and implementation of an online survey. The online survey invitation was sent out to thirty-two organisations and valid responses from sixteen organisations were received.
- **Stakeholder consultations** with forty-five individuals representing clinical, community, advocacy, and non-government services, with discussions focused on unmet needs, barriers to care and demand for services.

Key Findings

All individuals consulted welcomed this review. Stakeholders are passionate about and committed to the delivery of high-quality palliative care services in the ACT. They recognise and await the potential for this review to be a catalyst for iterative improvement to address service gaps and unmet need.

While the service mapping shows the availability of a multidisciplinary clinical and non-clinical workforce across the ACT, stakeholder interviews highlighted gaps in: (i) the capacity of services; (ii) siloed nature of the system; (iii) provision of clinical services in home; (iv) provision of supportive non-clinical services in hospitals and at home; (v) timely referral and access to Advance Care Planning; (vi) care-coordination; and (vii) transition of care. The stakeholders discussed key enablers and barriers to available service delivery and future demand on these services.

Based on the consultations the key finding together with next steps for consideration are included below.

EXISTING SERVICES AND FUTURE DEMAND

The mapping identified 63 health services across the ACT that provided palliative care and end of life care support and/or services. The service mapping and stakeholder interviews indicate that the health care services including palliative and end-of-life care services within the ACT are represented by a wide range of services including: (i) specialist palliative care services, mainly funded by the ACT Government; (ii) other clinical services providing palliative care including allied health services (public and private); (iii) non-clinical services such as social work and case management services; and (iv) bereavement support and spiritual care for patients and their carers (delivered by other non-government organisations).

Based on the information from the stakeholder consultations, higher hospital admissions related to palliative care could be associated with the limited availability of primary care, after-hours services and/or community services for people requiring palliative care in the community setting such as home. Primary care is imperative for building a strong healthcare system that ensures positive health outcomes, effectiveness and efficiency, and health equity.

The data and stakeholder consultations indicate that the demand on palliative and end-of-life care services is predicted to increase in the ACT due to the aging population, increasing prevalence of chronic conditions and increased life expectancy due to the advances in health technology. Predictions of the utilisation of palliative care services in the ACT indicate higher future demand on services based on the evidence that Palliative Medicine has the largest forecast average growth rate per annum for all medical specialties across the ACT for multi-day inpatient separations as well as for multi-day bed-days. Establishing future demand precisely is challenging due to the lack of systematic and reliable data gathering from all the service providers across the nation.

The key findings and next steps for consideration include:

1. **Service mapping process realised gaps in key information.** Consideration could be given to instituting an annual survey of service providers across the ACT that gathers service, workforce, and funding (including source) and cost data.
2. **Broad range of services available to people requiring palliative and end-of-life care.** The mapping identified 63 services across specialist and primary care clinical services and community based non-clinical services across the continuum of care. There are however some key gaps and unmet needs.
3. **Higher rate of palliative care related hospitalisations and longer length of stay in the ACT than observed in other Australian jurisdictions.** Findings from the review included issues relating to access and availability of specialist and primary care clinical services in the community setting, limited after-hours clinical services and limited-access to after-hours medication. Clare Holland House patients, who have access to the Home-Based Palliative Care program (HBPC), are provided with an emergency medication kit, to store at home to help prevent hospitalisations. This kit is, however, only available to patients who are eligible and receive care through the HBPC program, managed through Clare Holland House. These factors may be contributing to the higher rates of hospitalisation and ALOS.
4. **The aging of the ACT population will increase the demand for palliative care services.** The cohort of the ACT population aged 70 years and above is estimated to increase from 40,500 people in 2020 to 58,600 in 2030. It has been established that fifty percent of people using palliative care services are aged 70 and over and hence increasing the demand for palliative care and end-of-life care. Collecting comprehensive data for palliative care patients is crucial to ensure effective service planning.
5. **Workforce Plan needed.** Given the likely increased demand on services, a workforce planning process to inform the requirements for meeting existing and future demand for community-based services is likely required.

UNMET NEED AND SERVICE GAPS

The dominance of clinical services in the palliative and end-of-life care service provision was reported along with limited availability and workforce knowledge of palliative care provided through primary care and community services. The stakeholders expressed the need for specialist and primary care clinical palliative and end-of-life care services in the community setting; increased capacity and capability of in-home palliative care teams to offer emotional support; better access and availability of after-hours services; improved care co-ordination; and improved cultural competency. The key findings include:

6. **Limited availability of clinical and non-clinical palliative care services in the community setting and appropriate after-hours services.** These factors are narrowing choices for patients and carers as to where and how they receive services and may be leading to hospitalisations against their preferred wishes.
7. **Inadequate linkages (or pathways) between the paediatric palliative care specialist services in NSW and services in the ACT.** Given paediatric treatment needs to occur interstate, the connections with the practitioners or community care services in the ACT are not made. A palliative care pathway for paediatric patients that ensures continuity of care and links the parents to appropriate services is critical.
8. **No Indigenous specific Palliative and End-of-life framework in the ACT.** Such a framework has been developed in Western Australia and this could be reviewed in collaboration with First Nations organisations (service providers) to consider whether this is suitable for tailoring to the ACT context.
9. **Many service providers have not formally checked the cultural appropriateness of their services for persons of a culturally and linguistically diverse background.** Ideally, service providers should review

the cultural appropriateness of their services in collaboration with relevant cultural organisations/groups.

10. **Need to enhance knowledge of availability and linkages to grief, emotional, spiritual, and psychological support.** The need for such services was identified. Access to psychosocial support services, counselling and bereavement support for palliative care patients and carers was, however, considered to be critical.

SYSTEMS ISSUES

The stakeholder consultations indicate that there is scope to build workforce capacity and capability of generalist and allied health providers to support symptom management, homecare and ensure specialist palliative care remains 'specialist'. For optimal service provision across the continuum of care, there is also a need for the whole system to understand the scope of services delivered by each provider to ensure there is appropriate collaboration and alignment. It was also reported that integration between acute and community-based services could be strengthened with many providers working in a siloed manner. The lack of palliative care services available in community settings is a challenge in the context of a policy imperative to provide palliative care in the setting chosen by the patient, and an increasing patient (or parent of a child) preference for care in the home or residential setting. Based on the consultations the key finding together with next steps for consideration include:

11. **The palliative and end-of-life care system within the ACT is a fragmented and siloed service system.**
There is a strong view that the service system is fragmented and siloed and premised on historical funding and service arrangements and models. There was a perception from stakeholders that the palliative model of care used in the ACT was highly medicalised and a holistic multidisciplinary model is required. The key findings included suggestions to facilitate this, such as: (i) Developing a Memorandum of Understanding (MOU) between all the key palliative and end-of-life services that documents the agreed roles and responsibilities of each partner; (ii) Model of Care for Palliative Care Services in the ACT to clearly delineate palliation and chronic degenerative illness to improve referral pathways and plan for maintaining a patient's quality of life; (iii) Implement care coordination mechanisms from clinical to community services; (iv) Enhance the capacity and capability of the community nursing team to facilitate medication management; (v) Build the capability of the allied health workforce ; (vi) Build the capability of the Ambulance service to include palliative care treatment knowledge and skills similar to the model utilised by the South Australian Ambulance Service; and (vii) Support carers with referrals to support services to ensure their welfare.

BARRIERS TO CARE

Addressing barriers to palliative care requires a comprehensive approach that focuses on the physical, psychological, social, and cultural aspects of patient care. This requires multidisciplinary teamwork. Insufficient interdisciplinary teamwork across the system was identified as the key concern associated with barriers in providing patient-centred palliative care in the ACT. This also impacted negatively on the communication, care coordination and shared decision-making between health professionals. Lack of understanding by physicians of the palliative care and end-of-life care stages, goal of each stage and who to engage with was noted. A lack of confidence and understanding amongst health professional in decision-making that a patient has reached the palliative stage was discussed as a limitation to provide timely care. Other barriers to an open decision-making process included lack of readiness of patients and families to accept the diagnosis of palliation, and hesitance to have timely conversations around Advance Care Planning advice.

Transition of care of patients from one setting of care to another needs to be well coordinated and supported to ensure the experience for the patient and their family/carer is as stress-free as possible. Limited clinician knowledge around transition of care points were discussed as impacting transition of care. The consultations around transition of care into the community indicated that referral pathways that connect the community services with acute and hospital services are critical to plan and manage palliative care and end-of-life care in the community. Based on the consultations the key findings together with next steps for consideration include:

12. **A need for greater education and awareness.** Educating patients, families, and healthcare professionals about the benefits and goals of palliative care can assist in addressing misconceptions and promote understanding of the role of palliative care in improving quality of life.
13. **Communication and shared decision-making between patients, families, and healthcare providers could be improved.** Encourage discussions about goals of care, treatment options, and advance care planning. Ensure that patients' values, beliefs, and preferences are respected in decision-making processes.
14. **Improve and foster multidisciplinary teamwork across the sector.** Foster collaboration among healthcare professionals, including physicians, nurses, social workers, psychologists, and other specialists to reduce silos including across clinical and non-clinical services.
15. **Enhance active promotion of Advance Care Planning.** There needs to be greater promotion of and referral to the available Advance Care Planning service. This could be enabled by establishing criterion for timely promotion of Advance Care Planning.
16. **Siloed funding sources impacts access to palliative care services.** Individuals and services receiving funding under specific funding pools (e.g. aged care benefits, National Disability Insurance Scheme) are bound by associated expenditure rules and the limits of funding which impacts patients ability to make choices and decision making around their preferred care.
17. **HealthPathways need to ensure they reference referral to community organisations.** Palliative care specific pathways across the ACT need to include referrals to community organisations to enhance the holistic nature of care.

For effective and efficient palliative and end-of-life care journey for a patient a holistic, multidisciplinary team-based approach with a focus on community care services is needed.

1. Background and Context

1.1 Palliative and End-of-life Care

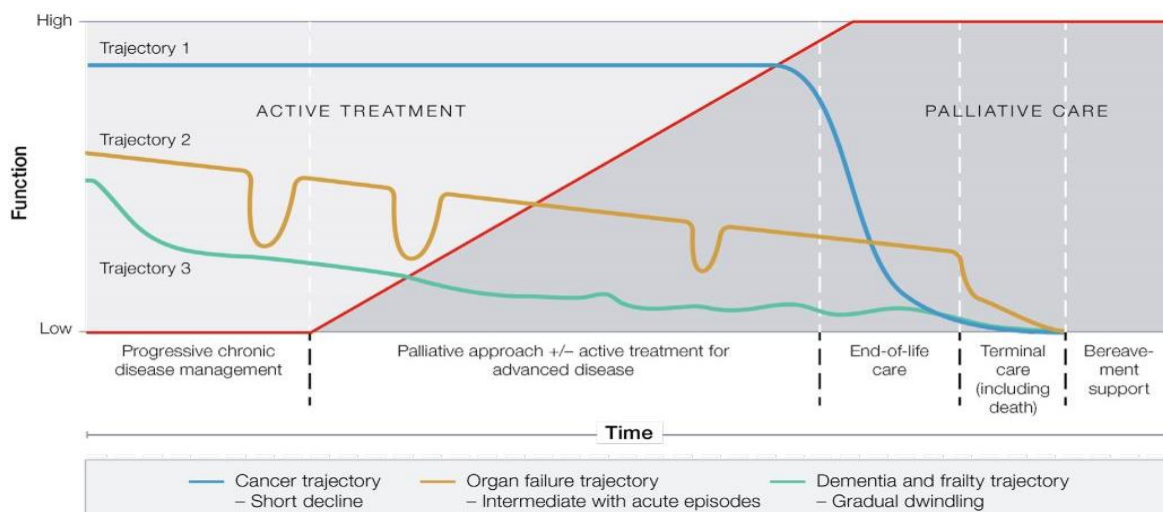
Palliative care is explicitly recognised under the human right to health and should be provided through person-centred and integrated approach that pays special attention to the specific needs and preferences of individuals[1]. The World Health Organisation (WHO) defines Palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”[1] The goal of a palliative approach is to improve or optimise a person’s level of comfort and function, improve wellbeing and to offer appropriate treatment for any distressing symptoms. Wellbeing plays a crucial role in palliative care as it aims to enhance the quality of life for individuals by focusing on physical, emotional, social, and spiritual wellbeing.

An important part of palliative care is ‘End-of-life care’ that focuses on bringing together a range of health professionals for people with end-stage illness to live out their life as comfortably as possible. The broader end-of-life care concept is defined as “End-of-life care includes physical, spiritual, and psychosocial assessment, care and treatment delivered by health professionals and ancillary staff. It also includes the support of families and carers, and care of the patient’s body after their death.” Two different components of the end-of-life definition include: (i) likely to die in the next 12 months (involving periods of exacerbated illness that may be reversible); and (ii) likely to die in the short term (within days to weeks), where clinical deterioration is likely to be irreversible. [2]

The terms ‘end-of-life care’ and ‘palliative care’ tend to be used interchangeably although are different concepts. End-of-life care typically refers to the 12 months prior to death, in contrast to palliative care which is care specifically tailored to assist with the effects of life-limiting illnesses.[2] Palliative care can be received for days, weeks, months, or even years, depending on factors such as the progression of the illness, treatment goals, and the patient's overall condition. [3]

A palliative approach also recognises that, especially for people with multiple chronic conditions, frailty and/or a life-threatening or life-limiting illness, that this is often the last chapter of their life, the length of which is unknown. As depicted in Figure 1, most people who die from chronic disease(s) progress along one of three typical illness trajectories to the end of their life. These are: cancer (short decline), non-malignant organ failure (intermediate decline with acute episodes) and frailty, dementia (gradual dwindling) [4]. Identifying that a person’s needs have shifted from routine chronic condition care to palliative care and then to end-of-life care is a key component to providing high quality care, but it is not a simple process and assessing clinical symptoms is not always an accurate indicator of prognosis.

Figure 1: Illness trajectories for chronic conditions, with the phases of palliative care towards the end-of-life



Source: Murray, S.A., et al., *Illness trajectories and palliative care*. BMJ, 2005

Multidisciplinary care is an essential component of palliative care as it is recognised that many people with life-limiting illnesses are not ‘cured’ but continue to live with these illnesses for many years. [5] A multidisciplinary holistic person-centred approach to palliative care builds upon principles such as shared decision-making, respect for individuality, dignity and autonomy, continuity of care and collaboration/communication between the individual, their family, community care and the healthcare team [6]. In Australia, palliative care is now provided in almost all settings where health care is provided, including specialist palliative care services, neonatal units, paediatric services, general practices, acute hospitals, residential and community aged care services, and generalist community services. A distinction is commonly made between care provided in hospitals (including hospices or dedicated palliative care wards) and care provided in the community (such as in the patient’s home or in residential aged care facilities).

1.2 Palliative and End-of-life Care policy framework in the ACT

For Australian healthcare system, improving palliative care has been a national agenda since 1990s. More recently, the National Palliative Care Strategy (2018) [7] and the aged care reforms (2020) instigated by the Aged Care Royal Commission[8] included frameworks and recommendations on improving palliative care. Other examples of initiatives that are part of the actions taken to improve the care of those needing palliative care include:

- The Greater Choice for At Home Palliative Care measure is funded by the Commonwealth Government and aims to improve access to the best palliative care at home, by supporting palliative care services in primary and community health setting, including generating the use of data to improve services and the use of technology to provide flexible and responsive care, including afterhours care. [9]
- The Capital Health network (ACT Primary Health Network) provided funding to Capital Chemist Wanniasa and Charnwood to deliver the pilot *After-Hours Palliative Care Delivery* program. This pilot was funded through funding provided by the Australian Government Department of Health and Aged Care. the pilot was unable to obtain data on the reason for needed access to after-hours medications.
- Australian Government Department of Health and Aged Care initiatives, such as the End of Life Direction for Aged Care (ELDAC, a national specialist palliative care and advance care planning advisory service), Palliative Aged Care Outcomes Program (PACOP), Palliative care outcomes collaborative (PCOC), Program of Experience in the Palliative approach (PEPA), and End of Life Essentials provide resources to health professionals including aged care workers on palliative care and advance care planning [10].

Specific to the ACT, multiple initiatives by the ACT government are the testament to their commitment to improve palliative and end-of-life care for individuals and their families across the ACT.

- In 2016, the ACT government funded the ‘The Communio Model of Care’ that sought to ensure that palliative care was delivered at the right time, in the right place by the right person, by confirming roles and responsibilities in the system, establishing service flows, management of demand and workforce development [11]. It was envisaged that the Model, and the accompanying ‘Road Map for Implementation’ (Roadmap), would serve as a guide to drive local system change in the ACT.
- As per recommendations from the Communio Report, in 2018, the ‘Territory Wide Palliative Care Service Project’ (The Project), was established (2020-2024). The objective of the Project was to provide palliative care services through a network of providers, to be appropriately governed, patient and family centric and underpinned by the vision and goals outlined in ‘the Model’ [12]. In accordance with the recommendations made by Communio, a ‘Territory Wide Governance Framework’ was developed in 2019. The Framework provides governance of palliative care services in the ACT and offer oversight on non-clinical palliative care and end of life care service planning and delivery. As a result of the CHS having responsibility for the Project, work has largely focussed on inpatient, acute and specialist aspects of palliative care service provision. While ACTHD acknowledged the extensive body of work that has been achieved by the Change Leader in this space, it recommended that future focus of the Project needs to shift to incorporate community health, community services, general practice, and non-government organisations to address the fundamental issues identified and to further meet the recommendations made by the Model.
- In November 2017, a Select Committee was established to inquire and report on five specific matters related to end-of-life issues which concern and affect ACT residents, including: “Current practices

utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care.” The committee published a report in 2019 that included twenty-four recommendations, of which twelve were specifically related to palliative care service provision in the ACT. [13]. It included a recommendation for the ACT Government to investigate various clinical and non-clinical service options available to individuals and whether these options meet the increasing demand for such services. As per the Recommendation 23 of the Select Committee, ACTHD intended to map or conduct a service function review, which will identify unmet need, barriers to care (including transitions of care)

- A 2021 directional paper, from ACTHD summarises the current status of Palliative and End-of-Life care in the ACT and includes recommendations regarding reviewing the governance arrangements, conducting a service function review and investigating training options for clinical and non-clinical health service providers.[14]
- The ACT government is focusing on supporting carers as can be seen from the ‘Carers Recognition Act’ published by the ACT government in 2022. [15] Carers for individuals requiring palliative care work to support the health, inclusion, and participation of their loved one when they are most vulnerable. To recognise the vital contribution carers, make to the Canberra community the ACT government passed the Carers Recognition Act in 2021. The Act establishes principles to respect, recognise and acknowledge carers’ support needs and circumstances.
- In 2022, the ACT Health published ‘The ACT Health Services Plan 2022 to 2030’ that incorporated actions to improve palliative care services within the ACT. [16] Overall Plan sets the Government’s vision for how to meet the needs of Canberra’s growing population and deliver health care for those in surrounding regions while acknowledging the increasing burden of disease along with a growing and ageing population. It suggests that this will drive growth in demand for inpatient and outpatient services and identifies a need to focus on geriatric medicine, rehabilitation, and palliative care and to improve access across the system to pain management services. The plan also includes the action on identifying service options to deliver more paediatric care at home for palliative care. Further focus on palliative care can be seen through the noted actions such as:
 - Develop an ACT Model of Care for Palliative Care Services
 - Establish dedicated palliative care inpatient beds at Canberra Hospital to deliver an improved care environment for inpatients who have palliative care needs.
 - Expand home based palliative care services across the ACT.
 - Increase access to palliative care respite services.

While the demand for palliative care is increasing over time due to an aging population and extending human life, in a resource limited sector, it becomes more critical to ensure the system is structured and resourced to provide the right services by the right healthcare provider in a timely fashion. Hence, the outcomes of the multiple initiatives- listed above led the ACT government identifying a need for the service function review within the ACT.

It is evident that over decades, the ACT government has made efforts to ensure access to high-quality palliative care services for residents in the region. Some key services funded by the ACT Health are (details of other services in section 3.1):

- Canberra Health Service, Specialist Palliative Care Service: Services are available for patients who are referred from a GP or within Canberra Health Services and includes adult specialist palliative care team: Nurse, doctor, social worker and psychologist. A Rapid Assessment Palliative Service is available. Currently work is underway to establish dedicated palliative care inpatient beds at Canberra Hospital, however it was noted that additional staffing for medical, nursing, and allied health will be needed to ensure the delineation of appropriate admissions verse inpatient consultation.
- Clare Holland House, Calvary Public Hospital Bruce: Opened in 2001, Clare Holland House, a dedicated Palliative Care Unit (27 bed Hospice), provides specialised care for individuals with life-limiting illnesses. Provides inpatient specialist palliative care service and outpatient clinics, community-based palliative care services, specialist outreach services and the Palliative Care Research Centre.
- Community Care Program, CHS: The ACT has community-based palliative care services to support patients who wish to receive care in their homes. These services provide pain and symptom

management, emotional support, and coordination of care, allowing patients to stay in familiar surroundings.

- Education and Training: ACT Health provides ongoing funding of approximately \$570,000 per annum, to Palliative Care ACT, to facilitate peak -body functions and to support ongoing training of volunteers in the ACT. These volunteers support palliative care patients in both hospital and community settings, delivering personal support and non-clinical support services.
- CHS has provided funding to develop the ACT end of Life and Palliative Care Education Pathway, the End-of-Life Champion Program and the Medical Officer training program, accessible for all Canberra Health Services staff and the Canberra Hospital and the North Canberra Hospital.
- Leo's Place: ACT Health provides ongoing funding of approximately \$640,000 per annum to facilitate the operation of Leo's Place in the ACT, currently managed by Palliative Care ACT. Leo's Place provides overnight respite, day respite and carer support. Carer support includes an access to advice, information, and self-care activities.
- Community Options: ACT Health provides ongoing funding of approximately \$110,000 per annum, for the '*Community Options Palliative Care program*' to Community Options, a not-for profit organisation in the ACT. This program is a coordination and referral service for non-clinical palliative care services and is designed to support Canberran's with peace of mind as they transition into end-of-life care at home.

Currently in the ACT, palliative and end-of-life care service delivery and allocation of resources are managed by a range of organisations and clinical and non-clinical service providers. There are numerous referral pathways and services available, however these may not be easy for consumers to identify and/or access. There is also a lack of centralised data on palliative care within the community setting. Accurate and comprehensive information on available services (and gaps) and understanding of the complexity of service provision is required to ensure delivery of the right services at the right time to the people who need it. It is expected that the future delineation of palliative care services in the ACT should extend to processes for transitions of care in, out and between services including clinical and non-clinical aspects of the services. Strategies that could enable an integrated approach to care across the palliative care continuum are required to ensure that people affected by life-limiting illnesses receive care that matches their needs and preferences. In doing so a priority to access and choice needs to be promoted [7]. Accordingly, the ACT Government is seeking through this review to identify and understand the unmet need, referral pathways, demand for services, service cost, barriers to care and demographics of patients and carers. The outcomes from this review will be a:

- Detailed list of all palliative care and end of life care services in the ACT (clinical and nonclinical) that are available across the palliative care illness (early, mid, late and bereavement), including costs for the service (where possible).
- Improved understanding of challenges associated with accessing palliative care and end of life care services in the ACT, including referral pathways and transitions between care.

2. Methodology

The review utilised a mixed methodology approach that included quantitative data collection and qualitative data collection simultaneously before undertaking final interpretation with greater focus on qualitative data. The tasks include reviewing documentation relating to the available palliative care services, mapping services including demand and utilisation, consulting identified services providers to gather knowledge of other services available, and consulting with relevant personnel/peak bodies/stakeholders within the sector to understand the referral practices, the factors contributing to unmet needs, service costs and barriers to care.

2.1 Review Framework

The framework (Appendix 1) ensured an agreed approach and methodology for all aspects of the documentation review, service mapping, consultation, data analysis, and reporting. It identified the data to be gathered and the source of that data for the key review question to be comprehensively addressed. The key themes for this review were:

- Mapping of existing palliative care and end of life care services
- Identifying demographic characteristics of the patients and carers
- Identification of unmet need
- Barriers to care
- Demand for services
- Cost of palliative care services

The presentation of findings from this service utilisation review in section three will follow these key themes.

2.2 Project Methodology

Figure 2 below summarises the methodology used to gather the information for this review.

Figure 2: Methodology used for information gathering for the service function review.

Mapping of the existing services	Identifying demographics	Identifying unmet need and demand	Understanding costs
<ul style="list-style-type: none"> • Document/Desktop Review • Key informant interviews • Survey • Stakeholder interviews 	<ul style="list-style-type: none"> • ACTHD dataset • Publicly available data (AIHW, NHMD etc) 	<ul style="list-style-type: none"> • Key informant interviews • Survey • Stakeholder interviews • Service utilisation data by AIHW 	<ul style="list-style-type: none"> • Survey • Interviews • Research report • Palliative care cost related data by AIHW

2.2.1 Document Review

A range of relevant documentation including data sources were reviewed to a) ensure the critical contextual information is gathered, b) identify developments in ACT in the palliative care space and c) inform the development of our stakeholder consultation guides. Information from these documents is referenced throughout this report.

2.2.2 Key Informant Interviews

A small number of key informant interviews with stakeholders (Table 1) identified by the project sponsor were conducted with two main purposes:

- 1) to further assisting in ensuring the proposed project processes (qualitative and quantitative) will produce expected outcomes on issues given the key informants detailed knowledge of the project background.

- 2) engaging these key influencers and decision makers early in the project, further ensuring the process is well supported (e.g., by other key colleagues or pointing to critical literature or documentation).

List of the key informants interviewed is provided below.

Table 1: List of key informants interviewed.

Organisation	Number of Key Informants Interviewed
Capital Health Network	1
Palliative Care ACT	1
Canberra Health Services Consumer Reference Group (CRG)	1
Canberra Health Service	3

2.2.3 Quantitative Data Collection

The aim was to gather data around number and types of services available, number of people requiring the services and/or using the services, number of carers supporting people requiring palliative care and/or end-of-life care. Research into available data indicated that there is a limited amount of publicly available data on palliative care and end-of-life care episodes as well as data on carers. The following data (Table 2) was used for this report.

Table 2: Reports and Data Sources

Source	Data Available
ACT Health Directorate- Policy, Partnerships and Programs Division	<p>Palliative care-related hospitalisations (Separations) where palliative care was a component of the provided during all or part of the episode between 01/07/2017 to 30/06/2022 June 2022 by sex and Indigenous status, including:</p> <ul style="list-style-type: none"> • palliative care hospitalisations with a care type of <i>Palliative care</i> • other end-of-life care hospitalisations with a recorded diagnosis of <i>Palliative care</i>. <p>-Hospitalisations</p>
AIHW	<ul style="list-style-type: none"> – Publicly available palliative care services data (latest available data as of May 2023) <ul style="list-style-type: none"> ○ Australia’s Health 2022: Palliative care section ○ Medicare-subsidised palliative medicine services, 2021-22 ○ Medicare-subsidised palliative medicine services, 2020-21 ○ Palliative care for people living in residential aged care, 2021-22 ○ Palliative Care Workforce, 2020 ○ Palliative care related medication 2021-22 ○ Palliative care patient outcomes 2021
National Hospital Morbidity database (NHMD)	<ul style="list-style-type: none"> – Trends in hospitalisations associated with palliative care and end-of-life care, 2019-20 – Admitted patient data by funding source for palliative care and end-of-life care hospitalisations, 2020–21. – Admitted Patient Care 2020-21: Palliative Care (sourced from NHMD)
Health Direct Australia & Palliative Care Directory Australia	<ul style="list-style-type: none"> – National Palliative Care Services Directory indicating numbers and types of services available. – ACT Community Assistance and Support Program (CASP) Service Directory

The data was analysed using descriptive and explanatory analysis to understand the current status and trends in demographic data on consumers and carers. Descriptive analysis was also used to present the summary of the palliative care and end-of-life care services available in the ACT.

2.2.4 Service mapping

The structured approach to service mapping included three phases:

i. Desktop Audit: Services and workforce

The desktop audit was aimed at documenting an initial list of palliative and end-of-life care services and associated workforce across the ACT. Sources for the information included:

- ACT Government website for available specialist services, primary palliative care services (clinical and non-clinical), other community services and private service providers [17]
- National Palliative Care Services Directory [18]
- National Health Workforce Dataset
- Internet searches.

ii. Service Provider Consultation

The information gathered via the desk-top audit was used to generate a list of service providers and their contact details along with any available information related to types of services offered, modality of services (face to face, telephone etc) and after business hours support. Services were subsequently be consulted via an online survey to gather further relevant details such as funding sources, cost to consumers and barriers and enablers for service provision.

iii. Finalisation of the dataset

An excel document with the details of the services was designed in consultation with the Health Directorate. This final mapping file is provided with this report.

2.2.5 Stakeholder Consultation

A total of 63 service provider organisations and health services were contacted for interviews or the surveys. These responses included multiple individuals from one organisation being interviewed or organisations participating in the interviews as well as surveys. There was representation from all groups where input was sought. There are no gaps in information from certain cohorts.

(A) SURVEYS

An online survey tool was developed in collaboration with the ACTHD to many target the service providers for whom providing palliative care is not their primary service provision activity. An invitation to participate in an online survey was sent out to 32 organisations from which 18 responded (50% response). The list of services that participated in the survey is included in Appendix 2.

(B) INTERVIEWS

The stakeholders to be consulted were classified into two main groups as described below. All interviews were via Teams online and two team members were present at all the interviews to ensure reliable data gathering.

i. Palliative Care, End-of-Life and related Service Providers

The primary purpose of the consultations with this group was to both confirm or refute information gathered during the desktop audit and to further expand on the detail and to understand the challenges and barriers to service provision. The detailed list of stakeholders consulted is included in Appendix 3.

ii. Peak Bodies, Advocates for Persons Needing Palliative or End-of-Life Care

The primary purpose of the consultations with this group was to understand the challenges and barriers to service provision for the specific consumer groups or service providers that they represent. The detailed list of stakeholders consulted is included in Appendix 4.

2.2.6 Synthesis and analysis

A mixed method approach for analysis was used to analyse the services related data. All quantitative analysis was conducted using Excel. Information gathered from interviews, focus groups and the review of program documentation was analysed both descriptively and thematically against the key questions in the review framework

and is reported accordingly. In summary, the information collected through the various quantitative and qualitative processes was triangulated to validate the overall review findings for the purposes of identifying: unmet need, costs of services, service demands and barriers to care and finally to provide recommendations.

2.2.7 Limitations

The methodology for service mapping allowed for contacting most of the service providers across the ACT. The strength of this review is the excellent participation of the stakeholders in the consultation process and the robust service mapping methodology. However, there are certain limitations to this report that need to be considered while interpreting the findings.

- 1) Service mapping: Despite extensive efforts to gather palliative care service information by service mapping methodology, it is likely that we were unable to identify all programs and services operating in the ACT that deliver palliative care. The capacity of all the services was not possible to map due to limited response to our survey and phone calls. By nature, health services are challenging to map. Thus, it is possible that report underrepresents the true number of palliative care programs and services present in the ACT.
- 2) Limitation on the ACT specific palliative care data: AIHW data provides mostly national figures on palliative care services, however where there is State/Territory level data available, it has been used in the report. These limitations are also true for the cost related data and workforce data. Most of the data is from public hospitals and no private sector data was publicly available for this report.
- 3) Survey data limitation: The details gathered via the survey on the workforce numbers and capacity are not representative of the sector and provide limited information. Palliative care funding related data obtained via survey is limited in informing the service cost or funding. Medicare-subsidised palliative medicine services data is used to reduce this gap in the information.
- 4) Limitations on data provided by the Policy, Partnerships and Programs Division Health Directorate: Limitations noted on the data provided by the ACTHD was potential inaccuracy of the 2017-18 data due to the movement of databases in 2018.
- 5) Consumer and carer consultations were out of scope for this review due to short timeline however the review ensured that multiple organisations and groups representing consumers and carers are interviewed.
- 6) Voluntary assisted dying (VAD) was mentioned and discussed by many stakeholders. The key concern around lack of understanding and practices around respecting patients' preferences and beliefs were expressed and the implications around a need for hospice that understands beliefs of people from culturally diverse and other marginalised backgrounds. However, the VAD project is being separately implemented by the ACTHD and is out of scope for this report.

Section 3 presents the findings from the consultations, service mapping and the online surveys. These findings are discussed in five section that highlight the gaps, challenges and opportunities in providing palliative and end-of-life care in the ACT.

3. Gaps, Challenges and Opportunities

This chapter follows the framework established for this service function review; mapping of services and addressing the key review questions in doing so it summarises the gaps, challenges and opportunities in the palliative and end-of-life services. The detailed review framework is included in Appendix 1 and specific questions associated with each section are listed at the start of the section.

3.1 Mapping of Existing Services

Section 3.1 focuses on the two key areas of;

- **Mapping of existing palliative care and end of life care services** (section 3.1.1 and 3.1.2). Current use of healthcare services across the ACT and details of the services that are focused on palliative care and end-of-life care.
- **How much do these services cost?** (sections 3.1.3, 3.1.4 and 3.1.5). Current funding available for services was gathered from various publicly available resources and also from the service provider surveys. Although there is no comprehensive data available on funding, the review uses some MBS data to establish the costs and answer the question: “How much funding is provided to these services and from which source?”

3.1.1 Service Mapping

Four main sources of information were used to inform the mapping of palliative care services in the ACT region with the methodology described more fully in Chapter 2 above. This included:

1. Desktop review, website search and consultation with key informants and stakeholders working in the palliative care area.
2. Online survey of organisations providing palliative care and end-of-life services and associated Community Assistance and Support Programs (CASP).
3. Existing palliative care service directory created by Palliative Care Australia.
4. ACT Community Assistance and Support Program (CASP) Service Directory.

The searches provided a list of 63 different organisations with multiple contacts within each organisation. This comprehensive list of services was used to invite services to participate in the interviews or in the online surveys. Forty-five stakeholders were interviewed, and the online survey invitation was sent out to 32 service organisations. We received a total of 18 valid responses to the online survey from 16 organisations (50% response rate). The key categories for palliative care services are available from the ACT Government’s-health website [17]. It was agreed that the services will be categorised under these categories for mapping the services across the ACT and are listed below.

The breadth of services available can be seen from the summary table 3 below. The sections 3.3 to 3.5 further discuss the capacity, access and connectedness between these services.

Table 3: Summary of palliative and palliative care related, clinical and no-clinical , services across the ACT

Specialist Palliative care	Primary Care/Community Clinical Services	Community-based palliative care focused non-clinical services	Other relevant services* in the ACT	Carer focused including grief and bereavement services	Organisations, Committees, and reference groups
<p>-Clare Holland House:</p> <ul style="list-style-type: none"> • Hospice • Outpatient clinic • Home based palliative care program. • Palliative Aged Care Specialists Program (PEACE) <p>The Canberra Hospital:</p> <ul style="list-style-type: none"> • -Specialist Palliative care Team, CHS • -Paediatric Palliative care service, CHS • -Advance Care Planning Program Team, CHS • - • -Renal Supportive Care Clinic, CHS <p>Queanbeyan Palliative Care Services, Queanbeyan HHS</p>	<p>-Community Care Program, CHS including LINK</p> <p>-Canberra Region Cancer Centre, CHS</p> <p>-Capital Health Network</p> <p>-Companion House</p> <p>-Next Practice Deakin</p> <p>-ACT Ambulance Service</p> <p>-ACT Motor Neurone Disease (MND) service</p> <p>-Canberra After Hours Locum Medical Service (CALMS),</p> <p>-Coordinare – South-eastern NSW PHN</p> <p>-Directions Health Services</p> <p>-Nurse next door service</p> <p>-Nursing and Midwifery, CHS</p> <p>-Paediatric Liaison and Navigation Service (PLaNS),</p> <p>-The Winnunga Nimmityjah Health and Community Service Supportive Care Clinic</p> <p>-Rehabilitation, Aged and Community Services Canberra Health Services (specialist services but not necessarily palliative care specific)</p> <p>-Cancer Coinciding Service, TCH</p>	<p>-Palliative Care ACT including Leo's Place</p> <p>Respite</p> <p>-Community Options Palliative Care Support Program</p> <p>-Advance Care Planning ACT Program</p> <p>-Be My Voice</p> <p>-CanTeen</p> <p>-Violet</p> <p>-ACT Motor Neurone Disease (MND) service NSW/ACT (information service for the ACT)</p> <p>-R & R Respite Services</p>	<p>-ACT Government, Justice and Community Safety Directorate</p> <p>-Advocate of the ACT - General Advocacy Services (ADACAS)</p> <p>-Council on the Ageing ACT</p> <p>-Australian Red Cross ACT</p> <p>-ACT Council of Social Services</p> <p>-ACT Ambulance Service</p> <p>-Capital Complementary Therapies - Capital Health Network (CHN)</p> <p>-CatholicCare Canberra</p> <p>-Community Options INC</p> <p>-Goodwin Home Care</p> <p>-Prestantia Health Public</p> <p>-Woden Community Service (WCS)</p> <p>-Meridian</p> <p>-Meridian Aged Services Navigation</p> <p>-Cancer Council ACT</p> <p>-Dementia Australia</p> <p>-Hepatitis ACT</p> <p>-The Canberra Alliance for Harm Minimisation and Advocacy</p> <p>-CatholicCare</p> <p>-Kincare</p> <p>-The Alexander Maconochie Centre</p> <p>-ACT Disability, Aged and Carer Advocacy Service</p> <p>-Anglicare ACT</p> <p>- Capital Region Community Services</p> <p>-Woden Community Service</p> <p>Community Services #1</p>	<p>-Australian Centre for Grief and Bereavement</p> <p>-Canberra Grief Centre</p> <p>-Carer Help</p> <p>-Carers ACT</p> <p>-CareSearch</p> <p>-ACT community Health – Community Care Social Work</p> <p>-ACT Coronial Counselling Service</p> <p>-Beyond Blue</p> <p>-Cancer Council ACT</p> <p>-Canberra young widows and widowers support group.</p> <p>-Clare Holland House</p> <p>-Dead parent Society</p> <p>-Dementia Australia ACT</p> <p>-DonateLife ACT</p> <p>-Everyman</p> <p>-Grief Line</p> <p>-Grief Link</p> <p>-Kids helpline</p> <p>-Lifeline</p> <p>-Mensline Australia</p> <p>-Parentline</p> <p>-Reach Out Australia</p> <p>-Stella Bella Little Stars Foundation</p> <p>-The Compassionate Friends ACT and Queanbeyan Relationships Australia</p>	<p>-Aboriginal and Torres Strait Islander Health Partnerships (Policy, Partnerships and Programs) - Partnership Team, ACT Health</p> <p>-Palliative Care Governance Committee, ACTHD</p> <p>-Consumer reference group for End of Life and Palliative Care</p> <p>-Canberra Multicultural Community Forum (CMCF)</p> <p>-Australian and New Zealand Society of Palliative Medicine (ANZSPM)</p> <p>-Public Advocate of the ACT</p> <p>-GP Policy Advisor – ACT Health Directorate</p> <p>-ACT Palliative Care Operations Management Committee</p> <p>-End of Life Communications Working Group</p> <p>-Health Care Consumers Association of the ACT</p> <p>-ACT Council of Social Services (ACTCOSS)</p> <p>-Council of the Ageing (COTA)</p> <p>-The Aged & Community Care Providers Association (ACCPA)</p> <p>-Multicultural Communities Council of the Illawarra (MCCI)</p> <p>-Federation of Indian Associations of the ACT Inc</p>

Note: Services listed across more than one category of services; * Not palliative care specific service but provides support to palliative care providers and patients

SPECIALIST PALLIATIVE CARE SERVICES

Table 4 below summarises specialist palliative care services across the ACT with these being confirmed through the stakeholder consultations. The stakeholders discussed the need for a specialised palliative care workforce supported by palliative care trained generalist to close the gaps in service provision. The conversation around respecting patient preferences at the end-of-life indicated the importance of palliative care health services being open to other cultural beliefs and norms.

Table 4: Specialist Palliative Care Services, ACT

Service or Program Name	Services provided	Number of Staff or available facility
Clare Holland House (CHH)	<ul style="list-style-type: none"> All patients must be referred to Calvary's Specialist Palliative Care Services by their General Practitioner, Specialist, another health service or an aged-care facility. Calvary Bruce Public Hospital's Community Specialist palliative care services operate from Clare Holland House. Provide outpatient clinic services, care in the home or residential setting, and inpatient hospice services. Palliative Care Needs Rounds [19] is a service provided to residents in Aged Care Facilities by a dedicated team of specialist palliative care nurses from Clare Holland House. The service reaches into 28 Aged Care Facilities in the ACT. Community Specialist palliative care services offer home visits, facilitate access to equipment, provide telephone support, support bereaved amongst other services. Clinical Services Specialist palliative care consult services to North Canberra Hospital and the Canberra Hospital. Outpatient clinics – Consult/Registrar ACT Motor Neurone Disease service NSW/ACT – Specialist palliative/Medical Consultant/Registrar Renal Supportive Care Service TCH – Specialist Palliative Care input provided by CHH. Winnunga Supportive Care Service – Specialist Palliative Care input from CHH. After hours Consult/Registrar cover through ACT (24/7). Education Weekly Multidisciplinary education sessions Fortnightly Registrar Education sessions Monthly Senior Clinical Review Meeting ACT PEPA Program In service education to nurses and allied health staff. Research North Canberra Hospital/CHH Centre for research in Palliative Care and EoLC conducts multidisciplinary translational research in palliative care. 	<ul style="list-style-type: none"> 27 bed hospice Resources for Patients, Family and Carers 3 FTE Medical Staff Specialists 4 FTE Advanced Trainee Registrars 1 FTE RMO at CHH 67.5 FTE nursing staff (RN's 1, 2, 3, 4, Nurse practitioners working across inpatient, outpatient and home base palliative care. 1.8 FTE nursing education team. 16.8 FTE Allied health – team lead, physiotherapists, occupational therapists, social workers, psychologist, allied health assistance and pastoral cares. 6.7 FTE admin support. PCACT volunteers provide companionship and comfort to clients; supporting families/carers; assisting with transport for appointments; accompanying clients for walks; assisting at mealtimes; assisting with letter writing or reading to patients; providing hand and foot massages; and helping on the CHH reception desk (after hours).
Canberra Health Service (CHS) specialist	<ul style="list-style-type: none"> Service is available for patients who are referred by a GP or from within Canberra Health Services Provide care in various settings including Canberra Hospital. Adult specialist palliative care team: Nurse, doctor, social worker, and psychologist 	<p>For medical hours</p> <ul style="list-style-type: none"> 1 FTE staff specialist 1 FTE of BPT registrar

Service or Program Name	Services provided	Number of Staff or available facility
palliative care team	<ul style="list-style-type: none"> • Rapid Assessment Palliative Service available • The Enhanced care program an outpatient service focused on care needs of people who are disadvantaged or vulnerable. Provides access to flexible clinic services and telehealth. A collaborative case conferencing model is developed and being implemented for patients from various primary care providers where patient stories are bought by primary care clinicians to case conferencing with the specialist palliative A palliative care plan is developed under these case-conferencing arrangement. 	<ul style="list-style-type: none"> • 0.2 FTE seconded staff specialist support from CHH
Paediatric Palliative Care Service, CHS	<ul style="list-style-type: none"> • Paediatric Palliative Care Nurse based at Canberra Hospital working alongside paediatrician and treating team to provide support either in hospital or at home. • Children are predominantly referred to Sydney Children’s Care Network and hence work closely with them to ensure continuity of care when child returns home 	<ul style="list-style-type: none"> • One FTE paediatric palliative care nurse
Queanbeyan Palliative Care Services, Queanbeyan HHS¹	<ul style="list-style-type: none"> • Referrals are accepted from any source. • Although situated in New South Wales and funded by Palliative Care NSW, this service is accessed by some residents of the ACT. • The service is provided by community nurses, GPs, and other doctors, and by staff in hospitals and residential care facilities. • Specialist palliative care staff are also available to provide support with problems that are more complex. • Specialist Palliative Care nurses provide assessment, advice, support, and care planning on a consultative basis for patients at home, in acute care facilities and RACFs, working collaboratively with primary care providers. • Monday-Friday specialist nursing service with generalist nursing backup on weekends. Limited on-call specialist service on weekends. 	<ul style="list-style-type: none"> • Nurses • Doctors
Renal Supportive Care Clinic, CHS²	<ul style="list-style-type: none"> • Renamed from “Renal Palliative care” to “Renal Supportive Care”. • Offer specialist symptom management and support and End of Life care management for chronic kidney disease patients and their significant others. Provide inpatient consultations, outpatient clinics by referral, telephone consultations, home visits and nursing home visits by appointment only. • The Renal Supportive Care nurse supports people with chronic kidney disease who are experiencing severe symptoms related to their illness. The nurse also supports patients and families who opt not to have dialysis treatment. The team works alongside palliative care to help maintain the quality of life and plan for future. 	<ul style="list-style-type: none"> • One FTE Nephrologist • One FTE nurse • Part time social worker • Dietician
Advance Care Plan Services, CHS	<ul style="list-style-type: none"> • The Advance Care Planning Program is available at Canberra Health Services. • The service is available within hours, Monday to Friday 8:30am to 4:30pm 	<ul style="list-style-type: none"> • 1 FTE Manager • 1.4 FTE Program Officers

¹ <https://www.snswhd.health.nsw.gov.au/our-services/palliative-care-services>

² https://www.canberrahealthservices.act.gov.au/__data/assets/pdf_file/0003/1935741/CHS_Renal-supportive-care-Information_Consumerhandout_V4_accessible-FA.pdf

PRIMARY CARE CLINICAL SERVICES PROVIDING PALLIATIVE CARE

Clinical services in primary care and/or community settings that specifically mention providing palliative care service on their websites are listed below (Table 5). These include services delivered through Canberra Hospital as well as other clinical services in the community.

Table 5: Primary Palliative Care Clinical Services

Service	Description	Number of Staff or available facility
Examples Clinical Services provided by Canberra Health Services (hospital and community based)		
Community Care Program, CHS	<ul style="list-style-type: none"> GP, Community Nursing and Allied Health teams³ provides person-centred care for people with a range of conditions and health care needs. Nursing: At home or clinics Accept after hours/weekend/public holiday referrals from health professionals only. These referrals are made via the LINK team. LINK team: Specialist Clinical Nurse Consultants provide expert advice and support in the areas of continence, stoma, wound management, primary palliative care, chronic and complex care, and post-acute care. 	<ul style="list-style-type: none"> LINK nurses One FTE GP Nursing, Nutrition, Occupation Therapy, Physiotherapy, Podiatry
Paediatric Liaison and Navigation Service (PLaNS), CHS⁴	<ul style="list-style-type: none"> To help the child and their family get the care, information, and support that is right for the child. To help navigate the health system for parents with a child under 18, who has complex health needs or is seriously ill and they need to travel outside the ACT for specialist medical care 	<ul style="list-style-type: none"> Not available
Rehabilitation, Aged and Community Services Canberra Health Services (specialist services but not necessarily palliative care specific)	<ul style="list-style-type: none"> Provides integrated clinical services in hospital, outpatient settings and at home for people with acute, post-acute and long-term illnesses. RACS services include prevention, assessment, diagnosis, treatment, support, rehabilitation, and maintenance of conditions. 	<ul style="list-style-type: none"> Not available
Examples of Disease Specific Clinical Services		
ACT Motor Neurone Disease (MND) service NSW/ACT⁵	<ul style="list-style-type: none"> Support group within ACT Support to people with MND through the NSW_ACT branch of MND Australia People living with MND might be referred to palliative care services at the beginning of their diagnosis to support their condition. Some people access palliative care throughout the course of the disease and at the end of the life. 	<ul style="list-style-type: none"> A MND NSW/ACT Regional Advisor and access to: <ul style="list-style-type: none"> Doctors Social workers Allied health professionals

³ <https://www.canberrahealthservices.act.gov.au/services-and-clinics/allied-health>

⁴ https://www.canberrahealthservices.act.gov.au/data/assets/pdf_file/0009/2195424/CHS-Paediatric-Liaison-and-Navigation-Service_A4_AADIGITALFA.pdf

⁵ <https://www.mndnsw.org.au/>

Service	Description	Number of Staff or available facility
Canberra Region Cancer Centre, CHS ⁶	<ul style="list-style-type: none"> • Cancer Counselling Service (two of three people requiring palliative care have cancer diagnosis) • Available to people who are accessing the public health system in the ACT who have a cancer or a diagnosis of cancer in the last 3 years and their family/carers. • This service is available to those aged 16 years and over. 	<ul style="list-style-type: none"> • Social Workers • Psychologist
Examples of Clinical Services within Community Setting		
The Winnunga Nimmitjahn Health and Community Service Supportive Care Clinic	<ul style="list-style-type: none"> • Aboriginal community controlled primary health care service operated by the Aboriginal and Torres Strait Islander community of the ACT 	<ul style="list-style-type: none"> • Doctors • Nurses • Dental clinics • Allied health professionals
Next Practice Deakin Medical Clinic	<ul style="list-style-type: none"> • Private general practice with general practitioners, geriatrician, outreach doctor, clinical psychologist and pharmacist all onsite that includes palliative care as one of the key services. 	<ul style="list-style-type: none"> • Multiple

COMMUNITY-BASED NON-CLINICAL SERVICES PROVIDING PALLIATIVE CARE RELATED ADVICE

Community based non-clinical services include services that are delivered by peak bodies along with the community services that specifically focus on palliative care and end-of-life care support services.

Table 6: Community based non-clinical services supporting Palliative Care

Service	Description
Palliative Care ACT	<ul style="list-style-type: none"> • Peak Body: advocates and promotes quality of life (QoL) • Recruit, train and support volunteers • DAISY: directory of community resources • PACT Volunteers visit clients living at home and in residential aged care facilities. They provide a range of services including Life Story writing. The time and duration of each visit depends on the client's assessed needs. PACT volunteers also visit Clare Holland House and complete shifts ranging from 2 – 3 hours. They are usually two volunteers on each shift-
Palliative Care ACT-Leo's Place Respite care	<ul style="list-style-type: none"> • Home-like respite accommodation for up to 4 clients overnight as well as 4 clients for day respite. • Provides, overnight respite, day respite and carer support. • Carer support includes access to advice, information, and self-care activities.
Community Options Palliative Care Support Program	<ul style="list-style-type: none"> • Palliative Care Coordinator assists people, their carers and families in managing practical in-home supports in the end stages of life. • Case-management of in-home support and community-based support • Provide personal care, domestic help, social support, respite and case management. • No medical/clinical help.
Advance Care Planning ACT	<ul style="list-style-type: none"> • Advance care planning (ACP) supports clients and families in planning for the management of and choices in relation to their future health care. ACP is based on the principles of autonomy and dignity.

⁶ <https://www.canberrahealthservices.act.gov.au/services-and-clinics/services/cancer-counselling>

Service	Description
Be My Voice	<ul style="list-style-type: none"> Provides information to community and health providers about Advance Care Planning (ACP) guidance and assistance.
CanTeen	<ul style="list-style-type: none"> Canteen provides tailored support for young people impacted by cancer. Canteen supports 12–25-year-olds dealing with their own diagnosis, a close family member’s cancer or the death of a loved one. Services now extend to parents, because when they cope better with cancer and communicate openly, their children are likely to experience less distress and anxiety.
The Violet Initiative	<ul style="list-style-type: none"> A not-for-profit organisation that provides free information and support focusing on the last stage of life and the grief and loss that accompanies.
R & R Respite Services	<p>Provides a broad range of supports including:</p> <ul style="list-style-type: none"> Respite Services/Emergency Respite Personal Care Assistance Domestic Assistance (washing and ironing etc) Social Support/Transport (shopping, banking and medical visits) 24 Hour and Overnight Services Garden Maintenance.

OTHER SERVICES

Other community services were identified during the desktop searches and through the stakeholder consultations. These services do not necessarily focus on palliative and end-of-life care specific services, however, play a critical role in providing clinical and/or non-clinical support for people during vulnerable times in a person’s life. These services are listed below, and further details of these services are in the excel document attached with this report.

Table 7: Key examples of other services and private sector providers

Name of the institution	Description of the services related to Palliative care
Australian Centre for Grief and Bereavement	An independent, not-for-profit organisation providing support for bereaved and grieving Australians.
Canberra Grief Centre	Specialise in the provision of services to support grief, bereavement and trauma associated with a loss.
Carer Help	Support carers to prepare, plan and cope with caring for a person with terminal illness and at the end of life.
Carers ACT	Provides support to all unpaid carers. Connecting with other carers, provide advice and guidance, give carers a break when needed and offer services to make caring easier.
CareSearch	Funded by the Australian Government Department of Health and Aged Care to provide a range of palliative care information for patients, carers, families and health professionals.
Cancer Council ACT	A non-government, not-for-profit community organisation that aims to promote a healthier community by reducing the incidence and impact of cancer in the ACT region.
Dementia Australia	As part of the service offering, Dementia Australia provides palliative care advice for those affected clients and their carers. The program is a personalised, nurse-led support providing advice, as well as clinical and emotional support.
Hepatitis ACT	Not a palliative care specific service, however, it works closely with cancer care, palliative care and community support services to ensure patients/carers affected by hepatitis receive required information and support services.
Community Options INC	A not-for-profit community-based organisation that provides complex and intense care coordination services to older people, people with disabilities and their families and friends.
ACT Disability ,Aged and Care Advocacy service	ACT Disability, Aged and Carer Advocacy Service is an independent not for profit advocacy organisation. We promote and protect the rights of people with disability, people experiencing mental ill-health, older people, and their carers.

Name of the institution	Description of the services related to Palliative care
Australian Red Cross ACT	Community support services for aged care services including palliative care patient services.
ACT Ambulance Service	The ACT Ambulance Service (ACTAS) is responsible for providing emergency and non-emergency ambulance services to the ACT community.
Capital Complementary Therapies Centre	A private health centre that provides traditional therapies such as homeopathy, herbal medicine, acupuncture, and massage therapy. Palliative care patients are referred to these services.
Capital Health Network (CHN)	CHN commissioned Capital Chemist Wanniasa and Capital Chemist Charnwood to deliver the 'After Hours Home Palliative Medicines Program' for the last four years. The program no longer exists however allowed for timely provision of palliative medicines to a patient's home (including Residential Aged Care Facilities (RACF)) and education to the caregivers. The program included palliative care education for the community pharmacist, so that they have the confidence and skills to support dying patients and their caregivers. In April 2022, the Palliative Care Planning Manager commenced at CHN and has begun extensive stakeholder consultation to understand the current palliative care landscape across the ACT.
CatholicCare Canberra	Providing a wide range of community-based support services including counselling and family support and other services including homelessness, disability support (NDIS services), mental health, aged care, youth outreach, drug and alcohol or housing support.
Goodwin Home Care	Delivers government subsidised programs such as Home Care Package and Commonwealth Home Support Programme to support independence, wellness, and reablement. It also provides privately funded home care services for those clients who are not eligible for government-funded package or waiting to be approved for the funded services.
Kincare	In-home aged care services connected with care pathways, ensuring the most appropriate in-home care services for patients. It also offers domestic assistance, social support, respite care, personal care, client assessment and care coordination.
Meridian	Peer-led organisation that provides health and social support services to communities in the ACT region. Meridian offers a wide range of community-focused wellbeing services. Volunteers use lived experience to lead the way in providing safe, inclusive, and affirming support for all experiences and identities. Have a wellbeing team and registered mental health professionals, including Psychologists and Counsellors.
Meridian Aged Services Navigation	Meridian's Aged Services Navigation Team deliver face to face care finder services, in an environment where the person feels comfortable, such as in their home, café, park or office.
Prestantia Health Public	Provide outreach care to housebound older people, those residing in aged care and disability homes.
Council on the Ageing ACT	Provides a range of support programs including the Seniors Information Line, an ACT-wide information and referral service that works with palliative care services in ACT.
The Canberra Alliance for Harm Minimisation and Advocacy (CAHMA)	CAHMA provides services & programs to support the health & human rights of people who use drugs & drug treatment services. This can include people who are requiring palliative and/or end-of-life care.
Woden Community Service (WCS)	Community services provided include aged care support and mental health and wellbeing that includes assessment and care coordination.

PALLIATIVE CARE WORKFORCE

The palliative care workforce is made up of a broad range of professional groups. It includes specialist palliative medicine physicians, palliative care nurses, GPs, allied health professionals, other medical specialists (such as oncologists and geriatricians), as well as other health workers, support staff and volunteers. However, the existing national data sources only capture information on physicians and nurses with a primary specialty of palliative medicine [20].

- Workforce data on demographics and average hours worked per week are not available by jurisdiction.
- Nationally, between 2016 and 2020, there was a 29.1% increase in the number of palliative medicine physicians employed and a 9.5% increase in palliative care nurses.
- Average hours worked by palliative medicine physicians and palliative care nurses varied by state and territory. For palliative medicine physicians, however, the ACT and NT data is not presented due to its small counts. For

palliative care nurses, average clinical hours worked per week were 29 hours for ACT (Australia 31 hours) (See Table 8 on the next page).

- FTE and clinical FTE rates for palliative care nurses in the ACT was same at 0.2 FTE per 100,000 population.

Table 8: Average hours worked per week, FTE and FTE per 100,000 population of employed palliative care nurses, by states and territories 2020

State/territory	No of hours worked	Average hours worked per week	Average clinical hours worked per week	FTE* (n)	Clinical* FTE (n)	FTE per 100,000 population	Clinical FTE per 100,000 population
NSW	1,054	35	33	975	912	3.8	3.5
VIC	1,113	31	29	916	861	3.6	3.3
QLD	728	33	31	631	599	2.5	2.3
WA	403	32	31	337	323	1.3	1.3
SA	273	31	29	225	211	0.9	0.8
TAS	117	31	30	96	91	0.4	0.4
ACT	71	33	29	62	55	0.2	0.2
NT	38	36	35	36	35	0.1	0.1
Australia	3,797	33	31	3,278	3,087	12.8	12.0

Source: AIHW, 2022 Palliative care services in Australia: Palliative care workforce 2020 (retrieved from Table Wk.4)

Note: *FTE=clinical & operational roles, Clinical FTE=Solely clinical role

3.1.2 Utilisation of Palliative Care Hospital Services in the ACT

Palliative care is delivered not only through government agencies but also private and not-for-profit organisations in a range of health care settings. These could be located within the ACT or in other jurisdictions. The services include specialist inpatient and community-based palliative care services, paediatric services, geriatric services, public and private hospitals, general practices, disability services, and residential and community aged care services [21]. Utilisation data on these services is very limited and utilisation of hospital based palliative care services is summarised below.

Nationally, in 2020-21 [21]:

- there were just over 90,700 palliative care-related hospitalisations in public and private hospitals.
- about 2 in 5 (42%) palliative care hospitalisations recorded a principal diagnosis of cancer
- 1 in 2 hospitalisations (53%) ended with the patient dying in hospital (65% for palliative care hospitalisations and 40% for other end-of-life care hospitalisations).

Admitted patient palliative care and other end-of-life care (2015-16 to 2020-21) in Australia outlines the following for palliative care-related hospitalisations provided by the ACT public health system [22].

- There is no private hospital data publicly available at the time of this report. In 2020-21, the age standardised rate of in the ACT was 29.9 per 10,000 population, this was higher than the national rate of 27.8 per 10,000 population (See Table 9 below).
- The rate of palliative care hospitalisations (hospitalisations with a care type of *Palliative care*) was 18.4 per 10,000 population and 11.4 per 10,000 population for other end-of-life care in 2020-21 (hospitalisations that included a diagnosis of *Palliative care*)
- The ASR for palliative care-related hospitalisations in the ACT decreased from 35.7 per 10,000 population in 2015-16 to 29.9 per 10,000 population in 2020-21. This decrease may not suggest a decrease in the need for palliative and end-of-life care in the ACT. Rather, it needs to be considered in light of other contextual events

such as COVID-19 restrictions and/or the introduction of palliative care programs implemented through other settings such as primary care.

- In 2020-21, the ACT had the highest average length of stay (ALOS) across all jurisdictions for palliative care-related hospitalisations (11.6 days, excluding same-day separations, Australia 9.2 days). However, it should be noted that the ACT has only one in-patient unit at present for palliative care admissions. As per PCOC data which benchmarks palliative care services throughout the country shows that the ALOS is well within the accepted levels compared to other jurisdictions.
- ALOS for palliative care hospitalisations was 10.1 days (Australia 8.3 days) and 12.8 days (Australia 10.4 days) for other end-of-life care hospitalisations in the ACT.

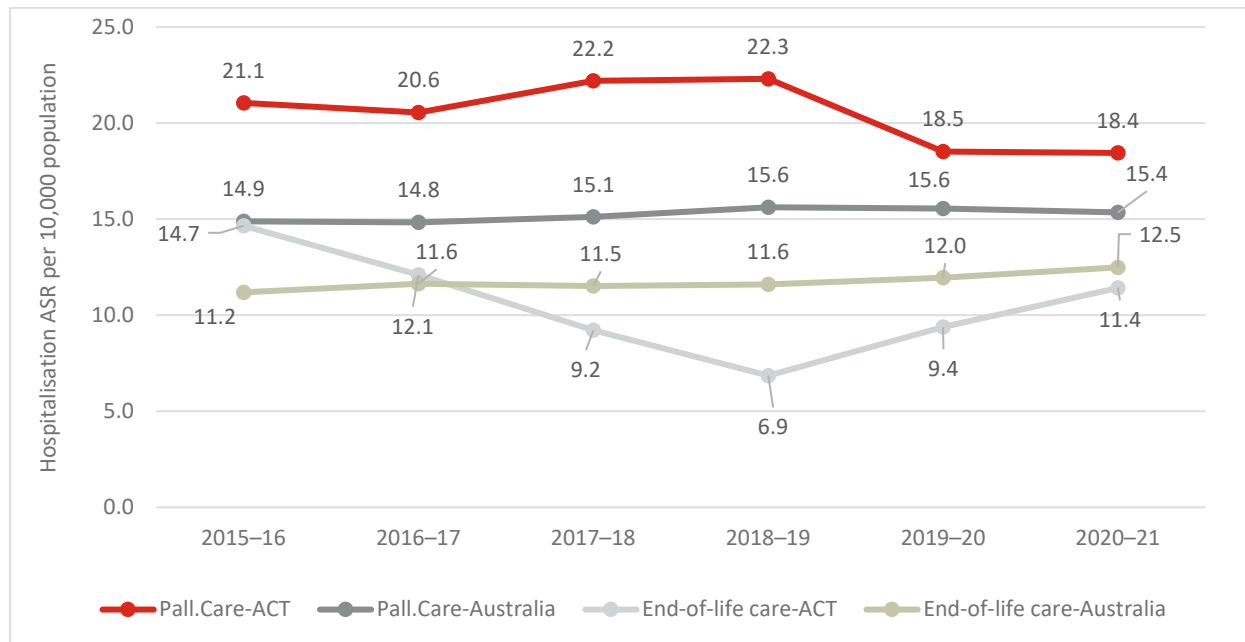
Table 9: Aged standardised hospitalisation rates per 10,000 population (public hospitals only) for palliative care, other end-of-life care, and total palliative care-related care, states and territories, 2015–16 to 2020-21

State/territory	2015–16	2016–17	2017–18	2018–19	2019–20	2020-21
Palliative care hospitalisations						
NT	26.2	28.7	29.9	27.3	27.2	28.4
Qld	19.3	19.2	19.9	21.1	22.2	21.9
ACT	21.1	20.6	22.2	22.3	18.5	18.4
NSW	16.0	16.1	16.6	17.3	16.7	16.9
Tas	14.9	13.9	15.6	14.3	13.8	14.5
WA	13.6	14.5	13.9	13.2	14.1	13.5
Vic	11.8	11.4	11.0	11.3	10.8	10.6
SA	10.2	9.6	9.9	11.4	11.3	9.3
Australia	14.9	14.8	15.1	15.6	15.6	15.4
Other end-of-life care hospitalisations						
NT	22.4	22.5	14.9	15.6	21.4	22.8
Tas	22.1	23.8	21.5	19.5	17.2	17.6
Vic	18.6	17.6	17.9	17.2	16.2	16.3
SA	17.3	19.0	16.4	16.1	19.0	15.9
NSW	7.9	8.5	9.1	9.8	10.7	12.1
ACT	14.7	12.1	9.2	6.9	9.4	11.4
WA	7.6	8.9	8.2	9.5	9.5	10.5
Qld	4.2	5.7	5.8	5.7	6.3	7.0
Australia	11.2	11.6	11.5	11.6	12.0	12.5
Total palliative care-related hospitalisations (hospitalisations for palliative care and other end-of-life care)						
NT	48.5	51.3	44.9	42.8	48.6	51.2
Tas	37.0	37.7	37.2	33.8	31.1	32.1
Vic	37.0	37.7	37.2	33.8	31.1	32.1
SA	30.4	28.9	28.8	28.5	27.0	26.8
NSW	27.5	28.6	26.3	27.5	30.3	25.2
ACT	35.7	32.7	31.4	29.2	27.9	29.9
WA	21.2	23.5	22.1	22.7	23.6	24.1
Qld	23.5	24.8	25.7	26.8	28.5	29.0
Australia	26.1	26.5	26.6	27.2	27.5	27.8

Source: AIHW, 2023. Palliative care services in Australia: Admitted Patient Care Palliative care 2020-21: Table APC.11 sourced from National Hospital Morbidity Database, AIHW

Palliative care hospitalisation rate in the ACT is higher than Australian rate; but end-of-life care hospitalisation is slightly lower [22] (Fig 3). Estimated utilisation of palliative care services in the ACT Health Services Plan 2018-2028 indicates that Calvary Public Hospital Bruce (CPHB) Palliative Medicine has the largest forecast average growth rate per annum of 5.2 per cent of all medical specialties across the Territory for multi-day inpatient separations. Palliative medicine has also a forecast average increase per annum of 4.5 percent for multi-day bed-days at CPHB between 2017–18 and 2031–32 [16]. Australian data and reports suggest utilisation of specialist palliative care services across all care settings (home, residential facilities, hospital and hospice) continues to exceed current specialist palliative care workforce capacity.

Figure 3: Palliative care and other end-of-life care hospitalisations per 10,000 population, from 2015-16 to 2020-21, ACT and Australia



Source: AIHW, 2023. Palliative care services in Australia: Admitted Patient Care Palliative care 2020-21: Table APC.11 sourced from National Hospital Morbidity Database, AIHW

Hospitalisations for palliative related in the ACT public health system.

Admitted patient care data was provided by the Policy, Partnerships and Programs Division of the ACT Health Directorate. Hospital separations (hospitalisations) provided by, or on behalf of, the ACT public health system were included where the hospitalisation had a recorded care type of *Palliative care* or where a hospitalisation included a recorded diagnosis of palliative care. [23].

In the period between 01/07/2017 – 30/06/2022 (See Table 10):

- there were 6,355 palliative care-related hospitalisations with a recorded care type of *Palliative care* (4,353) or a recorded diagnosis of palliative care (2,002) where the care type is not *Palliative care* (2,002)
- just over half of hospitalisations (50.3%) were for males and 49.7% were for females.
- 94 (1.4%) hospitalisations were for people of Aboriginal and Torres Strait origin and 97.7% for non-indigenous Australians (data only available by Indigenous status, no CALD data available).

Table 10: Palliative care hospitalisations^(a) (hospitalisations for palliative care and other end-of-life care) by sex and Indigenous status

Demographic characteristics	Number	Percent (%)
Sex		
Male	3,198	50.3
Female	3,156	49.7
Total^(b)	6,355	100.0
Indigenous status		
Aboriginal and Torres Strait Islander Origin	94	1.5
Neither Aboriginal nor Torres Strait Islander origin	6,209	97.7
Not stated/Inadequately described	52	0.8
Total	6,355	100.0

(a) Palliative care hospitalisations include hospitalisations with a recorded care type of *Palliative care* or a recorded diagnosis of Palliative care (Z51.5) where the care type is not Palliative care (b) Total includes 1 separation with sex recorded as *Other*.

Source: ACT Health Directorate, ACT Health Data Repository, 2023

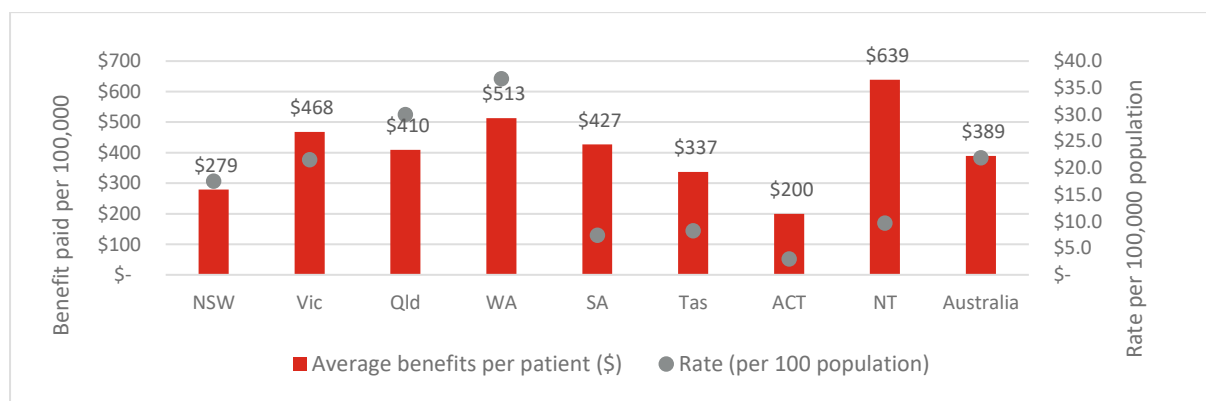
3.1.3 Cost of the Services

Currently there is limited cost data available on palliative care services delivered in the community and primary care settings. Data on the Medicare Benefits Schedule-subsidised services provided by general practitioners and non-palliative care medical specialists, and the number of palliative care beds in hospitals, both acute and subacute are not captured in national palliative care data [24].

The data provided here includes specific settings where systems are in place to record (or code) a palliative care service, in particular specialist palliative care. Through the online survey of ACT working in Palliative Care, limited responses were provided in relation to the cost of accessing the services. Nonetheless, it did inform on the type of funding sources and approximate amount of funding received by these organisations as presented in subsection 3.1.4.

The data on benefits paid by the MBS for palliative care specialist services is available from the AIHW. Over \$5.6 million was paid in benefits for MBS-subsidised palliative medicine specialist services during 2021–22, which is equivalent to an average of \$389 per patient; 81% of these benefits were for palliative medicine attendances and 19% for case conferences Figure 4 below shows the average benefits paid (\$ per patient and the rate per 100,000) on MBS-subsidised palliative medicine specialist services in 2021-22 [25]. As shown, NT had the highest average benefits per patient at \$639 followed by WA (\$513 per patient), and the ACT had the lowest average benefits paid per patient (\$200) (Fig 4).

Figure 4: Benefits paid (\$) on MBS-subsidised palliative medicine specialist services in 2021-22, by states and territories, amount (\$) paid per patient and the rate per 100,000 population.

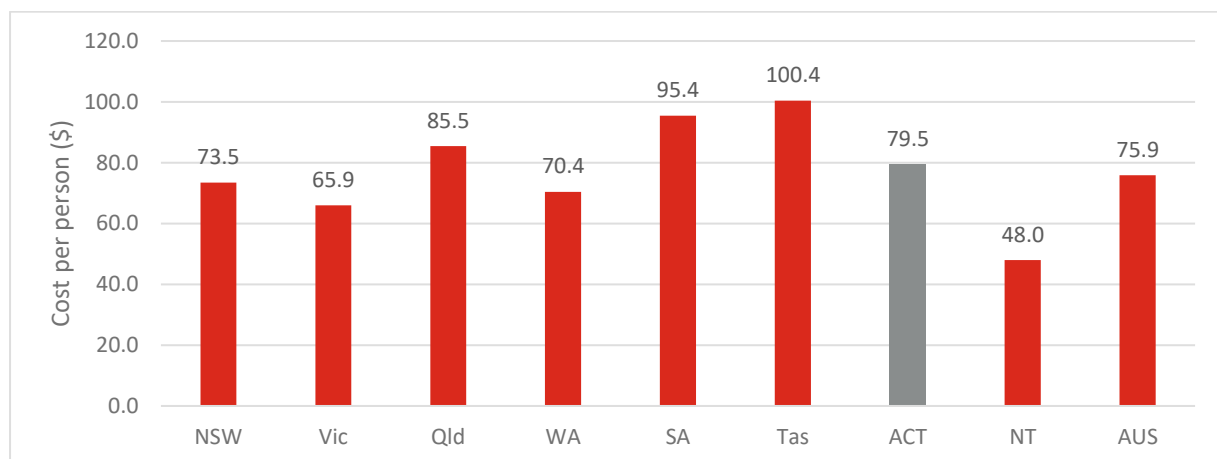


Source: AIHW, 2022 Palliative care services in Australia: Medicare-subsidised palliative medicine services 2021-22

In 2021-22[26],

- Nationally there were 1.3 million palliative care related prescriptions provided to about 453,300 patients costing around \$34.4 million. The cost of pain relief medication accounted for 87% (or \$30 million) of all palliative care prescription expenditure.
- In the ACT, a total of \$621,857 was spent on palliative care medication; 94% of which was spent on pain relief medication, 3.2% on medications for gastrointestinal symptoms and 2% of expenditure for psychological symptoms. Cost per person was \$79.5; this is slightly higher than the Australia average cost of \$75.9 (See Figure 5 below).

Figure 5: Palliative care medication expenditure, cost per person, by states and territories, 2020-21



Source: AIHW, 2022 Palliative care services in Australia: Palliative care-related medications 2021-22

Palliative care is usually provided with no out-of-pocket costs at the point of service under the Medicare Benefits Scheme in the public health system. However, not all palliative care related expenses are covered by Medicare. Therefore, patients may incur some out-of-pocket expenses such as specialised equipment, 24-hour nursing staff, private hospital stays, some respite care or alternative treatments [27]. Some individuals may have private health insurance coverage, which can provide additional benefits for palliative care services. The coverage may vary depending on the insurance plan and level of coverage chosen. Nevertheless, there is limited data regarding palliative care out of pocket costs. Consultations also revealed that some of the palliative care services are obtained by patients under the NDIS or Aged Care funding schemes.

3.1.4 Funding Sources

There was no comprehensive source of funding data for palliative care provided through primary care settings. However, admitted patient care data provides palliative care hospitalisation data. The funding sources for palliative care hospitalisation include public funding (Medicare), Private health insurance, Department of Veterans' Affairs (DVA) as well as other sources such as charity/philanthropy. Public funding is the main source of funding for both palliative care (70.3%) and end-of-life care services (82.4%) in the ACT followed by private health insurance, 24.1% and 12.7% respectively.[21] This pattern was similar to that of other states and territories.

Information gathered from the survey responses during this project informed about the type of funding sources and approximate amount of funding received by the organisations that responded. Some organisations were funded by multiple sources. From 16 organisations that completed the survey, 12 organisations were federally funded and 10 were state funded (See Figure 6). There were six organisations that are funded by both state and federal government while 10 organisations are funded from three or more different sources [28].

Table 11: Number of services by type of funding sources, Total n=16

Funding Type	Number of organisations receiving funding
Federal	12
State	10
Private	7
Charity	7
Other	5

Note: The total is not 16 as some organisations are funded by multiple resources

Data from Abt Associates, Palliative Care Service Mapping Survey data 2023, Palliative Care Service Function Review Project [28]

Complete funding details were provided by 14 (14/16) organisations (See Figure 6 below) through the online survey. While not all provided details of their funding, stakeholders indicated that there is insufficient funding in palliative care to address the future demand in terms of workforce.

Figure 6: Amount of funding by type of funder, n=14 responses



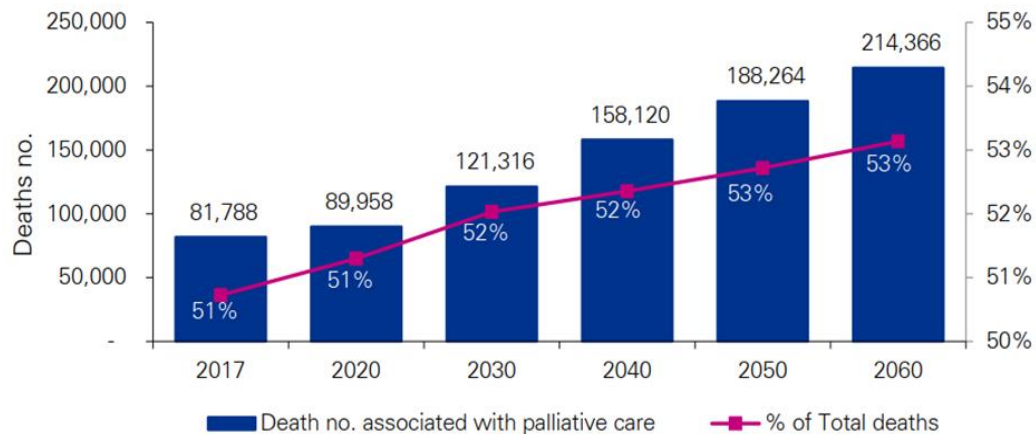
Source: Abt Associates, Palliative Care Service Mapping Survey data 2023, Palliative Care Service Function Review Project [28]

3.1.5 Potential Return of Investment

Palliative Care Australia commissioned KPMG health economists to undertake research on the economic value of palliative care. The research studied the Australian population’s future palliative care needs (Fig 7) and proposed effective interventions in consultation with clinical and academic experts [29, 30].

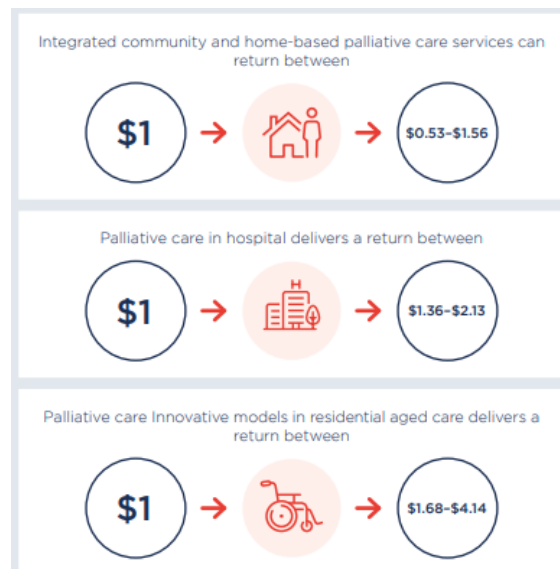
The KPMG report recommends investing in palliative care as it reduces the end-of-life costs to Government and improves health and social outcomes for people experiencing life-limiting conditions. The Fig 8 below presents estimates of the returns on every \$1 invested in palliative care. These returns can be achieved through investing in coordinated home, community, and aged care/residential care services where that prevents the higher cost end-of life care of a hospital setting. Palliative Care Australia Roadmap 2022-2027 [31] used this estimate as a basis of their future strategy in investing in Palliative care in Australia.

Figure 7: Estimates of need for palliative care in Australia 2017-2060



Source: Palliative Care Australia and KPMG analysis 2019; Sleeman et al (2019) [29, 30]

Figure 8: Return of investment of every \$1 invested in palliative care, by service type



Source [29]: KPMG (2020), Investing to Save: The economics of increased investment in palliative care in Australia cited in Palliative Care Australia Roadmap 2022-2027 Note: In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.

3.1.6 Key Learnings

The key learnings from the mapping include:

1. **Service mapping process still realised gaps in key information.** The service mapping provided a good understanding of the clinical services and some understanding of community services across the ACT. Although the online survey helped to gather reasonable information on aspects such as funding sources, opening hours and after-hours availability, amounts of funding by source, workforce and utilisation data was not so well addressed in the service responses. Consideration could be given to instituting an annual survey of service providers across the ACT that gathers service-related information (opening hours, outreach services, after-hours services, wait times), workforce (FTE, profession, skills, and gaps), and funding (including source) and cost data. It could be expected that reporting will improve over time as services get used to the annual survey and see the benefits of access to reliable information about the whole sector (ensuring privacy aspects are appropriately addressed).
2. **Broad range of services available to people requiring palliative and end-of-life care.** The mapping identified 63 services across specialist and primary care clinical services and community based non-clinical

services across the continuum of care. There are however some key gaps and unmet need that is discussed in further detail in section 3.3.

3. **Higher rate of palliative care related hospitalisations and longer length of stay in the ACT than observed in other Australian jurisdictions.** Findings from the review included issues relating to access and availability of specialist and primary care clinical services in the community setting, limited after-hours clinical services and limited access to after-hours medication. These factors may be contributing to the higher rates of hospitalisation and ALOS. These factors are discussed further in section 3.3.
4. **ACT had the lowest average benefits paid per patient on MBS-subsidised palliative medicine specialist services.** The average benefits paid were highest in NT (\$639 per 100,000 population) followed by Western Australia (\$513 per 100,000 population) and Australian Capital Territory had the lowest average benefits (\$200 per 100,000 population). This learning requires further investigation.
5. **Investment in palliative care reduces the end-of-life costs to Government and improves health and social outcomes for people experiencing life-limiting conditions.** These returns can be achieved through investing in coordinated home, community and aged care/residential care services that mitigate against the higher cost end-of life care in a hospital setting (see section 3.1.5).

3.2 Characteristics of the Patients and Carers

As palliative care is provided through various health and non-health settings, having comprehensive data on patients and carers is challenging. AIHW data on palliative care-related prescription, people receiving MBS subsidised palliative care medicines and palliative care use among residential aged care clients has been used to estimate the approximate number of people using palliative care via various settings. This was also supplemented with Palliative care data provided by the Policy, Partnerships and Programs Division of the ACT Health Directorate.

This section focuses on two key questions:

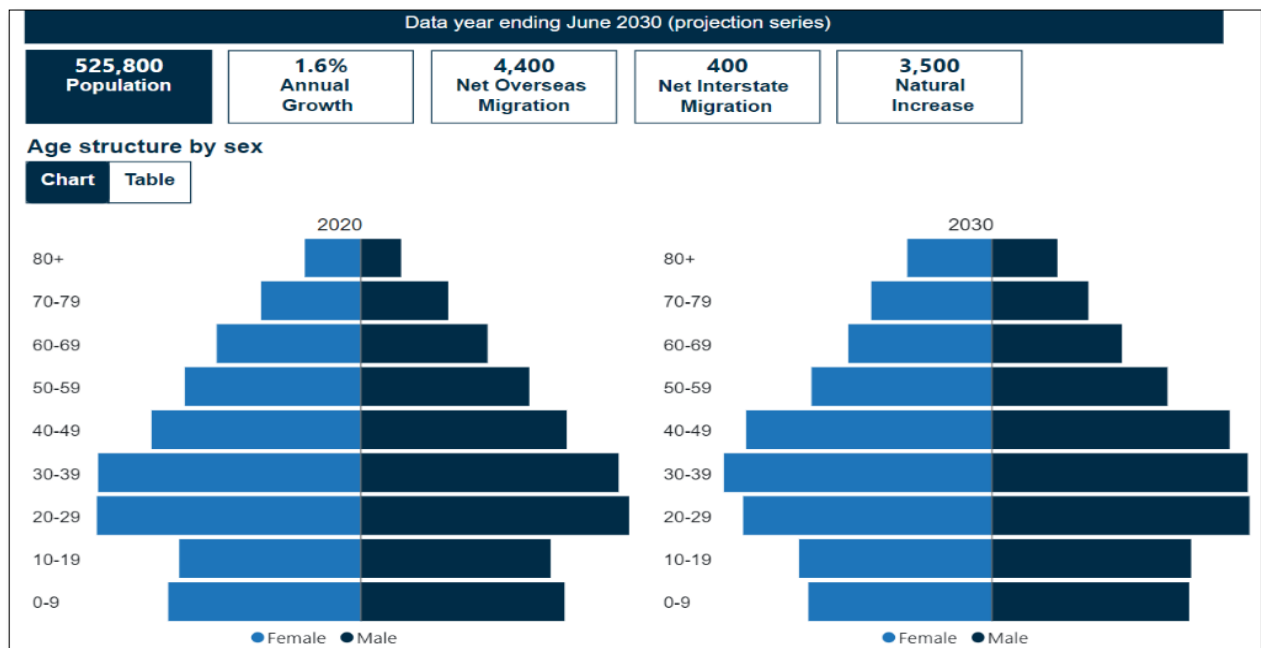
- a. *How many people require palliative care and end-of-life care services in the ACT annually?*
- b. *How many people are carers of those requiring palliative care and end-of-life care services in the ACT annually?*

3.2.1 People Requiring Palliative and End-of-life Care Services

An aging population, increasing prevalence of chronic complex conditions and increased life expectancy due to advances in the technology are the key factors that contribute to a higher demand on services that realise an improved quality of life. It is expected that with an ageing and growing population, the demand for palliative care and end-of-life care will rise substantially. It has been established that fifty percent of people using palliative care services are aged 70 and over [22].

Figure 9 below compares the population structure across the ACT in the year 2020 with that projected for the year 2030. It illustrates an increasing number of persons aged 70 years and above, rising from 40,500 people in 2020 to 58,600. [32]. This will certainly drive the demand for palliative and end-of-life care services.

Figure 9: Population structure in the ACT, comparison between 2020 and 2030.



Source: Australian Government Centre for Population, State and Territory Projections

Palliative Care Outcomes Collaboration Data

The data on the number of people requiring palliative care services for the ACT is not readily available. However, in 2021, across Australia, 58,700 patients received palliative care from the 177 palliative care services voluntarily participating in the Australian Palliative Care Outcomes Collaboration (PCOC) program [33]. The summary on the national level from this data indicates that:

- Highest proportion of palliative care services are required for people aged 65+ and specifically the age group 75-84 years
- There is a small difference between percentage episodes reported by gender (men around 4% higher compared to women)
- People living in higher socio-economic (SES) disadvantage report a greater number of episodes of palliative care, and this follows the social gradient where the lowest number of episodes are reported by people from lowest socio-economic disadvantage.
- A small proportion of episodes of care are noted from Indigenous Australians (1.9% only)
- 2 in 3 patients had a diagnosis of cancer (66% of all palliative care patients).

Overall, nationally the palliative care admissions to residential aged care facilities in 2021-22 indicated the following[34]:

- Higher percentage of female residents in RACFs (55%) had palliative care needs compared to male (45%)
- 3 in 5 (59%) were aged 85 years and over.
- 1 in 5 (21%) had cancer listed as the first condition based on their ACFI appraisal, compared with 3.7% for those appraised as requiring other care.
- Death was the main reason for leaving the RACF for these individuals with only 0.6% returning to the community.
- Percentage of people using palliative care service among people living in Permanent Residential Aged Care (PRAC) was the highest in ACT (38.9%) among all other states and territories. (See Table 12 below)

Table 12: People using permanent residential aged care with hospital leave, by care type and states and territories, 2021-22

State/territory	Palliative care		Not palliative care	
	n	%	n	%
NSW	533	29.6	20,145	26.0
Vic	305	25.0	15,965	25.6
Qld	281	33.2	15,893	32.8
WA	106	26.2	5,765	26.2
SA	82	29.3	5,225	24.7
Tas	46	25.7	1,115	18.6
ACT	35	38.9	782	25.9
NT	5	55.6	232	37.0
Australia	1,393	28.8	65,122	27.0

Source : AIHW, 2022 Palliative care services in Australia: Residential Aged Care 2021-22;

Medicare and Pharmaceutical Benefits Scheme (PBS) Data

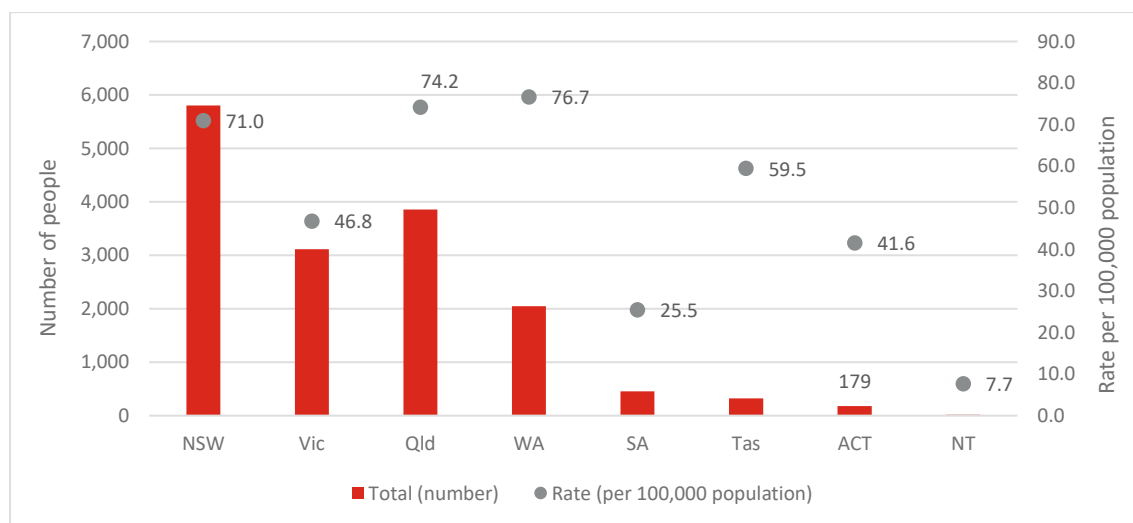
Some information is available from MBS and PBS data. Among people who received at least one MBS-subsidised palliative medicine specialist service in 2021-22, there were slightly more males – 7,300 males compared with 7,200 females (or 57 compared with 55 per 100,000 population, respectively) [25].

Nationally, 453,300 people were dispensed with at least one palliative care-related prescription in 2021–22, that is 2.0% of the Australian population (or 2,000 per 100,000 people). Although, this data is not available for the ACT, applying this percentage to the ACT population of 456,700 (as at 30 June 2022)[26], it would be estimated that about 9,100 people might require at least one palliative care-related prescription in the ACT annually.

Medicare-subsidised specialist services cover patient consultations provided in various settings such as hospital, consulting room, patient’s home or RACF, as well as case conferencing. In 2021-22 nationally, 14,500 patients received 69,100 palliative medicine specialist services (or 270 services per 100,000 population). [25]

In 2020-21, 179 patients received palliative care services in ACT, the third lowest rate (41.6 per 100,000) in Australia (See Figure 10 below)[35].

Figure 10: People receiving MBS-subsidised palliative medicine specialist services by states and territories, 2020-21 (number and rate per 100,000 population)



Source: AIHW, 2022 Palliative care services in Australia: Medicare-subsidised palliative medicine services 2020-21

3.2.2 Carers of those requiring Palliative and End-of-life services in the ACT

Informal care is generally defined as the unpaid care provided to older (65 years and over), dependent or disabled persons by a person with whom they have a social relationship, such as a spouse, parent, child, other relative, neighbour, friend, or other non-kin connection. This may involve assistance with core activities such as mobility, self-care and communication or non-core activities such as help with household chores or other practical errands, transport to doctors or social visits, social companionship, emotional guidance or help with arranging professional care [36]. Informal/unpaid carers provide a significant contribution to the health and wellbeing of Australians in need of support and assistance. Most hours of informal care are provided by primary carers, and these caring requirements place a significant impact on carers, forcing many to either reduce their hours worked or withdraw from the labour force altogether. The estimated age-standardised fulltime employment rate for primary carers is 23.7% in 2020, in comparison to the population average of 43.1% [37]. There is no specific data on carers providing care for people requiring palliative or end-of-life care. It is reported by Carers Australia [38] that the significant rates of low wellbeing amongst carers might be due to barriers to accessing informal and formal support, lack of free time, and/or financial stress.

Information on the characteristics of people who are carers of people requiring palliative care is not readily available in the ACT, however, data from other sources can be reflected upon to provide some information. In 2021, 12.8% of Australians aged 15 and older were providing unpaid assistance to a person with a disability, illness, chronic condition, or old-age related frailty [39]. A 2018 report indicates [40] that in Australia:

- There were 2.65 million carers, representing 10.8% of all Australians (down from 11.6% in 2015)
- Females were more likely to be carers (12.3% of all females) than males (9.3% of all males)
- There were 235,300 young carers (under the age of 25), down from 274,700 in 2015.
- Seven in ten (71.8%) primary carers were women.
- Over one-third (37.4%) of primary carers had a disability, twice the rate of non-carers (15.3%)
- The most common reason primary carers gave for taking on a caring role was a sense of family responsibility (70.1% of all primary carers)
- Half (50.2%) of all carers lived in a household in the lowest two equivalised gross income quintiles, twice that of non-carers (25.6%).

Carers ACT service provides comprehensive support services including quality information, community education, advocacy, and direct support services to unpaid Carers. It indicates that there are 42,000 Carers in ACT, 7000 of which are registered with Carers ACT [41]. There is no data on how many of these carers support people requiring palliation or end-of-life care. Lack of availability on specific data on carers was also mentioned by the stakeholders as a key concern.

3.2.3 Key Learnings

In describing the characteristics of the people requiring palliative and end-of-life care and their carers include:

1. **The aging of the ACT population will increase the demand for palliative care services.** The cohort of the ACT population aged 70 years and above is estimated to increase from 40,500 people in 2020 to 58,600 in 2030. It has been established that fifty percent of people using palliative care services are aged 70 and over and hence the demand for palliative care and end-of-life care will rise substantially in the ACT in that time.
2. **The data on the number of people requiring palliative care services for the ACT is not systematically collected and readily available.** Collecting comprehensive data for palliative care patients is crucial to ensure effective service planning, commissioning, care coordination, evaluate outcomes, and identify areas for improvement. Consideration should be given to how data collection processes could be systemised, enhanced, or extended. This could include demographic, geographic, and socio-economic background data and service utilisation by types of services received in various settings to improve understanding of and planning for palliative care service provision.

- 3. The data on the carers supporting people requiring palliative care services for the ACT is not readily available:** Collecting comprehensive data for carers is crucial to ensure effective service planning and areas of support required. This will help to improve quality of life for the carers.

3.3 Unmet Need and Service Delivery Gaps

Despite significant advances in understanding the benefits of early integration of palliative care with disease management, many people living with a chronic life-threatening illness either do not receive any palliative care service or receive services only in the last phase of their illness. This section predominantly summarises themes from the qualitative stakeholder interviews unless indicated otherwise and addresses the key review question of; ***Are there people in our community who are not accessing palliative care and end-of-life care services due to unmet needs or service delivery gaps?***

3.3.1 Availability of Palliative Care Services in the Community

Holistic palliative care is characterised by a patient-centred approach incorporating patient choices in where that care is received at different points in their journey. This should include settings such as the patients home or the residential facility along with hospitals and hospices. Clinical palliative care services in the community aim to provide specialised care and support to individuals with serious illnesses outside of the hospital setting. The key components commonly found in these services include pain and symptom management, emotional and psychosocial support, care coordination, advance care planning, spiritual support, bereavement support, and education and training [42]. These community-based clinical palliative care services enable the patient and their family and carers to be managed and supported in the home setting rather than being restricted to hospital care when this is not their preferred choice.

In the ACT, there exists three service settings outside the hospital in-patient setting that provide palliative care: the outpatient palliative care clinic at the CHS, CHH hospice (including outpatient clinic, home based palliative care program and the PEACE program) and respite care at Leo's place (see section 3.1.1 for details). However, the service mapping found limited evidence of other in-home care clinical services specifically focused on palliative and end-of-life care. One example of currently available home care services includes the specialist team at the CHS supporting case conferencing to provide care which allows the primary care medical teams to address complex symptom management and help with difficult decision making or CHH providing nursing care in-home. The LINK team nurses, CHS work after-hours to deliver care in the community and their predominant workload is palliative and end-of-life care clients It is clear that some clinical services are available in the community setting however there was a consensus view amongst stakeholders consulted that this workforce was insufficient and particularly after-hours as discussed in the following section.

When services are provided appropriately in the community or in primary care settings, there is strong evidence that it reduces hospitalisations. It is possible, that the insufficient clinical services in home setting are reflected in the ACT data on hospitalisations and ALOS for palliative care. The ACT had the third highest hospital admissions related to palliative care across Australia in 2020-21 and the highest average length of stay in hospital for both, palliative and end-of-life care (section 3.1.2 for details). Specialist services in the community and optimising primary care can help to minimise the need for hospitalisations and reduce the length of hospital stays by addressing health issues proactively and ensuring comprehensive and coordinated care.

This was also confirmed by the stakeholders who mentioned the need for skilled healthcare professionals, such as doctors and nurses to provide expertise in managing physical symptoms like pain, ensuring patients' comfort and choice.

3.3.2 After Hours Service Access

There are around fourteen services available within the ACT that provide after-hours care however two of these are respite care services and five of these services provide telehealth and/or online support. These services exist however do not have capacity to address the demand. Access to palliative and end-of-life care services after-hours was the most consistent and prominent issue raised by the stakeholders consulted. This is resulting in patients needing to move to acute care or inpatient services, contrary to their wishes. The LINK team nurses in the ACT work after-hours to deliver care in the community and their predominant workload is palliative and end-of-life care clients [43]. These highly trained nurses implement palliative care and end-of-life care plans, take emergency calls

for pain relief and management and visit patients with concerned or distressed family at night. However, stakeholders indicated that the service is unable to meet the demand after-hours and this demand is increasing. The defunding of the after-hours pharmacy was also a concern raised by multiple stakeholders and survey respondents.

Some gaps in the after-hours demand is addressed by the ACT Ambulance service. In the ACT there are two 'Extended Care Paramedics' (ECPs) providing services between 11am and 11pm, but none in a critical period overnight where other services are highly limited. When called for palliative care or end-of-life care purposes, the patients might require pain medication that paramedics don't have the knowledge or permission to provide. If there is no care plan, it further complicates the treatment pathway. There is no phone helpline for paramedics to gain support in such situations. If paramedics cannot resolve the situation, they are forced to take the patient to hospital, often against the patient and family/carer wishes. Further to this, the Ambulance service noted that this often creates feelings of discomfort and angst for paramedics often culminating in moral injury and trauma.

The Health Care Consumers' Association (HCCA) has advocated for the establishment of a 24/7 territory-wide palliative care phone support and information line for patients and carers in the ACT. This would aim to address some of the after-hours support gaps in the ACT palliative care system and help improve the end-of-life experience among patients and carers. Similar services operate in other states in Australia [44]. These phone support services provide specialist advice for health professionals as well as consumers, carers, and families.

3.3.3 Paediatric Palliative Care Services

As noted in the workforce shortages section, the paediatric palliative care service is limited to a single full-time equivalent position. No paediatric palliative care specialist services exist in the ACT requiring an adult specialist or sometimes paediatrician to be involved in the coordination of treatment. Many children must travel to Sydney to seek inpatient palliative treatment. While undergoing the treatment interstate, the connections with the practitioners or community care services in the ACT are not made and when the child is ready to come home for end-of-life care, the communication with an unfamiliar workforce and navigation of the system becomes traumatic for the child and parents at the most challenging time of their lives.

A stakeholder mentioned that:

"While only a small proportion of children require palliative care services, there is strong evidence that a child's death has extensive impacts on parent's and siblings' physical and mental health. Therefore, not only timely and appropriate care for a child is necessary for pain management at the end of life but also providing supports to the parents is critical."

3.3.4 Palliative Care for First Nations and Culturally Diverse populations

No culturally specific palliative and end-of-life care clinical services were identified through the mapping or reported by the stakeholders, however, the Aboriginal Dreaming Quilts program for those at end of life at TCH and CHH was highlighted. The consultations more-so reported on the importance of ensuring cultural accessibility and service engagement issues for these population groups. These concerns were reflective of broader system level issues relating to culture, such as cost of travel, cultural competency of service providers, complexity in navigating the health system, lack of engagement in decision making process and general lack of trust in the system. There was overall agreement that services needed to ensure that they were cognisant, respectful, and wherever possible able to uphold the various cultural and spiritual beliefs and practices of people who are not from the dominant culture in relation to death and dying. It was noted that:

"There is a lot of fear from the First Nations community around palliative care as they do not feel like they have the 'education' of how to approach services or talk about it with other members of the community."

Stakeholders suggested the following:

- development of Aboriginal End of Life Palliative Care Framework similar to Western Australia
- promotion of CALD services to community through community leaders and services that not only focus on patients but also on carers.
- ensure translators have health literacy to understand cultural nuances in delivering health information.
- promote use of resources to improve the cultural competence of RACF workforce such as Partners in Aged Care (PICAC) training[45].

3.3.5 Palliative Care for Vulnerable and Diverse populations

As described in table 3 (section 3.1.1) the Enhanced care program delivered by the Canberra Health Services is an outpatient service focused on care needs of people who are disadvantaged or vulnerable. This provides access to flexible clinic services and telehealth. A collaborative case conferencing model is developed and being implemented for patients from various primary care providers where patient stories are brought by primary care clinicians to case conferencing with the specialist palliative A palliative care plan is developed under these case-conferencing arrangement. Stakeholders indicated that this service is successful and can't fulfil the demand.

Stakeholders described a gap in palliative care for people from specific vulnerable backgrounds such as AoD, mental health and people experiencing homelessness. The following issues were described that apply explicitly to this cohort:

- Lack of experienced and willing workforce to treat and case manage this challenging cohort. People from these groups were described as having very complex needs that were not being well serviced in general, and palliative care requirements were an added complexity and required very experienced clinicians care coordination.
- The sector would benefit from conscious efforts to provide services that are Gender/Diversity inclusive and culturally appropriate.

3.3.6 Issues for Carers

Person and family-centred care is an essential part of palliative care and with a growing number of people living longer with chronic conditions and an aging population this impact on carers is expected to grow further. Respite, bereavement, and other care needs to be tailored to the individual and their families taking into account their choices and preferences. However, there is limited information to facilitate insights into the supports provided to the carers including, pre- and post-death to families and carers [46]. Those carers with more complex needs may access support services through state and territory funded specialist palliative care services or broader health, mental health, disability, and social service programs. The Health Care Consumers' Association (HCCA) identified palliative care as one of their five priorities for health services. It stressed the role and involvement of families and carers in Palliative care policy development, service codesign and the delivery of services to ensure issues of importance to them are reflected. Having consumer's (patients and cares) representation in health-service governance structures and committees was suggested in the recent HCCA submission to the ACT Government Budget 2022/23 [44].

The service mapping indicates that there are Stakeholders indicated that the palliative care services are not promoted widely in the community making it harder for a carer to reach out to the services. This also holds true for the vulnerable populations where there are cultural differences or language barriers.

The stakeholders proposed increased availability and knowledge regarding grief support and services that consider spirituality as a part of the process of grieving would be of benefit to the ACT community. This would likely be broader than for palliative and end-of-life care situations.

At times, there can be significant trauma felt by the carers around palliative and end-of-life care treatment, followed by death of the loved one and bereavement. This impact is accentuated by the death of a young person especially when a child passes away. A specific need for specialised grief and bereavement services for parents and siblings in such cases was highlighted by multiple stakeholders.

A stakeholder summarised these concerns as follows:

“Caring role ends when someone dies and there are little grief care/counselling services for the Carer. Services need to understand the particular grief of someone who has been the primary carer for a long time.”

3.3.7 Key Learnings

The key learnings in relation to unmet need and service delivery gaps in the ACT include:

The stakeholder consultations focussed on identifying unmet need, highlighted concerns related to availability and access to services along with cultural appropriateness of the services. It also highlighted the need for access to bereavement and psychosocial support for family and carers. Key learnings and next steps for consideration include:

1. **Limited availability of specialist and primary care clinical palliative care services in the community setting and appropriate after-hours services.** These factors are narrowing choices for patients and carers as to where they receive services and may be resulting in admission to hospital against their preferred wishes. Consideration should be given to:
 - a. enhancing the availability of clinical services in the community setting
 - b. developing an after-hours palliative care service model in collaboration with key players (e.g. specialist palliative care team, LINK nurses, Ambulance Service). This would include exploring access to medication after-hours.
 - c. potential establishment of a 24/7 territory-wide palliative care phone support and information line for patients and carers to help improve the end-of-life experience among patients and carers who are in a community setting.
 - d. evaluate the collaborative case conferencing model, developed by CHS specialist palliative care unit, for palliative care patients in primary care for its impact on quality of care and widen the scope of the model if deemed successful.
2. **Linkages (or pathways) between the paediatric palliative care specialist services in NSW and services in the ACT should be strengthened.** Given paediatric treatment needs to occur interstate, the connections with the practitioners or community care services in the ACT are not made. A palliative care pathway for paediatric patients that ensures continuity of care for the patients and links the parents to appropriate services is critical. This includes referrals and supports for the family in the ACT to facilitate transition of care. It may also be necessary to review and amend as required the palliative care specific HealthPathways for the ACT to ensure they are inclusive of referrals to community organisations.
3. **There is no Indigenous specific Palliative and End-of-life framework currently operational in the ACT.** Such a framework has been developed in Western Australia and this could be reviewed in collaboration with First Nations organisations (service providers) to consider whether this is suitable for tailoring to the ACT context.
4. **Many service providers have not formally checked the cultural appropriateness of their services for persons of a culturally and linguistically diverse background.** Ideally, services should review the cultural appropriateness of their services in collaboration with relevant cultural organisations/groups.
5. **Knowledge of, availability and linkages to grief, emotional, spiritual, and psychological support could be enhanced.** The need for such services was identified as being broader than for just palliative and end-of-life care situations and wouldn't necessarily be a remit of the sector. Access to psychosocial support services, counselling and bereavement support for palliative care patients and carers was, however, considered to be critical.

3.4 System To Meet Service Need and Demand

From an analysis of the survey mapping data and triangulation against the qualitative interviews and survey responses, this section addresses the key review question of; **Are the current services meeting the demand of those who are requiring care? If not, why not?** However, in doing so, it more broadly reports on findings in relation to how the palliative care system is structured at the highest level within the ACT and the issues that are of a system-wide nature.

3.4.1 Need for Holistic Model

Stakeholders indicated that the specialist palliative care model operating from Canberra Health Services (CHS) provides its service to patients wherever they are situated within the hospital as there are no designated palliative care beds currently. This has been a limitation on integrating various support services specific to the palliative care for a patient. Despite this model being recognised as best practice, it is viewed by many stakeholders that the current model of care is a 'medicalised' model as opposed to a holistic, where care is multidisciplinary and includes non-clinical support (for example counselling, spiritual care) as required.

A stakeholder affirmed:

“Persons needs and goals may be not arounds medicines but spiritual and other needs. It has to be multidisciplinary, and it can’t be any other way”.

However, there was an acknowledgement by stakeholders that this is historically driven and that limited funding likely drives this approach so the resource limitation can be effectively managed. This aligns to a broader view that the entire palliative care system is currently under-resourced and unable to meet future demand in its current configuration.

3.4.2 Clarity of Service Provider Roles and Responsibilities

Service scope and the clarity of the roles of a specialist versus primary palliative care service was described as necessary by several stakeholders. Towards the end of life, the role of a specialist palliative care service is to provide specialist advice and hand over the care to the generalist or community care providers. The following stakeholder findings indicate the need for improved clarity of service provider roles and responsibilities to ensure that palliative management is appropriately tailored to the needs of the individual at that point in time, acknowledging that the broad workforce shortages (including a lack of desire to work in the sector) impact the scope of available services.

- Specialists are “handholding” in the very end stage of life which at many times is not required, with symptom management within the capability of allied health professionals, other generalists, or primary care physicians.
- Some GPs can feel uncomfortable or disempowered to have conversations with their patients about palliative care. A lack of skills in addition to a lack of knowledge of available appropriate resources was suggested as the reason for this low confidence. A stakeholder expressed:

‘Good palliative care clearly requires people being able to access GPs and GPs to have time and experience and are adequately remunerated to work on their part of the palliative care solution’.

3.4.3 Fragmentation of Sector

The service mapping shows that there are many services providing palliative and end-of-life care services across ACT, but stakeholders note them as being fragmented. The fragmentation of services has significant impact on patient demand in several ways such as challenges to accessing services, communication and coordination issues, duplication of services, fragmented continuity of care and conflicting treatment plans. There was a strong view that the palliative and end-of-life care sector care is fragmented with providers not working collaboratively but rather working in their own ‘silo’. Whilst the reasons for this were not explicitly provided, it seems highly probable that a resource limited sector, where providers need to rationalise their scope of service, and there is some lack of knowledge of other available services are going to impact taking time for greater collaboration. The following stakeholder findings support a fragmented sector:

- Communication and integration between clinical services (CHS and CHH) and community-based services requires improvement. Poor care coordination, the lack of awareness of what services were being provided at any one time (particularly from private providers), poorly timed or duplicated referrals and not focussed on specific needs, create barriers for people requiring symptom management.
- Service referrals to community services are often limited to internal networks and there was no way of knowing what services were available resulting in some services with long waiting lists.
- Allied health practitioners can support symptom management if provided with opportunities as their capabilities are currently not being utilised on palliative care; noting the opinions of stakeholders consulted may not be representative of all allied health workers.

3.4.4 Workforce Shortages

As mentioned in section 3.1.1, nationally, in 2020, the FTE rate for palliative medicine physicians was 1.1 FTE per 100,000 population in Australia. The rate for the ACT was not presented due to its small numbers. [20].

Stakeholders noted that there were currently workforce shortages across the entire ACT health system, exacerbated by an aging population and higher life expectancy that will challenge the current workforce to address the future demand. As noted in section 3.1 and service delivery gaps in section 3.3, the availability and access to the palliative care service workforce is an issue nationally as well as within the ACT. This was supported by stakeholders who

identified specific workforce shortages including community-based services, renal and paediatric support and specific allied health disciplines that would benefit from increased capacity and/or capability. A specific demand for bereavement support (mental health/social work/ counsellors) for family/carers was identified by multicultural communities with a note that *“the complexities of grief required an experienced mental health workforce.”*

3.4.5 Role and Recognition of Carers as Primary Care Co-ordinators

Stakeholders noted that carers are not always fully consulted, advised, or well supported on the whole palliative and end-of-life care journey. One stakeholder noted:

“They are invisible. They provide a significant proportion of care. [We] Don’t refer them for support, don’t ask them how they are going, [or] ask them about decisions being made. The issue of the client [is] Medicare billed, and the other person is not critical. [The biggest] issue is the invisibility of carers.”

Stakeholders raised the principles of the *Carer Recognition Act 2021 (ACT)* [15] (the Carer Act) affirming that both the carer and the patient have the right to input into decision-making. There was an indication from stakeholders that the patient-centred and more critically ‘privacy principles’ approach implemented that precluded the family/primary carer are likely related to a lack of knowledge and/or awareness of the ACT Carer Act. The following stakeholder findings also apply to the role and recognition of carers as primary care coordinators:

- Palliative care patients that are referred to Clare Holland House Specialist Palliative care will have a PCOC assessment completed with each episode of care, which includes an assessment of carer. The care provided by Specialist Palliative care at this facility requires carer input and feedback,
- The absence of an Advance Care Plan and lack of experience and/or understanding from the carer regarding the likely timing of passing, leaves other services such as the Ambulance service in a challenging situation where they are obligated to act contrary to the patient’s wishes.
- Whilst carers provide a considerable proportion of the care, they are often not asked about their welfare, nor are they referred to support services. It was acknowledged that carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life and should be recognised as individuals with their own needs within and beyond the caring role. A stakeholder noted:

“We have taken away from death the real impact of death which is: what is its impact on people who are left behind?”

3.4.6 Key Learnings

The stakeholder consultations indicate that the current demand for services is not being met particularly in the community setting and there is a need for all within the system to understand the scope of services of each provider to ensure there is service alignment for optimal service provision across the continuum of care. There is also scope to build workforce capacity and capability of generalist and allied health providers to support symptom management, homecare and ensure specialist palliative care remains specialist. Based on these consultations the key learnings together with next steps for consideration include:

1. **A stakeholder perception that a palliative care service needs to be holistic.** There was a perception from stakeholders that the palliative model of care used in the ACT was highly medicalised and a holistic multidisciplinary model is required (see section 3.4.1).
2. **Care coordination could be improved.** There could be benefit in developing a Memorandum of Understanding (MOU) between all the key palliative and end-of-life services that documents the agreed roles and responsibilities of each partner and include explicit ‘ways of working’ to improve care coordination and awareness of services (see section 3.4.2).
3. **Referral pathways made clearer.** Ensure the operating Model of Care for Palliative Care Services in the ACT clearly delineates palliation and chronic degenerative illness to improve referral pathways and plan for maintaining a patient’s quality of life until a need for palliation arises to reduce the demand on specialist palliative care services (see section 3.4.3).

4. **Allied health workforce could be better utilised:** Build the capability of the allied health workforce to support patient care (symptom/pain management) and some basic aspects of care at home through palliative care specific training (see section 3.4.4).
5. **Workforce planning:** given the perspective of workforce shortages, consider undertaking a workforce planning process to inform the requirements for meeting existing and future demand for community-based services. (See section 3.1 and 3.4.4)
6. **Increase Ambulance service capability:** Build the capability of the Ambulance service to include palliative care treatment knowledge and skills to play a greater role in supporting patient outcomes and/or experience, especially after-hours, similar to the model utilised by the South Australian Ambulance Service (see section 3.4.4). This would be further enabled by access to specialist advice and support out-of-hours.
7. **Increase capacity in community nursing team:** Community nursing team would benefit from a nurse practitioner role to facilitate medication management (see section 3.4.4).
8. **Increase capacity in paediatric palliative care:** A part-time paediatric palliative care specialist might be appropriate to ensure continuity of care for children within the ACT (see section 3.4.4).
9. **Absence of an Advance Care Plan:** The absence of an Advance Care Plan was noted to put both carers and health professionals such as the Ambulance service in challenging positions when they are obligated to act contrary to the patient's wishes (see section 3.4.5). Consideration needs to be given as to how this can be further promoted in the ACT.

3.5 Barriers to Care

From analysis of the survey mapping data and triangulation against the qualitative interviews and survey responses, this section addresses the key review questions of:

- a) *Are there barriers to care that limit access to services across the palliative care and end-of-life care journey (early, mid, late, bereavement stage)?*
- b) *What are the barriers to care that impact care coordination (transition) in and out of services throughout the patient's palliative care and end-of-life care journey?*

3.5.1 Understanding and Discussing Palliative and End-of-life Care

When it is identified that a patient needs palliative care, the approach needs to be introduced in a clear and sensitive way where patients have the time to explore their prognosis and think about their care options. Psychological, spiritual, cultural and social factors may all affect the perception of symptoms therefore psychosocial distress, spiritual issues, and practical needs should be handled appropriately according to the preferences of patients and their families [47]. A comprehensive care plan that is developed at this point should be medically sound and have the patient's wishes and values at the forefront [48]. The care plan is determined according to the goals of the patient and family with the guidance of the multidisciplinary health care team and is regularly reviewed [49]. Since the clinical decisions concern patients' family members and society as well as the patients, it is important to protect the rights and dignity of all parties involved in the clinical decision-making process at the palliative care or end-of-life care stages.

Physicians and nurses encounter difficulties in their practice of palliative care. They need a good understanding of ethical principles and precedents [50]. Similarly, the goal of end-of-life care for dying patients is to prevent or relieve suffering as much as possible while respecting the patients' wishes. However, physicians face many ethical challenges in delivering end-of-life care [51]. Recent systematic reviews and meta-analyses demonstrate that early integration of specialist palliative care can improve quality of life for patients with advanced, incurable illness, including reducing symptom intensity, hospitalisation, aggressive treatments, and associated costs at the end of life [52-54]. However, definitions of early integration vary and the evidence suggests that 'for full benefits of palliative care to be realised, continuity by a multidisciplinary team is needed for at least 3–4 months before death' to realise maximum benefit [55]. Many stakeholders indicated a sector-level issue relating to defining and having a sufficient understanding of the palliative care and end-of-life care stages. Specifically, the difficulty was noted in understanding:

- When should routine disease care be transitioned to palliative care?
- When should palliative care transition to end-of-life care? What is the goal in each stage?
- Who needs to be involved and what should they be contributing? What planning is required?

A lack of confidence amongst health professional in decision making that a patient has reached the palliative stage results in a delayed start to the palliative care journey. Understanding when palliation is imminent and transitioning to it is critical. Determining this point is not always straightforward particularly with advances in medical care. As stakeholders noted:

“Palliative care previously was defined as care of the client with last 12 months remaining of their life. With advanced techniques in renal care, cardiac care and respiratory care, patient live much longer than 12 months if conditions are managed effectively using case-management models.”

It was also mentioned that:

“Many health professionals do not feel confident to engage in a discussion about palliation and death and think that it is the responsibility of a nurse or palliative care specialist to have those conversations.”

The following example from Renal Care speaks to the importance of having early and timely discussions around palliative and end-of-life care:

“In renal care planning for withdrawal from dialysis takes a lot of time and conversations with patients. The hospital staff and nurses are not well trained in supporting those discussions. Also, there is a huge shift in treating patient on a treatment like dialysis. There is a significant practice creep as many patients are started on dialysis well into their 80s. While these patients have extended life expectancy due to dialysis, many live with significant caring needs, and poor quality of life. A timely referral for advance care planning with patients is required along with the timely conversations regarding dialysis being a temporary measure.”

Stakeholders also offered other suggestions including:

- palliative care educator at the hospital to support clinicians to improve the awareness around the palliation and end-of-life care decision making. This can also include educating the healthcare staff around the misconception that a patient will feel highly uncomfortable with discussions relating to their death needs.
- improve collaboration between aged care services (example dementia care) and palliative care services for continuity of care.

3.5.2 Acceptance of Diagnosis of Palliation by Patients and Family/Carer

Multiple stakeholders indicated that there is a lack of knowledge and understanding amongst patients and their families about palliation that very often makes it challenging for them then to accept the diagnosis and stage they are at. This may occur when palliative treatment choices and belief systems may not align. At the end-of-life or while making treatment choices there is a fear of the unknown for patients and it is made complicated by their own beliefs of what having treatment means. The impact of choices made is not fully understood many times and confuses patients further. Furthermore, language used by clinicians or service names can contribute to an acceptance of palliation and improved service uptake by patients. As mentioned in one example:

“A rebrand from ‘Renal Palliative Care Unit’ to ‘Renal Supportive Unit’ has helped to improve patients’ attitude to palliative and end-of-life care when dialysis is required. “

3.5.3 Decision Making Around Appropriateness of Treatments at the End-Of-Life Care Phase

Three terms that may arise in end-of-life care discussions are ‘withholding treatment’, ‘withdrawing treatment’ and ‘palliative sedation’. They are often misunderstood and yet understanding these terms can greatly assist in decision-making and ensuring quality of life [56]. The stakeholders discussed this issue around decision making with regards to the treatment continuation or dosage of the medications that allow patients to be in less pain as they approach the end of their life. It was also indicated that in some instances lack of knowledge regarding the process around end-of-life care influences the clinician behaviour. For example, in renal supportive care, there is always a critical discussion around helping a patient understand that dialysis is a temporary treatment provided to improve quality of life, however, at some point withdrawing the dialysis (when it becomes unsafe) might be a choice that they will

have to make. This task is difficult for the clinicians and many healthcare staff morally struggles with this decision making.

3.5.4 Advice Around Advance Care Planning

Advance care planning (ACP) enables patients to make decisions about the health care they would or would not like to receive if they were to become seriously ill and unable to communicate their preferences or make treatment decisions. This also helps to ensure that their loved ones and health providers know what matters most to the patient and respect their treatment preferences. Ideally, advance care planning results in patient preferences being documented in a plan known as an “Advance Care Directive” and the appointment of a substitute decision-maker. The usefulness was indicated by the ambulance paramedics who mentioned that when a patient on palliation has an advance care directive documented, it enables them to make better, patient-centred decisions.

There was broad stakeholder feedback on a need to strengthen advance care planning processes including timeliness of it and to promote ACP amongst the community. An example of where every patient gets a referral for an ACP comes from the renal supportive care unit. These patients get referred to the advance care planning team and enduring power of attorney (EPOA) which was mentioned as a *“should be the process for every terminally ill patient or patients with multimorbidity.”*

As noted in the mapping section, an Advance Care Planning Program is available at Canberra Health Services. The service is available within hours, (Monday to Friday 8:30am to 4:30pm) however the stakeholders mentioned that it is important for clinicians to be aware of the service and at what point in patient journey should they refer to this service. Advance Care HealthPathways are available within the ACT [57].

3.5.5 Workforce Capability and Knowledge

Workforce issues discussed by the stakeholders included not only the number of staff and their availability but also their knowledge and capabilities as a barrier to effective care. However, many clinical/allied health stakeholders interviewed did indicate that they had undertaken The Program of Experience in the Palliative Approach (PEPA) training [58] and it was considered practical and useful. PEPA forms part of the Palliative Care Education and Training Collaborative (the Collaborative). Some of the key issues in relation to; understanding delineation between palliative and end-of-life care have been discussed in section 3.5.1, however, further feedback included:

- Best practice palliative care is multidisciplinary by nature. The workforce needs to be engaged across community care, primary and specialist care for better outcomes. However, limited knowledge regarding ‘what services are available’ and ‘what are appropriate referral pathways’ further lead to challenges in coordinating timely care.
- Understanding capabilities of the healthcare teams who play a role in palliative and end-of-life care help to provide holistic care with a focus on whole of the system view rather than the medicalised models of care. The example was provided by multiple stakeholders who suggested that:

“There is a general lack of understanding of the existing skill sets among allied health teams in symptom management such as breathlessness and pain control. Allied health professionals are underutilised in palliative care”.

Other education pathways were identified by stakeholders and included the ‘ACT end of Life and Palliative Care Education Pathways’ the Champion Program, and the Clare Holland House ‘Transition to Palliative care nursing program.

Multiple stakeholders indicated that educational aspects regarding palliative care as a holistic care model are important where the whole person and medical, spiritual, cultural aspects are considered. This again highlights the need for improved knowledge in this sector. It was also highlighted that a lack of awareness of where to find a centralised directory to connect with the community and other services contributed to the lack of knowledge regarding the services amongst clinicians.

While HealthPathways is looked upon as a good starting point for the primary care clinicians to help them navigate the system and ensure they are linking with the healthcare professionals and organisations that are working in palliative and end-of-life care; current referral pathways do not adequately address the steps to be taken by the treating clinician or patients to obtain care. HealthPathways may be an area to explore further to ensure an ideal and connected patient journey is achieved and not duplicated while taking in consideration patient choices and

there are referrals to community organisations within the pathways. The list of currently available palliative care HealthPathways are best accessed from the HealthPathways website. [57].

3.5.6 Transition of Care

The movement of a patient from one setting of care to another needs to be well coordinated and supported for better patient outcomes and to ensure the experience for the patient and their family/carer is as stress-free as possible. Along with improving clinicians' knowledge around transition of care points, limitations with the Digital Health Record (DHR) system were discussed by the stakeholders as one of the key issues in terms of transition of care. While a complete and appropriate referral is expected at the time of transition, the DHR system allows only one primary reason to be coded when referring to community health intake which makes it difficult for the nursing staff to provide comprehensive care as they are not aware of the other referral reasons. For a patient, their journey from living with a chronic condition to palliative to end-of-life care requires multiple transitions through the system and finally to home-based care thus requiring multiple referrals at every episode. These referrals need to be in timely manner using most efficient system available.

The transition of care into the community and referrals associated with that were also discussed by the stakeholders indicating that the skills in community services to manage symptoms might be underutilised as a lot of needs at the end-of-life stage are practical (not requiring specialist clinical skills), and healthcare staff with the right knowledge can provide the care required to die peacefully. It was suggested that the referrals need to extend engaging with the community organisations at this stage including incorporating community care in the HealthPathways.

3.5.7 Barriers to Palliative Care Services for Other Vulnerable Populations

Stakeholders discussed issues around access to palliative care services for individuals receiving funding under the aged care benefits and/or National Disability Insurance Scheme. It was noted that the silos in the system that look at various funding resources separately (NDIS, Aged Care, Palliative care) could be reviewed to achieve effective and efficient service provision.

For example,

- Various concerns around services provided under aged care packages and supports provided under palliative care and EOL care were expressed by the stakeholders. For example, while the home care package recipient can technically buy in some palliative care services many times other service requirements need to be prioritised for the patient (such as showering, home cleaning). This use of funding for palliative care limits funding for other much needed services. Also, anyone with a level 4 HCP does not qualify for community nursing but should qualify for palliative care nursing. A lack of understanding and education at the provider agencies regarding advice on how to manage these funds was highlighted as an issue.
- Under the NDIS, lack of funds for respite care in paediatric palliative care, the complex system that requires navigation when funds are required for palliative care and lack of communication between provider were reported as key concerns.

3.5.8 Key Learnings

Based on the consultations, some key learnings in relation to addressing barriers to care include:

1. **A need for greater education and awareness:** Educating patients, families, and healthcare professionals about the benefits and goals of palliative care can assist in addressing misconceptions and promote understanding of the role of palliative care in improving quality of life. This might include:
 - a. a palliative care educator at the hospital to support clinicians to improve the awareness around the palliation and end-of-life care decision making (see section 3.5.1 and 3.5.3)
 - b. seeking expert advice into using language that allows patients and families to understand and accept the diagnosis of palliation (see section 3.5.2)
 - c. promotion of existing training programs to services to increase awareness and knowledge of the palliative care approach (such as PEPA to primary, secondary and tertiary service providers and PICAC [59] (Partners in Culturally Appropriate Care) to aged care providers) (see section 3.5.5).

2. **Communication and shared decision-making between patients, families, and healthcare providers could be improved.** Open and honest communication between patients, families, and healthcare providers could be improved. Encourage discussions about goals of care, treatment options, and advance care planning. Ensure that patients' values, beliefs, and preferences are respected in decision-making processes (see section 3.5.3).
3. **Improve and foster multidisciplinary teamwork across the sector.** Foster collaboration among healthcare professionals, including physicians, nurses, social workers, psychologists, spiritual workers, and other specialists.
4. **More active promotion of Advance Care Planning needs to occur.** There needs to be greater promotion of and referral to the available ACP service. This could be enabled by establishing criterion for timely promotion of advance care planning. Equally important, the workforce need to be trained to be comfortable to commence this discussion with the patient, family and/or carers (see section 3.5.4).
5. **Improve care coordination and continuity:** Ensure smooth transitions of care between different healthcare settings and providers. Implement care coordination mechanisms from clinical to community services to facilitate effective communication, minimise fragmentation, and ensure continuity of care (see section 3.5.6).
6. **HealthPathways need to ensure they reference referral to community organisations.** Palliative care specific pathways across the ACT need to include referrals to community organisations (see section 3.5.6)
7. **Siloed funding sources impacts access to palliative care services.** Individuals receiving funding under specific funding buckets (e.g. aged care benefits, National Disability Insurance Scheme) are bound by associated expenditure rules and the limit of funding. Patients and carers need to make decisions about what they prioritise to purchase, and this can result in not accessing important palliative care services. However, as they are receiving these funds, they are prevented from accessing other funding sources to meet the service gap they are experiencing.

4. Key Findings

All individuals consulted welcomed this review. Stakeholders are passionate about and committed to the delivery of high-quality palliative care services in the ACT. They recognise and await the potential for this review to be a catalyst for iterative improvement to address service gaps and unmet need.

The service mapping and stakeholder interviews indicate that the existing palliative and end-of-life care services within the ACT are represented by a wide range of services including: (i) specialist palliative care services, mainly funded by the ACT Government; (ii) other clinical services providing palliative care including allied health services (public and private); (iii) non-clinical services such as social work and case management services; and (iv) bereavement support and spiritual care for patients and their carers (delivered by other non-government organisations).

While the service mapping shows the availability of a multidisciplinary clinical and non-clinical workforce, stakeholder interviews highlighted gaps in:

- i) the capacity of those services
- ii) siloed nature of the system
- iii) provision of clinical services in home
- iv) provision of supportive non-clinical services in hospitals
- v) timely referral and access to Advance Care Planning
- vi) care-coordination and
- vii) transition of care.

The stakeholders discussed barriers to available services and future demand on these services. The key findings from this review are included below under each of the review themes.

4.1.1 Existing Services and Future Demand

The mapping identified 63 health services across the ACT. The service mapping and stakeholder interviews indicate that the existing health care services including palliative and end-of-life care services within the ACT are represented by a wide range of services including: (i) specialist palliative care services, mainly funded by the ACT Government; (ii) other clinical services providing palliative care including allied health services (public and private); (iii) non-clinical services such as social work and case management services; and (iv) bereavement support and spiritual care for patients and their carers (delivered by other non-government organisations).

Based on the information from the stakeholder consultations, higher hospital admissions related to palliative care could be associated with the limited availability of primary care, after-hours services and/or community services for people requiring palliative care in the community setting such as home. This can be seen from the palliative care related ACT public hospital admissions data of 2020-21 shows the third highest rate of palliative care related hospitalisations and the longest length of stay in the ACT compared to other jurisdictions in Australia. Primary care is imperative for building a strong healthcare system that ensures positive health outcomes, effectiveness and efficiency, and health equity.

The data and stakeholder consultations indicate that the demand on palliative and end-of-life care services is predicted to increase in the ACT due to the aging population, increasing prevalence of chronic conditions and increased life expectancy due to the advances in health technology. Predictions of the utilisation of palliative care services in the ACT indicate higher future demand on services based on the evidence that Palliative Medicine has the largest forecast average growth rate per annum for all medical specialties across the Territory for multi-day inpatient separations as well as for multi-day bed-days. Establishing future demand precisely is challenging due to the lack of systematic and reliable data gathering from all the service providers across the nation. Although Palliative Care Outcomes Collaboration (PCOC) gathers systematic data from services that provide palliative care, participation of services in PCOC is voluntary hence limiting the information available to understand demographic distribution, geographic areas of need and relevant demand for care specific to the ACT.

The key findings and next steps for consideration include:

1. **Service mapping process realised gaps in key information.** Consideration could be given to instituting an annual survey of service providers across the ACT that gathers service, workforce, and funding (including

source) and cost data. It could be expected that reporting will improve over time as services get used to the annual survey and see the benefits of access to reliable information about the whole sector (ensuring privacy aspects are appropriately addressed).

2. **Broad range of services available to people requiring palliative and end-of-life care.** The mapping identified 63 services across specialist and primary care clinical services and community based non-clinical services across the continuum of care. There are however some key gaps and unmet needs.
3. **Higher rate of palliative care related hospitalisations and longer length of stay in the ACT than observed in other Australian jurisdictions.** Investment in palliative care reduces the end-of-life costs to Government and improves health and social outcomes for people experiencing life-limiting conditions. These returns can be achieved through investing in coordinated home, community and aged care/residential care services that mitigate against the higher cost end-of life care in a hospital setting. Findings from the review included issues relating to access and availability of specialist and primary care clinical services in the community setting, limited after-hours clinical services and no access to after-hours medication. These factors may be contributing to the higher rates of hospitalisation and ALOS.
4. **The aging of the ACT population will increase the demand for palliative care services.** The cohort of the ACT population aged 70 years and above is estimated to increase from 40,500 people in 2020 to 58,600 in 2030. It has been established that fifty percent of people using palliative care services are aged 70 and over and hence the demand for palliative care and end-of-life care will rise substantially in the ACT in that time period. Collecting comprehensive data for palliative care patients is crucial to ensure effective service planning, commissioning, care coordination, evaluate outcomes, and identify areas for improvement. Consideration should be given to how data collection processes could be systemised, enhanced or extended.
5. **Workforce Plan needed.** Given the likely increased demand a workforce planning process to inform the requirements for meeting existing and future demand for community-based services is likely required.

4.1.2 Unmet need and Service gaps

The dominance of clinical services in the palliative and end-of-life care service provision was reported along with limited availability and knowledge of palliative care provided through primary care and community services. The stakeholders expressed the need for specialist and primary care clinical palliative and end-of-life care services in the community setting; increased ability of in-home palliative care teams to offer emotional support; better access and availability of after-hours services; improved care co-ordination; and improving cultural competency.

6. **Limited availability of specialist and primary care clinical palliative care services in the community setting and appropriate after-hours services.** These factors are narrowing choices for patients and carers as to where they receive services and may be resulting in admission to hospital against their preferred wishes. Consideration should be given to:
 - a. enhancing the availability of clinical services in the community setting
 - b. developing an after-hours palliative care service model in collaboration with key players (e.g. specialist palliative care team, LINK nurses, Ambulance Service). This would include exploring access to medication after-hours.
 - c. potential establishment of a 24/7 territory-wide palliative care phone support and information line for patients and carers to help improve the end-of-life experience among patients and carers who are in a community setting.
 - d. evaluate the collaborative case conferencing model, developed by CHS specialist palliative care unit, for palliative care patients in primary care for its impact on quality of care and widen the scope of the model if deemed successful.
7. **Linkages (or pathways) between the paediatric palliative care specialist services in NSW and services in the ACT should be strengthened.** Given paediatric treatment needs to occur interstate, the connections

with the practitioners or community care services in the ACT are not made. A palliative care pathway for paediatric patients that ensures continuity of care for the patients and links the parents to appropriate services is critical. This includes referrals and supports for the family in the ACT to facilitate transition of care. It may also be necessary to review and amend as required the palliative care specific HealthPathways for the ACT to ensure they are inclusive of referrals to community organisations.

8. **There is no Indigenous specific Palliative and End-of-life framework.** Such a framework has been developed in Western Australia and this could be reviewed in collaboration with First Nations organisations (service providers) to consider whether this is suitable for tailoring to the ACT context.
9. **Many service providers have not formally checked the cultural appropriateness of their services for persons of a culturally and linguistically diverse background.** Ideally, services should review the cultural appropriateness of their services in collaboration with relevant cultural organisations/groups.
10. **Knowledge of, availability and linkages to grief, emotional, spiritual, and psychological support could be enhanced.** The need for such services was identified as being broader than for just palliative and end-of-life care situations and wouldn't necessarily be a remit of the sector. Access to psychosocial support services, counselling and bereavement support for palliative care patients and carers was, however, considered to be critical.

4.1.3 Systems Issues

The stakeholder consultations indicate that there is scope to build workforce capacity and capability of generalist and allied health providers to support symptom management, homecare and ensure specialist palliative care remains specialist. For optimal service provision across the continuum of care There is also a need for the whole system to understand the scope of services delivered by each provider to ensure there is alignment. It was also reported that integration between acute and community-based services could be strengthened with many providers working in a quite siloed way. The lack of palliative care services available in community settings is a challenge in the context of a policy imperative to provide palliative care in the setting chosen by the patient and an increasing patient (or parent of a child) preference for that to occur in the home or residential setting. Based on the consultations the key learnings together with next steps for consideration include:

11. **A fragmented and siloed service system.** There is a strong view that the service system is fragmented and siloed and premised on historical funding and service arrangements and models. There was a perception from stakeholders that the palliative model of care used in the ACT was highly medicalised and a holistic multidisciplinary model is required. Care coordination, transition of care and referral pathways between providers need to be improved. The key findings included suggestions to:
 - a. Develop a Memorandum of Understanding (MOU) between all the key palliative and end-of-life services that documents the agreed roles and responsibilities of each partner and include explicit 'ways of working' to improve care coordination and awareness of services.
 - b. Ensure the operating Model of Care for Palliative Care Services in the ACT clearly delineates palliation and chronic degenerative illness to improve referral pathways and plan for maintaining a patient's quality of life until a need for palliation arises to reduce the demand on specialist palliative care services.
 - c. Implement care coordination mechanisms from clinical to community services to facilitate effective communication, minimise fragmentation, and ensure continuity of care.
 - d. Enhance the capacity and capability of the community nursing team through the development of a nurse practitioner role to facilitate medication management.
 - e. Build the capability of the allied health workforce to support patient care (symptom/pain management) and some basic aspects of care at home through palliative care specific training.

- f. Build the capability of the Ambulance service to include palliative care treatment knowledge and skills to play a greater role in supporting patient outcomes and/or experience, especially after-hours, similar to the model utilised by the South Australian Ambulance Service. This would be further enabled by access to specialist advice and support out-of-hours.
- g. Support the carer's by providing referrals to support services to ensure their welfare.

4.1.4 Barriers to Care

Addressing barriers to care in palliative care requires a comprehensive approach that focuses on the physical, psychological, social, and cultural aspects of patient care. This requires multidisciplinary teamwork. Insufficient multidisciplinary teamwork was identified as the key concern associated with barriers in providing patient-centred care. This barrier also impacted negatively on the communication, care co-ordination and shared decision-making between health professionals. Lack of understanding by physicians of the palliative care and end-of-life care stages, goal of each stage and who to engage with was noted. A lack of confidence and understanding amongst health professional in decision making that a patient has reached the palliative stage results in a delayed start to the palliative care journey. In later stages, the lack of knowledge around withdrawal or continuation of the treatment and appropriate dosage of medications impacts the patient's quality of life. It was suggested that a sector wide program of education and awareness will help to address this barrier. Other barrier to open decision-making process included lack of readiness of patients and families to accept the diagnosis and hesitance to have timely conversations around Advance Care Planning advice.

Transition of care of patients from one setting of care to another needs to be well coordinated and supported to ensure the experience for the patient and their family/carer is as stress-free as possible. Improving clinicians' knowledge around transition of care points and limitations within electronic recording system were discussed as impacting transition of care. The conversations around transition of care into the community indicated that referral pathways that connect the community services with acute and hospital services are critical to plan and manage palliative care and end-of-life care in the community.

Based on the consultations the key findings together with next steps for consideration include:

12. **A need for greater education and awareness.** Educating patients, families, and healthcare professionals about the benefits and goals of palliative care can assist in addressing misconceptions and promote understanding of the role of palliative care in improving quality of life. This might include:
 - a. a palliative care educator at the hospital to support clinicians to improve the awareness around the palliation and end-of-life care decision making.
 - b. seeking expert advice into using language that allows patients and families to understand and accept the diagnosis of palliation.
 - c. promotion of existing training programs to services to increase awareness and knowledge of the palliative care approach (such as PEPA to primary, secondary and tertiary service providers and PICAC [59] (Partners in Culturally Appropriate Care) to aged care providers)
13. **Communication and shared decision-making between patients, families, and healthcare providers could be improved.** Open and honest communication between patients, families, and healthcare providers could be improved. Encourage discussions about goals of care, treatment options, and advance care planning. Ensure that patients' values, beliefs, and preferences are respected in decision-making processes.
14. **Improve and foster multidisciplinary teamwork.** Foster collaboration among healthcare professionals, including physicians, nurses, social workers, psychologists, and other specialist.
15. **More active promotion of Advance Care Planning needs to occur.** There needs to be greater promotion of and referral to the available ACP service. This could be enabled by establishing criterion for timely promotion of advance care planning. Equally important, the workforce need to be trained to be comfortable to commence this discussion with the patient, family and/or carers.

16. **HealthPathways need to ensure they reference referral to community organisations.** Palliative care specific pathways across the ACT need to include referrals to community organisations.
17. **Siloed funding sources impacts access to palliative care services.** Individuals receiving funding under specific funding buckets (e.g. aged care benefits, National Disability Insurance Scheme) are bound by associated expenditure rules and the limit of funding. Patients and carers need to make decisions about what they prioritise to purchase, and this can result in not accessing important palliative care services. However, as they are receiving these funds, they are prevented from accessing other funding sources to meet the service gap they are experiencing.

5. Appendix

5.1 Appendix 1: Review Framework with the Data Sources

Key theme/question	Examples of Data/Information to be gathered	Data source	Actual Data source used
Mapping of existing palliative care and end of life care services			
Detail the services that are focused on palliative care and end-of-life care in the ACT	<ul style="list-style-type: none"> - Number of service providers in the area, categorised under service type. - Name and description of service - Types of services provided: e.g., inpatient, outpatient, outreach, telehealth, outside business hours. - Number of clients serviced. - Carer related services - Number of full time and part time employees 	<ul style="list-style-type: none"> - Documentation Review - Desktop Review of available services online - Service Provider engagement - National Palliative Care Services Directory [18] - National Health Workforce Data Set 	<ul style="list-style-type: none"> - AIHW data-overview of the palliative care service: <ul style="list-style-type: none"> o Pall care related hospitalisation per 10,000 population o Average length of stay (ALOS), for palliative care-related hospitalisations o FTE rate per 100,000 population of employed palliative medicine physicians and palliative care nurses, by states and territories, 2020. - Service mapping using the following: <ul style="list-style-type: none"> o Desktop/website review and consultation with key informants and stakeholders o Stakeholder survey data collected by Abt (but limited) o Existing National Palliative Care Services Directory filtered by location as ACT (https://nsd.palliativecare.org.au/s/search-service?map=yes&location=ACT) o ACT Community Assistance and Support Program (CASP): Service Directory (not palliative care specific but includes pall care support services)

Key theme/question	Examples of Data/Information to be gathered	Data source	Actual Data source used
Demographic characteristics of the patients and carers			
How many people require palliative care and end-of-life care services in the ACT annually?	<ul style="list-style-type: none"> – Number of people requiring services including people living in residential aged care – Number of elderly with chronic conditions across the ACT (predicted increase) – Demographic characteristics: age, gender etc 	<ul style="list-style-type: none"> – Data sourced from AIHW on Palliative care services in Australia [20, 24] – Data requested from ACT Government [23] – Other data sources as identified by the key informants 	<ul style="list-style-type: none"> – People receiving MBS-subsidised palliative medicine specialist services by MBS item groups, states and territories, 2020–21 (Palliative care services in Australia: Medicare-subsidised palliative medicine services: Table MBS.5) – People using permanent residential aged care, by care type and geography, 2020–21 (rate per 100,000 population) – Palliative care, other end-of-life care and all hospitalisations per 10,000 population, from 2015-16 to 2019–20, ACT and Australia – Palliative Care Schedule items: number of people with at least one palliative care related prescription, 2020–21 – Number of hospitalisations in ACT public hospitals for palliative related care 2017-18 to 2021-22
How many people are carers of those requiring palliative care and end-of-life care services in the ACT annually?	<ul style="list-style-type: none"> – Number of carers assisting – Demographic characteristics: age, gender etc 	<ul style="list-style-type: none"> – National Register of Palliative Care Consumers and Carers [60] – Other data sources as identified by key informants 	<ul style="list-style-type: none"> – No data on carers
Trends in number of patients and carers overtime	<ul style="list-style-type: none"> – Admitted relevant patient episodes over time. – Number of people requiring services over time – Number of carers over time 	<ul style="list-style-type: none"> – Data on palliative care and end-of-life care hospitalisations for ACT [22] – Other data sources as identified by the key informants. – Service Provider engagement 	<p>Demand for services overtime:</p> <ul style="list-style-type: none"> – Palliative care, other end-of-life care and all hospitalisations per 10,000 population, from 2015-16 to 2019–20, ACT and Australia – No data on carers

Key theme/question	Examples of Data/Information to be gathered	Data source	Actual Data source used
Identification of Unmet Need			
Are there people in our community who are not accessing palliative care and end of life care services due to unmet needs or service delivery gaps?	<ul style="list-style-type: none"> – Number of available services – Number of people who currently require services. – Access to care – Impact on quality of life due to unmet needs – Timeliness of receiving services – Felt need of the services and Normative Need 	<ul style="list-style-type: none"> – Documentation Review – Stakeholder Interviews – Service provider interviews – Admitted patient data from AIHW. – Other data sources as identified by the key informants 	<ul style="list-style-type: none"> – Qual info based on the synthesis of available quant and qual data about the service
Demand for Services			
Are the current services meeting the demand of those who are requiring care? If not, why not?	<ul style="list-style-type: none"> – Services available (standardised rate compared to other states) – Knowledge and perception of stakeholders including service providers 	<ul style="list-style-type: none"> – AIHW data on services – Stakeholder interviews – Service provider interviews 	<p>Proxy data used same as above for demand for services:</p> <ul style="list-style-type: none"> – Palliative care, other end-of-life care and all hospitalisations per 10,000 population, from 2015-16 to 2019–20, ACT and Australia – Desktop/research evidence
How much do these services cost?			
How much funding is provided to these services and from which source?	<ul style="list-style-type: none"> – Funding structures of service providers – Funding provided by the Government (Federal, ACT Gov under subacute care funding) – Funding obtained from various resources (MBS items, carer payments etc) 	<ul style="list-style-type: none"> – AIHW data on services – Stakeholder interviews – Service provider interviews – ACT Government representative interviews 	<ul style="list-style-type: none"> – No funding data is available. However, we aimed to collect it through the survey, and we received some but limited data regarding type of funding sources and approximate amount of funding. – Some funding related data from AIHW: <ul style="list-style-type: none"> – Benefits paid (\$) on MBS-subsidized palliative medicine specialist services in 2020-21, by jurisdiction, (rate per 100 population) – Palliative care medication expenditure, cost per person, by states and territories, 2020-21 – Admitted Patient data provides: APC.14: Funding-source proportion (%) of hospitalisations, for palliative care, other end-of-life care and all hospitalisations, by sector and state/territory, 2019–20. – Stakeholder survey data provides types of funding sources, and data on approx. amount of funding by type of organisations (limited data) – KPMG report: estimation of ROI in palliative care

Key theme/question	Examples of Data/Information to be gathered	Data source	Actual Data source used
How much does the consumer pay?	<ul style="list-style-type: none"> – Charges or Fees – Payment gaps – Out of pocket expenses 	<ul style="list-style-type: none"> – Key Stakeholder interviews – Service provider interviews – Document review – Desktop review 	<ul style="list-style-type: none"> – https://www.health.gov.au/topics/palliative-care/about-palliative-care/what-does-palliative-care-cost – https://www.caresearch.com.au/tabid/6180/Default.aspx
Barriers to care			
Are there barriers to care that limit access to services across the palliative care and end-of-life care journey (early, mid, late, bereavement stage)?	<ul style="list-style-type: none"> – Availability of the resources/services to refer to. – Knowledge about available services – Understanding and acknowledging the need for palliative and end-of-life care services – Health professional’s knowledge about the referral pathways and readiness to refer to services. – Appropriateness of eligibility criteria for admission into services – Case complexity – Cost of services (out of pocket expenses) 	<ul style="list-style-type: none"> – Key Stakeholder interviews – Service provider interviews – Document review – Desktop review 	<ul style="list-style-type: none"> – Interview data – Document review
What are the barriers to care that impact care coordination (transition) in and out of services throughout the patient’s palliative care and end of life care journey?	<ul style="list-style-type: none"> – Health professional’s knowledge about the referral pathways and readiness to refer to services. – Health professional’s recognition that someone has entered the last year of life and having the skills to discuss this with openness and sensitivity. – Training and education regarding care-coordination and transition phases – Communication between services and service providers – Barriers to referral pathways such as staff turnover 	<ul style="list-style-type: none"> – Key Stakeholder interviews – Service provider interviews – Document review – Desktop review 	<ul style="list-style-type: none"> – Interview data – Document review

5.2 Appendix 2: List of services that completed online survey.

Completed the survey

- ACT Motor Neurone Disease Service (NSW)
- Grief Australia
- Canberra Grief Centre
- Hepatitis ACT
- Cancer Council ACT
- KinCare
- Capital Chemist Charnwood
- Meridian
- Meridian Aged Services Navigation
- Capital Health Network
- CatholicCare Canberra
- Community Options INC
- Next Practice Deakin
- Dementia Australia
- Woden Community Service
- The Canberra Alliance for Harm Minimisation and Advocacy

5.3 Appendix 3: Palliative Care, End-of-Life and related Service Providers

Type of Services /Service Provider	Individuals Interviewed
Specialist Palliative Care	
Clare Holland House	• Two
Canberra Health Service (CHS)	• Two
Paediatric Palliative Care Service	• One
Primary Palliative Care: Clinical	
Community Care Program	• Four
Canberra Health Service Renal Supportive Care Clinic	• Four
Other Services: Clinical	
Canberra Health Service	• One
Rehabilitation, Aged and Community Services, CHS	• Six
GP Policy Advisor, ACT Health Directorate	• One

5.4 Appendix 4: Peak Bodies and Advocates

Service Provider	Individuals Interviewed
Palliative Care ACT (Leo's place)	Two
Carers ACT	One
ACT Ambulance Service	One
Council on the Ageing (COTA)	One
The Aged & Community Care Providers Association	One
Health Care Consumers' Association	One
ACT Council of Social Services	One
The Alexander Maconochie Centre	Two
Canberra Multicultural Community Forum	One
Multicultural Communities, Council of Illawarra	One
ACT Multicultural Council	One
Consumer reference group for End of Life and Palliative Care	Six
ACT Palliative Care Operations Management Committee	One
End of Life Communications Working Group	Two
Capital Health Network – Palliative Care and Older Persons	One
Aboriginal and Torres Strait Islander Health Partnerships (Policy, Partnerships and Programs) - Partnership Team	One

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