NT PHN Palliative Care Needs Assessment 2025

GREATER CHOICE FOR AT HOME PALLIATIVE CARE PROGRAM



phn NORTHERN TERRITORY
An Australian Government Initiative

RURAL Workforce AGENCY NT

CONTENTS

Acronyms 5
Executive Summary 6
1. Greater Choice for At Home Palliative Care Program 9
1.1. Greater Choice for At Home Palliative Care in NT 10
2. Methods 10
3. Health needs analysis 11
3.1. Community profile of disease and dying 11
3.2. Remoteness, costs and infrastructure 11
3.3. Socioeconomic Factors 12
3.4. Health Literacy 13
3.5. Cultural and Language Considerations 13
4. Service needs analysis 16
4.1. Funding models 16
4.2. Thin markets & access 16
4.3. Recruitment challenges 17
4.4. Roles available 17
4.5. Aboriginal and Torres Strait Islander Staff 18
4.6. Equipment 19
4.7. Medications 19
4.8. Service Integration 21
4.9. Health and digital systems 21
4.10. Education 23
4.11. Paediatric palliative care 25
4.12. What is going well? 25
5. Implications for implementation of GCfAHPC program the in the Northern Territory 26
5.1. Program Goals 26
5.2. Key program deliverables 27
5.3. Monitoring and Evaluation Framework 29
6. Appendices 31
Appendix 1: Feedback from stakeholder consultations 2023-2024 31
Appendix 2: Palliative Care Outcomes Collaboration 32
Appendix 3: Advanced personal planning in the NT 32

Appendix 4: End-of-life Directions for Aged Care 33

7. References 34
8. Further Information 36
Version history 36



Northern Territory PHN acknowledges the First Nations people of the Country on which we work and live, and we recognise their continuing connection to land, waters and skies. We pay our deepest respects to Elders present, emerging and across time.

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Acronyms

ABS	Australia Bureau of Statistics
ACD	Advanced Care Directive
ACCHO	Aboriginal Community Control Health Organisation
AHP	Aboriginal Health Practitioner
ALO	Aboriginal Liaison Officers
APP	Advanced Personal Plan (also known as Advanced Care Plan or ACP)
CALD	Culturally and Linguistically Diverse Groups
CKD	Chronic kidney disease
COTA	Council on the Ageing
CoP	Community of Practice
CPD	Continuing Professional Development
DHDA	Department of Health, Disability and Ageing
ED	Emergency Department
ELDAC	End-of-life Directions for Aged Care
EOLC	End-of-life Care
ESKD	End Stage Kidney Disease
GCfAHPC	Greater Choice for at Home Palliative Care
GP	General Practitioner
GPLO	General Practice Liaison Officer
IHACPA	Independent Health and Aged Care Pricing Authority
IPEPA	Indigenous Program of Experience in a Palliative Approach
NDIS	National Disability Insurance Scheme
NT	Northern Territory
NT PHN	Northern Territory Primary Health Care Network
PCOC	Palliative Care Outcomes Collaboration
MBS	Medicare Benefit Scheme
MHR	My Health Record
MMM	Modified Monash Model
MOU	Memorandum of Understanding
PEPA	Program of Experience in a Palliative Approach
SME	Subject Matter Experts
STI	Sexually Transmitted Infection
VAD	Voluntary Assisted Dying

Executive Summary

Quality palliative care ensures that individuals with life-limiting illnesses receive compassionate, holistic support that addresses their physical, emotional, social, and spiritual needs. In the Northern Territory (NT), however, the provision of palliative care faces unique contextual challenges that make its delivery particularly complex. Vast geographic distances, limited health infrastructure, workforce shortages, and difficulties in accessing specialist services all contribute to inequities in care. Additionally, the NT's rich cultural diversity, including the needs of Aboriginal and Torres Strait Islander communities, requires culturally safe, flexible, and community-led approaches that respect traditional beliefs about illness, death, and dying. Overcoming these challenges demands strong collaboration between healthcare providers, communities, and policymakers to ensure that all individuals in the NT can experience dignified and person-centred end-of-life care.

This paper presents an overview of palliative and end-of-life care needs in the Northern Territory (NT) for 2025 with a focus on identifying key needs and priority areas. It draws on local stakeholder consultations conducted in 2021, 2023 (see Appendix 1) and 2025, ABS and AIHW statistics, NT Government service data, and sector insights and we extend thanks to those who contributed to the development of this document.

This document should serve as a valuable tool to:

- Identify local gaps and issues in palliative care.
- Provide a data-driven foundation for The Greater Choice for At Home Palliative Care (GCfAHPC) in the NT, in alignment with program objectives.
- Prioritise gaps within the scope of the GCfAHPC Program, to respond to local palliative care systems.
- Support local services, providers and the community.

While this needs assessment revealed many needs, the below list focus of areas within potential scope of the GCfAHPC program to consider for action.

Workforce capacity building and education

- Community of Practice (CoP): There is capacity within some service providers to contribute to a CoP, however coordination is needed to facilitate this. Exploring the potential to establish CoPs that do not duplicate existing efforts would be of value. There are nationally funded models available which allow for NT participants in a CoP Palliative Care ECHO – Project ECHO.

- Identified Continuing Professional Development (CPD) topics can inform the delivery of sessions via the NT PHN education team and partner service (see section 4.10.1). Increased capacity to support palliative care at home could be supported further via:
  - Partnering with Subject Matter Experts (SMEs) and local culturally safe services to deliver capacity building activities maintaining on and expanding initiatives that support primary health care to enable care at home
  - Enabling clinicians to have conversations with patients about Advanced Personal Plans (APPs), goals of care, end-of- life issues and expectations and bereavement confidently.
  - Enabling patients to access key messages in plain understandable language that explain what to expect.
  - Providing carers and family with key messaging in plain language about how they can provide basic care to support a loved one to die at home.
  - Fostering a culture of embedding APPs and discussions around goals of care as part of routine care such as chronic conditions management.
  - Facilitating integration amongst service providers with a focus on putting patient's wishes and needs at the centre of care.
  - Promoting culturally safe care through i) Aboriginal and Torres Strait Islander staff and governance and; ii) Commissioning of an Aboriginal and Torres Strait Islander staff where possible
- NT PHN can promote educational resources developed by other Australian services to the primary health workforce e.g. Palliative care education and training (Australian Government Department of Health, Disability and Ageing); Palliative Care Education and Training Collaborative.

Medication management

- Increase awareness and understanding of the standardised National Core Community Palliative Care Medicines List by sharing the Caring@Home pharmacological resources, PalliMENDS phone App.
  - Encourage General Practitioners (GPs) to pre-emptively prescribe subcutaneous and buccal formulations using evidence-based resources and to collaborate with their patient's usual pharmacy to expedite timely access to medicines for symptom management.
  - Encourage residential care providers to set expectations for, and consider establishment of processes, including Imprest systems to facilitate pre-emptive prescribing and timely access to the medicines on the List.
  - Host the list on palliative care NT HealthPathways.

- Availability and governance of Lock boxes and syringe drivers to reduce need for breakthrough pain management by remote area staff could be explored.

- A facilitator is required to initiate discussion about latent capacity within private pharmacies to service palliative care patients in the NT particularly with respect to core medicine provision.

Coordination and Integration

- Territory-wide Coordination mechanisms that set clear referral, discharge, and digital information-sharing mechanisms are needed. Advocacy for nationally driven improvements to the functionality of My Health Record (MHR) and promotion of local use of MHR would benefit system coordination. While My Health Record is not meeting the need of the population with respect to APPs, a temporary solution could be consideration of alternative mechanisms to meet this need locally.
- Communities of practice as described in 'Workforce capacity building and Education' section could benefit awareness of regional service availability and referral pathways.

Advertising

- Advertising APPs, how to complete them and other relevant information related to palliative care may be a cost-effective measure to promote APPs in the NT.
- Available means for advertising key information include Council on the Ageing (COTA) newspaper, posters and flyers in primary care clinics, messaging on NT GP social media groups and GP Liaison newsletters.

Advocacy

- Many factors relevant to Territorians in the palliative care space are outside NT PHN's sphere of control and the scope of the GCfAHPC program. However, some of these factors may be susceptible to influence. Targeted advocacy to state and federal representatives in the following areas may be of benefit to the goals of GCfAHPC in the NT. Some key advocacy areas include:
    - Adapting funding periods where possible to acknowledge that 12-18 months is needed to plan and recruit to a program in a remote community.
    - Extending Medicare rebates to appropriately incentivise GPs for palliative care home visits.
    - Incentivising community pharmacies to stock the medicines on the "Community Palliative Care Medicines" list.
    - Publishing Palliative Care Australia resources in Aboriginal and Torres Strait Islander languages.
    - Highlighting that NT has some of the most remote, isolated communities in Australia and that the Modified Monash Model (MMM) may not be fit for purpose in defining the cost related to this.
    - Including quality control for APPs at a national level so that APPs housed on MHR are valid.
    - Strengthening integration of MHR in existing State/Territory-based systems so that APPs can be flagged easily in emergency situations.
    - Strengthening of nationally coordinated bereavement services to address reliance on psychological support that may be in short supply.
    - Strengthening remote service delivery models, such as outreach teams to support setting families up with caring at home and phone support. Where relevant, Independent Health and Aged Care Pricing Authority (IHACPA) funding models need to consider how these services, where replacing hospital care, may be contextually different in the NT- where locations are frequently more remote than possible to identify through the MMM very remote category and how these can be embedded into funding models.

1. Greater Choice for At Home Palliative Care Program

The Greater Choice for At Home Palliative Care (GCfAHPC) is an initiative funded by the Department of Health, Disability and Ageing (DHDA) that provides Primary Health Networks (PHNs) with resources for improving access to palliative care at home, with flexibility to meet diverse local needs.

The Program aims to enable people's preference for palliative and end-of-life care (EOLC) at home and in the community by enabling PHNs to undertake activities to meet the following four objectives:

- Improve access to safe, quality palliative care at home and support EOLC systems and services in primary health care and community care.
- Enable the right care, at the right time and in the right place, and reduce preventable hospitalisations.
- Generate and use data to support continuous improvement of services across sectors.
- Use available technologies to provide flexible and responsive care, including care after usual business hours

1.1. Greater Choice for At Home Palliative Care in NT

With funding allocated to our jurisdiction in late 2021, consultations with the sector allowed to identify the two focus areas below which have been the focus for the program to date:

- Strengthening Aboriginal and Torres Strait Islander communities' confidence to engage in and support palliative care.
- Improving communication and primary care capacity to support a palliative model of care.

Following an open tender in 2022, NT PHN invested significant efforts to build relationships with the palliative care sector in the Northern Territory (NT) which led to the co-design and commissioning of activities in 2023.

With funding to maintain service delivery until June 2029, it is anticipated that the findings of this needs assessment will support the commissioning activities for NT PHN within the scope of the GCfAHPCprogram.

2. Methods

A variety of data points informed this needs assessment, including:

- A desk top review and environmental scan. Note no information is included from Palliative Care Outcomes Collaboration (PCOC) (see Appendix 2) for details.
- Interviews and focus groups throughout August-October 2025 with seventeen local SMEs. This included palliative care specialist doctors and nurses, Aboriginal Health Practitioners (AHPs), care coordinators, general practitioners, allied health professionals and people working in the aged care sector.
- Thirteen individual responses for the 2025 Northern Territory PHN Residential Aged Care Needs Analysis Survey providing feedback specifically related to palliative care.
- Eleven responses from the 2025 Health Workforce Needs Assessment, from those working in palliative care and whom answered questions specifically about palliative care.

Thank you to all our valued stakeholders that contributed to informing this piece of work, NT PHN appreciates your time, knowledge and advocacy for patient centred care.

3. Health needs analysis

3.1. Community profile of disease and dying

The NT has an estimated population of 262,000[1], with 30% identifying as Aboriginal and Torres Strait Islander people, the highest proportion nationally. The population profile is younger than the national average, but premature mortality is significantly higher due to:

- Cardiovascular disease
- Chronic kidney disease
- Chronic obstructive pulmonary disease
- Cancers
- Injury and trauma (including road accidents and suicide)

Life expectancy in the NT is about 75 years for males and 79 years for females, around 5–6 years lower than the national average[1]. Among Aboriginal Territorians, the gap is much greater, around 15 years shorter than non-Aboriginal residents[2].

Most Territorians say they prefer to die at home or close to home, but the majority of deaths occur in hospital or residential aged care due to late referrals, lack of local capability, and logistical constraints[3].

The NT has a unique profile of leading causes of death compared to other Australian states, shaped by higher rates of chronic disease, external causes, and conditions with profound impacts on Indigenous populations[4]. Diabetes is a much more prominent cause of death in the NT (2nd leading cause, responsible for 7.9% of deaths) compared to the national average (3.2%). Territorians also die on average at a younger age[5]. External causes including intentional self-harm contribute a greater proportion of deaths in the NT than in other states[5]. Cancer and lung disease are common cause of death in the NT, as they are nationally[5]. Focus group participants reported that NT residents were more likely to die of complex chronic disease, including End Stage Kidney Disease or End Stage Bronchiectasis.

Chronic kidney disease (CKD) has a much greater impact in NT, especially among Aboriginal and Torres Strait Islander people, and replaces stroke as a leading cause when compared to the national profile. The NT has the highest rate of End Stage Kidney disease (ESKD) in Australia, estimated to be 0.72 per 1000, much higher than the corresponding national rate (0.2 per 1000)[6]. Unique challenges in the renal setting interface with palliative care needs in the NT, including the requirement for many Aboriginal people living remote to move to regional hubs to access life-saving dialysis services. This creates a population of displaced people with a very high mortality rate. People may move to a regional hub away from their country, family and community for many years prior to their death. While people may not necessarily be able to die on country, providing a good, or as good as possible, death includes considering how connection to family and country can be established. Due to the uniqueness of this problem to Northern Australia funding models may not include this as a consideration. In some instances, innovative programs are seeing to address this, see *"What's going well?"* for further details.

3.2. Remoteness, costs and infrastructure

Providing health care in very remote and hyper remote isolated areas presents significant ongoing challenges that affect both patients and health professionals. The number of people living in NT's very remote areas is higher compared to other jurisdictions, with 89.6% of the NT's population living in areas classified as very remote[7].

Approximately 75% of Australia's landmass is classified as very remote by the Australian Bureau of Statistics (ABS) using the Modified Monash Model (MMM). However, the Northern Territory contains some of the most isolated communities in the country. There are substantial differences between states as to what is defined as "very remote." Some areas in the Northern Territory could be considered hyper-remote or especially isolated, more isolated than very remote locations in other states. These include communities located on islands, those accessible only by unsealed roads, or those that are regularly cut off from vehicular transport during the annual monsoon season or due to limited infrastructure.

The cost of doing business in very remote and hyper remote isolated areas is extraordinarily high. Examples of this in the health care and palliative care context include, but is not limited to:

- Complex transporting and logistics for health care supplies.
- Work health and safety requirements, for example, often health care workers are required to travel to remote areas in teams.
- Long travel distances and limited transport options for health care staff.
- Available options to transport patients to health care services and/or home when needed.
- Cultural considerations such as where patients have no way of safely returning to their remote communities for End-of-life Care e.g. impairing families and carers wish to remain with them in their final days or placing extreme economical pressure on vulnerable families.
- Capacity of health care services in remote areas to store and transport human remains for people that choose to die on country to an urban site, which is generally required for postmortem care.
- The complexity of providing palliative care in very remote or hyper remote especially isolated areas are elaborated on in later sections of this document.

On the other hand, aged care, social care services and infrastructure, often needed in palliative care contexts, are frequently lacking or non-existent in remote, very remote and isolated communities in the Northern Territory. For example, residents of small communities may have no access to an aged care facility and very limited access to social support services such as meals on wheels or personal care in the home e.g. self-hygiene, cooking and other tasks to maintain independent living. Where such services are not available it is often not safe to allow people to return to country, hospital teams may choose to delay discharge at the detriment of individuals comfort and the cost of tertiary health care services.

Lack of access to social support and welfare programmes, outside the remit of health care service provision, have significant social and capital costs, with impacts stemming to clinical decisions and the ability for people to return home safely.

3.3. Socioeconomic Factors

Aboriginal and Torres Straight Islander people in remote NT have the worst economic outcomes compared to other States and Territories, with median personal weekly income 24.5% lower than the average elsewhere[8]. In addition to this the NT has a homelessness rate that is 12 times the national average[9].

The implications of these challenges extend to the delivery of palliative care. For instance, if six families share a single dwelling and a member from one of those family's needs to return home to die, this can create significant challenges in ensuring privacy, comfort, medication safety, and family connection, which are key elements of appropriate end-of-life care. Comprehensive palliative care service delivery in such settings may include costs such as power cards, housing and food for visiting family.

Culturally and linguistically diverse (CALD) people in the Northern Territory (NT) tend to have lower socioeconomic status on average compared to CALD populations nationally, facing compounded challenges related to income, employment, and service access[10]. CALD people in the NT are more likely to occupy lower income brackets and have higher unemployment rates than their CALD counterparts elsewhere in Australia, despite some possessing higher educational attainment and good English proficiency[10]. The NT's distinctive demographics mean that many CALD residents are either short-term migrant workers, recent arrivals, or refugees. As a result, these groups are vulnerable to economic insecurity, plus have limited access to culturally appropriate services, limited recognition of overseas qualifications, and greater isolation from established support infrastructure.

3.4. Health Literacy

Interview respondents reported that patients living in remote areas, on average, may have low levels of health literacy, making it difficult to access or understand mainstream materials including those on mainstream websites. As a result, there are significant challenges in communicating key aspects of end-of-life care, such as, how to care for someone at home, or the purpose and benefits of palliative medications. For example, many families may not wish to administer addictive medications to their loved ones. Where the health literacy of the family is low, they may lack confidence in managing medications, pushing the responsibilities for health care onto the health services available.

Practical education for families in end-of-life care is vital. Equipping families with simple, accessible resources that explain what to expect and how to provide basic care (such as pressure area care, mouth care, what happens to the body after death and medication support) can empower them to care for loved ones at home and reduce stress on the health system. This need also overlaps with discussion in the resources section of this report. Some excellent resources are already available and translated into Aboriginal and Torres Strait Islander nations languages, there is a need to promote these resources among health workers around the territory to increase access and use.

3.5. Cultural and Language Considerations

3.5.1. Culturally safe care

Approximately 26% of the Northern Territory's population is Indigenous[11]. The ongoing impacts of colonisation, racism, and intergenerational trauma have had profound and long-standing effects on the health and wellbeing of Aboriginal and Torres Strait Islander peoples and communities. These factors also influence individuals' willingness and ability to seek healthcare. Providing end-of-life care to Aboriginal and Torres Strait Islander peoples means recognising the importance of keeping Aboriginal and Torres Strait Islander culture and identity strong and respecting the value of traditional wisdom, spirituality and knowledge systems that continue to guide wellbeing, healing, and connection to Country. There is diversity within diversity, and not all Aboriginal and Torres Strait Islander people or communities are the same or want the same palliative care services, however many themes about culture emerged in interviews and focus groups focusing on caring for people at the end of their life in the NT.

It is frequently necessary to provide bespoke palliative care approaches to Aboriginal and Torres Strait Islander communities to reflect their unique cultural, spiritual, and community needs, which mainstream palliative care often fails to address. Effective models are often developed in partnership with communities, with Aboriginal and Torres Strait Islander governance, emphasize holistic, flexible, and culturally respectful support that honours end-of-life preferences, family involvement, and connection to land and culture. Care is safest when it is on-Country, with Elders involved and interpreters are present. For example, special considerations such as private spaces and offering gender specific care may be required, the need for specific aspects such as this will be

locally determined. Co-designing culturally appropriate solutions to care provision is challenging in short funding cycles where it may take 12-18 months to gain the trust of the community, determine what model of service provision is most appropriate and recruit to a position.

Community and relationships are of significance in Aboriginal and Torres Strait Islander culture which means that having conversations about dying lead by community members or trusted Aboriginal and Torres Strait Islander staff are invaluable to assist a culturally safe process. Family meetings are essential and may need to involve extended family and key cultural decision makers.

One provider raised that there is not sufficient information available about how to best provide care in a culturally supportive, cross-cultural way. He proposed that narrative research be undertaken to examine how Aboriginal and Torres Strait Islander people feel taking about death and what the best practice in raising conversations about Advanced Personal Plans and Dying would be.

3.5.2. Tools and Resources

While some excellent resources are available, providers described the lack of culturally appropriate resources, including materials in Aboriginal and Torres Strait Islander Nations languages. About 58% of the NT's Aboriginal population speak an Aboriginal language at home[12]. Despite the diverse cultural and linguistic makeup of communities in the Northern Territory, national websites about palliative care offer no content in local Aboriginal or Torres Strait Islander languages. Arranging Indigenous interpreters is frequently required in palliative care in the NT, coordination of this can be costly and time consuming and interpreters are not always available.

Focus group and interview participants reported that they valued the resources available through Palliative Care Australia, for example finding the caring at home pack[13] very useful. However, as noted earlier, most respondents noted that what is currently available is insufficient for the palliative care complexities faced in NT settings. Lack of localisation of some resources can result in care experiences that feel impersonal, inappropriate, or distressing for Aboriginal and Torres Strait Islander peoples.

Resources that explain palliative care in culturally relevant and understandable ways is needed. Enabling families with key messages that explain what to expect and how they can provide basic care to support a loved one to die at home (such as pressure area care, mouth care, what happens to the body after death and medication support) can empower them to care for loved ones at home, honour people's wishes and reduce stress and costs on the health system. Engagement with community leaders, AHPs, and cultural experts is essential to ensure this information is accurate, respectful, and community specific. Educational resources and tools that are visual and written in plain English should be developed to support understanding across diverse communities.

Advanced care planning, while sometimes appropriate, is itself born of a western world view. Therefore, the practice of advanced care planning may not be culturally appropriate, at times. For instance, a family member who may theoretically be a voice for a dying person may not want to hold that responsibility for cultural reasons. In other examples raised, a family may not wish to engage in advanced care planning until the time of a crisis. Even the act of thinking with such a strong individual future focus may not ring true for some people. See Appendix 3 for more information on Advance Personal Planning in the NT. In some communities Advance Personal Planning is considered culturally appropriate and has been working effectively, more information on this in the section *"What's going well?"*

Improved uptake of Advance Personal Planning (APP) where appropriate may assist with achieving better end-of-life outcomes, particularly when discussions begin early in a person's care journey. Early conversations enable individuals to plan for culturally and personally meaningful experiences, such as finishing life on Country, and can help prevent unwanted transfers to urban centres like

Darwin. Even where implementing strong Advanced Personal Planning protocols has been possible, practitioners note the form itself is wordy and confusing and could be improved to be easier to understand and more culturally safe. Some work has been commenced towards improving the current format of the NT Advanced Personal Planning tool. Many Aboriginal and Torres Strait Islander people are more culturally attuned to death and dying than other Australians, but they need the opportunity and support to engage in these discussions in a meaningful way.

The following resources were specifically highlighted

- Discussing Choices - Indigenous Advance Care Plans - A Learning Resource
- Supporting First Nations peoples with advance care planning - webinar for health professionals
- Aboriginal and Torres Strait Islander Peoples Palliative Care Resources - Palliative Care Australia

3.5.3. Dying on Country

Many Aboriginal and Torres Strait Islander people have a strong connection to country. It is also culturally significant for many Aboriginal and Torres Strait Islander people to die "on country" however many remote living Aboriginal and Torres Strait Islander people end up dying in hospital many hundreds of kilometres away from their community connections and family.

Where a person cannot physically return to Country, it is vital that service providers take steps to support spiritual and cultural connection in other ways. This includes involving Aboriginal Health Officers, incorporating traditional practices, and ensuring the care environment aligns with cultural values. Culturally safe care must be embedded as a core component of end-of-life services, not treated as an optional extra. Without this, the system risks further marginalising Aboriginal and Torres Strait Islander peoples at one of the most critical and vulnerable moments in life.

It is culturally significant to some Aboriginal and Torres Strait Islander people where a person dies. For example, in some communities if a person dies in a particular house other family members may not be able to occupy that house for a certain period of time. In other circumstances it would be important to cleanse the house prior to it being used again. This is potentially a major barrier to a person returning home to die, especially in the context of remote NT where there is a severe shortage of housing and 54% of the homes are considered overcrowded[14]. In some instances, this barrier can be overcome through use of aged care beds for dying, however, as noted previously, availability of aged care beds is limited in the NT.

3.5.4. Sorry Business

Once the person has passed away, sorry business, when people come and say their goodbyes, has important cultural significance. One provider noted that the grief and sorry practices are not consistently respected in non-Aboriginal community-controlled services.

3.5.5. Other cultural diversity

Other than the Northern Territory's significant Aboriginal and Torres Strait Islander population, the NT also has a culturally diverse population. The NT has a high percentage of overseas-born residents, about 41% of its population in 2021, compared to the Australian national average of 28% [15]. It is also a challenge to provide optimum care to mainstream and culturally and linguistically diverse populations given the diversity of needs of these cohorts and balancing with the needs of the population as a whole.

4. Service needs analysis

4.1. Funding models

Medicare Benefits Schedule (MBS) rebates are available to support GPs and allied health professionals in undertaking palliative care work, however a barrier to uptake is the awareness of these incentives which is reported to remain limited. Resources such as CareSearch can assist in raising awareness and supporting implementation however busy clinicians need support and training to be aware of these resources.

Some models of care such as in the ACCHO space do allow for home visits and this is reported to be really what is needed for palliative care. For general practitioners (GPs) to provide home visits for palliative care patients, significant structural and funding barriers must be addressed. Under the current Medicare model, private GPs attending a home visit, particularly in time-critical or end-of-life situations, can result in a substantial loss of income compared to seeing them in clinic. A single home visit with travel costs and travel time can mean missing out on seeing four to five patients in a busy day, making it financially unsustainable for many practices, despite the higher reimbursement for a complex patient including palliative care. One survey respondent also noted the potential risks associated with visiting someone at home as a single professional. Additionally, when a patient enters residential aged care further challenges in care occur. It is difficult for a GP to suspend their usual clinic load to attend to the need of a dying patient which can result in the GP being inclined to recommend transportation to ED which often leads to avoidable hospital presentation.

Introducing a dedicated Medicare item number for palliative-home visits, factoring in the additional opportunity cost of such a service, could help address this issue by providing appropriate remuneration for the time, travel, and complexity involved in delivering end-of-life care in the home. This would also help reduce unnecessary hospital admissions, which are costly and often contrary to patient and family wishes. It would be a cost-effective policy shift that aligns with the federal government's broader goal of supporting people to die at home. In the very remote context provision for clinician-to-clinician telehealth coming under Medicare may assist in service provision in a palliative care context.

While the Federal government's $25,000 end-of-life care packages are a positive step, these funds are often allocated to service providers that may not operate in rural and remote areas due to thin markets. Where services are available, they are likely considerably more costly compared to urban locations. This further entrenches inequity, as people living outside metropolitan centres may be unable to access the support needed to remain at home at the end-of-life.

As noted earlier discharging a palliative patient from hospital to a MM3 - MM7 area is extremely complex and time consuming. Adequate positions to allow for this coordination may not exist in hospitals. IHACPA pricing models may not have factored this complexity in specifically as this problem is relatively unique to Northern Australia.

One clinician also raised the potential need to support MOUs between NT Health and ACCHOs to allow flexible support and service delivery.

4.2. Thin markets & access

In the Northern Territory (NT), thin markets pose a significant challenge in delivering essential services, including palliative care services, particularly in remote and regional areas. A "thin market" refers to a situation where there are very few buyers and sellers, in this case, service providers and

clients, making it difficult to match supply with demand. Low population density, vast geographic distances, and limited infrastructure contribute to the scarcity of providers willing or able to operate in the NT. This lack of competition can also drive-up costs and reduce the quality of services, making it harder for government programs and support systems to operate effectively and equitably across the Territory. More specifically, in the context of palliative care, this means limited specialists, a reliance on agency, a transient workforce and a substantial increase of cost of doing business compared with other jurisdictions.

Geographic distribution affects service access:

- 45% of Territorians live in remote or very remote areas[16].
- Specialist palliative inpatient units are located in Darwin (Top End Palliative Care Unit – 12 beds) and Alice Springs (10 beds)[17].
- Outreach services exist but face challenges in covering large distances, especially for after-hours and crisis support [17].

Focus group and interview participants identified inequities in the availability of palliative care services, noting disparities between very remote and urban areas within the Northern Territory, as well as between regional hubs areas in the NT and regional hubs in other Australian states.

4.3. Recruitment challenges

Remote or rural locations presents a range of challenges which negatively impact workforce attraction and retention. In the context of health care, these include isolation, demands to work autonomously at an expanded scope of practice, high workloads due to limited staffing, personal safety concerns, reduced access to healthcare and support services, limited opportunities for professional development and career progression, high travel costs to visit family and support networks, and fewer educational or recreational options for children and families, all of which can impact staff wellbeing and morale.

In addition, when not enough visiting staff are available to accompany palliative care patients as they return home, this workload inevitably falls on local clinicians who are already thinly stretched. The emotional and physical burden of providing palliative care in small clinics with limited staff cannot be underestimated. Fatigue is common. Where staff are overburdened by the needs of palliative care patients this can contribute to staff burnout, mental health issues and inevitably high staff turnover. On a practical level, on the ground staff are involved in the decision whether a person is able to return home to die and where available support in not sufficient this may not be possible. Clinicians in regional hubs reported the need to navigate this discussion very carefully with on the ground staff and negotiate on behalf of their patient at times.

Housing shortages in remote areas of the NT are significant and may be a barrier to allowing staff to support palliative care patients including outreach staff when assisting patients to return home and staff in more permanent roles.

4.4. Roles available

Palliative care is a high-burden area of service delivery, requiring physical, emotional, and cultural support in the final stages of life. Families may be able to provide this care but need support from professional, especially as they first get started. In many remote, very remote or hyper remote isolated areas, there is extremely limited access to palliative services. As a result, individuals nearing the end-of-life may be transferred to urban centres, far from family, community, and Country. In other cases, patients may receive care in remote areas that is necessarily inequitable compared to what can be offered to people living in urban areas. All focus group and interview participants identified that lack of roles for health staff, especially outreach roles to assist in

establishing care in remote, very remote and isolated areas, is the biggest barrier to service provision in palliative are in the NT.

For example, in a small remote Aboriginal community there may be 1-2 staff members. A small clinic like this cannot feasibly offer 24-hour service delivery which may be needed to care for a dying person. In addition, if one of those staff members is called out overnight, it may be necessary to close the clinic the following day. There are other examples as to why the clinic may close for example due to threats against staff. In these examples, community members may only have access to emergency health care and in this context supporting families to provide palliative care may not be feasible. If someone returns to a remote community for end-of-life care, it would be highly beneficial to have a trained health care team available to stay for a few days during this transition, however current funding mechanisms for palliative care service delivery do not support such intensive models of care.

Additionally, there is limited after-hours coverage or phone support for palliative care NT wide. Increased staffing to allow for the development of an on-call rosters and flexible service models is necessary to support home visits in remote settings. While there is strong support across the health system and within communities for people to die at home, the current lack of accessible and responsive services makes this challenging. Without targeted resourcing, these aspirations will continue to be out of reach for many Australians living outside metropolitan areas.

Significant coordination is needed to return someone to Country which is resource intensive. It was the view of the focus group majority and interview participants that the current resourcing was not adequate to support palliative care at home for remote residents.

Voluntary Assisted Dying (VAD) is not currently legal in the Northern Territory. In October 2025, the NT Government officially announced it would begin drafting a VAD bill, responding to recommendations from an expert advisory panel and a parliamentary committee. Some focus group participants raised concerns about the capacity of an already overstretched palliative care service to add this to their business as usual and the equity questions that may result.

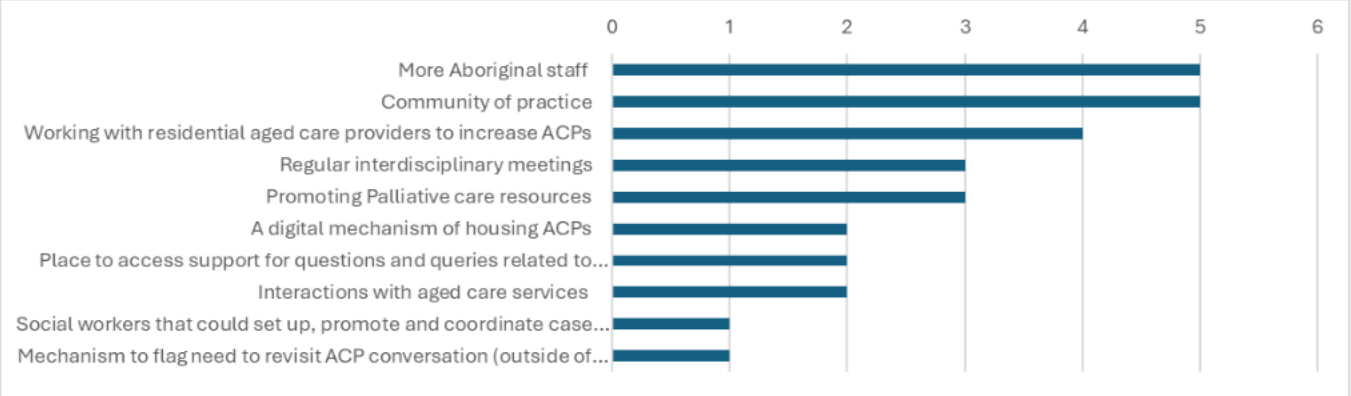
Advanced Personal Plans (APPs) take time to do well, in busy remote settings where emergency care is often prioritised, dedicated resources may be required to enable this non urgent work to be achieved alongside regular primary health care services. Remote, very remote and hyper remote isolated locations often have little support to coordinate bereavement services. Interview respondents commented that often people do not need formal mental health services, however where systems and supports are not in place to connect people to others to aid in the grieving process this can increase reliance on mental health services.

4.5. Aboriginal and Torres Strait Islander Staff

Aboriginal and Torres Strait Islander Health Professionals are invaluable in supporting Aboriginal and Torres Strait Islander people, providing care that is grounded in community knowledge, trust, and cultural understanding. Models of care that place Aboriginal and Torres Strait Islander staff at the centre are far more likely to be effective, as they strengthen relationships, improve communication, and ensure that services are culturally safe. However, in many remote areas there are not enough Aboriginal staff, and ongoing challenges exist to enhance the pipeline for training a skilled Aboriginal health workforce related to education standards and enablers for community members to partake. Respondents (n= 11) from the NT PHN Health Workforce Needs Assessment 2025 working in palliative care reported that increasing Aboriginal staff would be the most effective strategy to improve coordination of palliative care services in their local area (Graph 1, number represent the times respondents identified the strategy as a priority). This highlights the need for flexible workforce models, culturally appropriate training pathways, and greater investment in Aboriginal and Torres Strait Islander-led education and leadership opportunities within the health

sector including palliative care. This may include utilising support workers in care as part of the health care team for palliative care patients with no clinical background.

Graph 1: Responses to multiple-choice question: In your opinion, which strategies would most improve coordination of palliative care services in your local area? NT PHN Health Workforce Needs Assessment Survey 2025.



4.6. Equipment

Access to appropriate equipment is a critical aspect of supporting people to die at home. Individuals nearing the end-of-life commonly require a range of equipment such as oxygen, hospital beds, lifters, mattresses, oxygen canisters, four-wheeled walkers, medication, fans and commodes. In many remote and community settings, these items are not always readily available. In addition, unlike urban areas, there is frequently no shop available where such items can be purchased which puts the burden of supply and storage on the, already-stretched, health care services.

There are needs for equipment in the NT context which differ from other jurisdictions. For example, in remote communities many homes may not have suitable mattresses. Often public hospitals provide a small amount of basic equipment to enable discharge home. Generally, the freight on these items is passed on to the primary care centre, in most cases the freight costs will be greater than the cost of the equipment. While many communities will have been provided with some basic equipment at some stage these items do not necessarily last long and are often damaged or go missing, reducing availability for future patients. At times equipment is donated to palliative care services when people pass away.

The lack of equipment not only impacts patient comfort and dignity but can also delay hospital discharge. Hospitals may be reluctant to release patients without assurance that necessary equipment is in place at home, leading to extended admissions that are costly and contrary to patient wishes.

4.7. Medications

Access to palliative care medications in rural and remote communities presents complex challenges that significantly impact the ability to deliver high-quality end-of-life care.

One respondent proposed that there would be benefit from increasing awareness and understanding of the standardised National Core Community Palliative Care Medicines List by sharing the Caring@Home pharmacological resources, PalliMENDS phone App. This could include;

- Encouraging GPs to pre-emptively prescribe subcutaneous and buccal formulations using evidence-based resources and to collaborate with their patient's usual pharmacy to expedite timely access to medicines for symptom management.
- Encouraging Residential care providers to set expectations for, and consider establishment of processes, including imprest systems to facilitate pre-emptive prescribing and timely access to the medicines on the list.
- Hosting the List on palliative care NT HealthPathways.
- Advocating for initiatives that fund community pharmacies to stock the medicines on the list.

4.7.1.1. Prescriptions

Survey respondents reported instances of delays in prescribing palliative medications which can result in patients passing away in the hospital unnecessarily. Furthermore end-of-life medication packs may not be suitable for storage in a remote community, due to concern about medication diversion, it is generally preferable to make sure medications are prescribed for an individual which allows careful tracking and maintaining accurate prescription and usage records. Patchy internet connectivity in remote areas can limit the use of telehealth and eScripts to facilitate quality medication provision.

4.7.2. Regional contexts

Urban patients in regional areas such as Darwin, Katherine and Alice Springs do not have access to 24-hour pharmacies. Currently, there is no streamlined solution for timely access to palliative medications after hours. In most cases, need for access to such medication can be predicted and planned. Pre-emptive prescription of subcutaneous and buccal formulations can also assist, as can training to increase confidence in using these preparations. In an emergency situation having these medications available through designated sites may prevent a hospital admission. Establishing designated sites, such as hospital emergency departments or residential aged care facilities, where families could collect pre-prepared end-of-life packs, dispensed by community pharmacies, could significantly improve access. In addition to this, one interview respondent noted that there is the potential to better utilise the latent capacity within private pharmacies to bridge service gaps for palliative care medication between hospital and primary care. This respondent also noted that a facilitator of such a collaboration between NT Health and private pharmacy providers is needed to ignite this discussion.

4.7.3. Remote, very remote and hyper remote isolated areas

In remote areas concern about medication diversion means often the medication is stored in health clinics rather than in the patient's home. In many households, and particularly overcrowded households, the presence of children or other vulnerable individuals increases the risk of accidental ingestion or misuse, which adds to this need. Consequently, patients in need of regular symptom relief may require clinic visits or frequent home visits by staff, placing additional pressure on already stretched services. While some communities have implemented lock boxes for safe storage of medications in the home, others lack the resources to do so, despite community support for such solutions.

Syringe drivers are highly effective in managing symptoms and reducing the need for acute interventions, especially overnight. This can be beneficial in remote settings where clinics have limited staff. However, there is limited availability of syringe drivers, which can cost $3,500–$4,000 each and have high ongoing maintenance costs. For example, currently there are only eight syringe drivers available for loan across the Top End, which is at times insufficient to meet demand. Some clinics have purchased syringe drivers in an effort to reduce overnight call outs for overstretched staff. Availability and governance of equipment to reduce need for breakthrough pain management by remote area staff could be explored.

4.8. Service Integration

Focus group participants reported that their experience of service integration in the NT was variable. It could be good at times, especially when there was an identified palliative liaison or coordinator of care; and weak at other times when discharge summaries from hospital lack clear home plans or equipment lists. The lack of adequate feedback loops including after-hours advice lines contributed to this being unreliable.

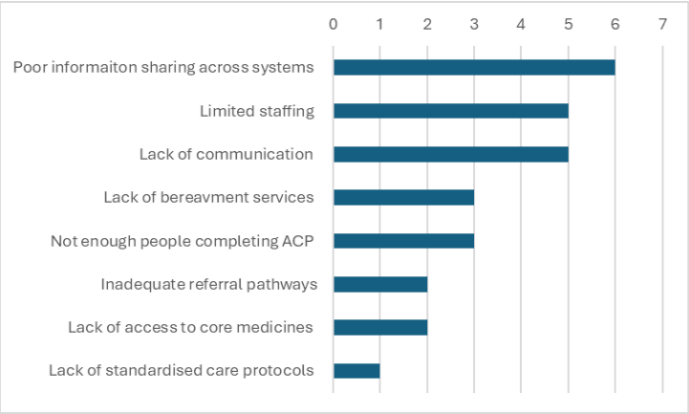
One respondent reported that there is often an ingrained culture of limited information sharing and which can create silos, reduce collaboration, and hinder service delivery. This respondent proposed that this can be addressed through intentional relationship development between service providers. By fostering trust, mutual understanding, and shared goals, agencies can break down silos, promote collaboration, and create more integrated and responsive services for the public. Carers NT run Darwin Aged and Disability meetings which are an example of a successful interagency collaboration addressing these types of challenges.

Early patient referral to palliative care services is also key, allowing time to build strong therapeutic relationships with patients and carers and to establish Advance Personal Plans (APP).

4.9. Health and digital systems

Respondents (n=11) from the NT PHN HWNA 2025 who indicated that they worked in palliative care most commonly reported poor information sharing across systems as the biggest barrier to effective coordination of palliative care in the NT.

Graph 2: What do you believe are the biggest barriers to effective coordination of palliative care in your region?
NT PHN Health Workforce Needs Assessment Survey 2025



The current challenges with digital health information systems present barriers to effective, coordinated palliative care. This is especially significant in rural and remote settings where continuity of care is so difficult.

Providers reported that many people in the NT have opted out of *My Health Record* due to concerns about privacy and cyber security, which limits its potential as a centralised, accessible source of real-time health information. Clinicians report that individuals do not necessarily want 'all' their medical information to be available online or to follow them around from clinic to clinic. For instance, if a person has previously had a sexually transmitted infection (STI) or a suicide attempt they may consider this sensitive information and may not wish for this to be known by every clinician they see. This may be a barrier to feeling comfortable using *My Health Record*. They may be more inclined to choose to have a specific item such as an APP more easily accessible and stored online. While this capacity is currently available within *My Health Record* it may not be widely understood.

Promotion of resources such as Hide or remove documents from a record may assist with uptake. This issue may also in part explain why the Queensland model of APPs being on a separate system has had better engagement than *My Health Record*.

Clinicians suggested promoting, rebranding or advertising the benefits of *My Health Record*, including access to medical history, allergies, and care preferences when patients travel or present to different services, could go some way to improving uptake. More targeted community education, focusing on privacy protections, client-controlled information sharing, and the benefits during emergency or after-hours care, may help build trust and increase participation.

While My Health Record is potentially a good place for Territorians to have their APP, the APP document itself does not direct people to upload it onto My Health Record. Territorians completing their APP are directed, by the form, to lodge it with the Public Guardian and trustee. This office is not available after hours, on weekends or at the point of care. This anomaly is likely to be addressed in upcoming updates to the APP form itself.

Another key barrier in the current system is the lack of integration across platforms. If someone's APP is complete in My Health Record a clinician will not receive a flag or alert in the main hospital system. The clinician will need to open a new system and complete a search, the absence of the record in My Health Record does not mean the document does not exist.

APPs could be undertaken by any clinician that starts the conversation however the current systems of storing APPs is lacking interoperability. The current practice in NT hospitals is that clinicians in tertiary care in the NT encourage individuals to house APPs on Clinical Workstation/ JadeCare, which may include flags for APP, but this hospital based clinical system and as a result the flags and documents are unfortunately not visible to GPs in community. It is critical that clinicians are aware of a patient's wishes, at the point of care, especially in emergency situations, for many reasons. For example, if a remote area nurse is calling the hospital because a patient is critical and the decision is being made whether to transport them to hospital, the hospital clinician needs to know the patient's wishes. However, a system visible to both hospital, emergency and community clinicians would be vastly preferable to this current patched solution.

Issues of APP quality control also exist. At times members of the community complete an APP and do not finalise it in a way that the APP would be considered legal. For instance, it may be missing a simple signature and therefore be invalid. To avoid this, some interview respondents suggest a system such as that in Queensland, or a centralised email address for APP submission which allows for simple administrative quality checks could help ensure minor errors were corrected before their likely clinical impacts. Past needs analysis in the NT has suggested this be achieved by allowing authorised access to the APP register currently maintained by the public trustee or exploration of electronic access of APPs. It was also noted previously that the office of the public Guardian and Public trustee cannot upload documents onto My Health Record because they are not healthcare providers.

One interview respondent suggested that identifying particular flags to start an APP such as being admitted to a nursing home, starting dialysis or a new cancer diagnosis can be a highly effective way of maximising APP completion. This respondent further recommended that regular auditing of APP coverage can assist with targeting improvements in uptake.

Improving systems integration and digital coordination, rather than relying solely on increased service delivery, could be a powerful enabler in supporting more people to die on Country. Establishing a single, networked digital platform that integrates APP, medical history, and care preferences, and is accessible across services and locations, would improve communication between clinicians and reduce unnecessary transfers. This approach also respects patient

autonomy by allowing individuals to choose which parts of their APP are uploaded and shared. Capacity-building efforts should focus on training staff in document review, digital literacy, and culturally safe communication to ensure that information is both accurate and reflective of patient wishes. In the long term, system-wide coordination and better use of existing technologies could help shift from reactive service delivery to proactive, patient-centred planning.

4.10. Education

4.10.1. Education to Health Care Staff

Education and upskilling of clinical staff including Remote area nurses, remote GPs, AHPs and Aboriginal Liaison Officers (ALOs) is a critical component of strengthening end-of-life care in remote communities. Training outreach to community-based staff is essential. Education must also be ongoing, as high staff turnover in remote settings can quickly erode local knowledge and capacity. Workshops are an effective mechanism to deliver targeted, practical training and should be supported and expanded.

One interview participant noted that in a small, isolated settings education has an additional challenge. Death may not be an everyday occurrence however this does present a challenge with how to time and integrate training. This participant proposed that integrating basic palliative care training and placements or hands on experience with existing standard training pathways. Thereby framing palliative care as a core skill from the start. For example, this training could be expanded in GP registrar training, readiness for remote training, nursing or AHP training pathways.

One focus group participant raised that guidelines do not exist in how to manage the complications of providing palliative care in a remote setting. This would include how to approach discussions about death and dying in a culturally sensitive way as well as addressing the practical issues such as what to do about housing, heat, overcrowding, managing family, attitudes to death and dying, negotiating with the staff due to the amount of extra work that is involved.

Stakeholders noted that the PEPA (Program of Experience in a Palliative Approach) and iPepa (Indigenous Program of Experience in a Palliative Approach) course included valuable information enabling health care staff to build capacity in provision of palliative care. Further feedback about this course is that people working in very remote areas might need longer placements and on the job supervision to be able to manage the complexities presented in very remote and isolated contexts. The suggestion was for a week placement in a specialist service and a week placement in a remote location. In addition, it was noted that where clinics are small or have very few on the ground clinicians, capacity to participate in the course may be limited particularly as there is no funding available for replacements or locums to cover the workload during the course period. One participant reported that if this content was made available online this may enhance people working in very remote contexts to access the material.

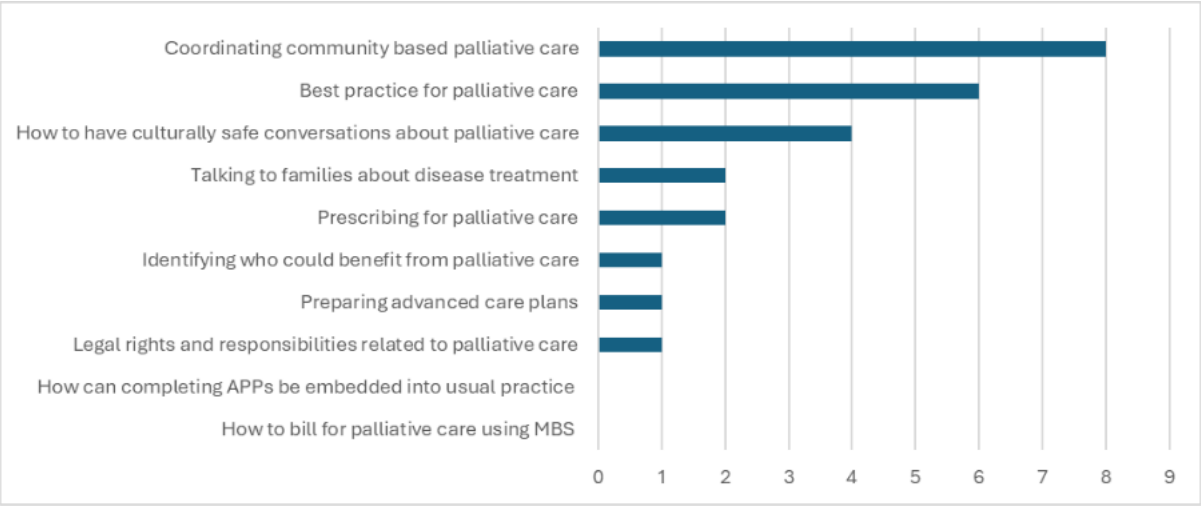
Participants in one focus group suggested that an orientation pack to NT palliative care and or a NT wide community of practice in the palliative care space would go some way to increase education, knowledge sharing and collective learning. This links with the feedback from the Health Workforce Needs Assessment where a community of practice was the equal most selected strategy to most improve coordination of palliative care services (graph 1). Others noted that there is potential capacity for specialist, hospital services to provide upskilling if this could be coordinated.
Despite the potential benefits of completing an APP, where it is culturally appropriate, responsibility for initiating these discussions is often unclear specialists often expect GPs to lead discussions, while GPs expect specialists to take the role. In reality, initiating APP should be a shared responsibility across the care team. Education can assist with GPs feeling confident in their role in completing APPs.

Recommended CPD topics for health staff suggested by focus group and interview participants include;

- Non-pharmacological approaches to comfort and care
- Raising APPs in a culturally sensitive way
- Symptom control
- Anticipatory medications
- Bereavement support
- How to use syringe drivers
- How to provide medication in the palliative care space
- Empathy
- eTherapeutic guidelines
- Assessing symptoms
- How to talk about death
- Myths of morphine
- Awareness of available
- MBS item numbers available for palliative care
- Cross cultural care
- Communication and patient handover.

One interview respondent also noted that there is a lack of monitoring and oversight to ensure things such as cultural education are undertaken by organisations. Respondents (n = 11) to the NT PHN Health Workforce Needs Assessment Survey 2025 who indicated that they worked in palliative care most commonly reported the need for professional development in the areas of coordinating community based palliative care, best practice for palliative care and how to have culturally safe conversations about palliative care.

Graph 3: Which of these topics would you like to have further training or print material in?
NT PHN Health Workforce Needs Assessment Survey 2025



4.10.2. Education to aged care staff or NDIS carers

Survey respondents from aged care sites noted that they are potentially open to receiving more education in the palliative care space. In-house learning management systems may be able to be used to disseminate information to aged care professionals. It was reported that offering a mix of online modules and in person sessions was preferable to meet the learning needs and availability of various people. The existing Advanced residential aged care home (RACH) education package project being implemented by NT Health, aiming to train and upskill nurses and aged care staff, could offer an avenue for potential collaboration in this space.

Multiple focus group participants reported that there is a gap in the education available to NDIS carers in the palliative care space. While this issue potentially affects a small group of people, lack of appropriate training may be a barrier preventing people being discharged from hospital. Targeted education for NDIS staff would address this gap.

4.11. Paediatric palliative care

In the NT there are no services available for paediatric palliative care, this is gap is filled by specialist services in other jurisdictions. NT services generally provide reimbursement for the cost of this service provision if it is provided by a hospital setting. The estimated number of children and young people aged 0 - 21 years in the Northern Territory living with a life-limiting condition who might benefit from paediatric palliative care services was 360 in 2018, this was the highest per 100 000 population of any jurisdiction in Australia (146.9/100 000)[18].

4.12. What is going well?

Providing palliative care in the Northern Territory is undeniably complex, yet clinicians and health services across the NT consistently demonstrate remarkable resilience, adaptability, and commitment. They work creatively with the resources which are available, often going above and beyond to ensure that people receive compassionate and culturally appropriate end-of-life care. Interviews highlighted numerous examples of excellent practice, showcasing innovative, community-led, and collaborative approaches that make a real difference to individuals and families during some of the most difficult times of their lives.

4.12.1. Success and Innovations

APP Champions: For example, in the Top End, the Groote Eylandt community and health centre provide a strong example of successful integration of APP into service delivery. With dedicated APP champions and a low staff turnover, they have embedded APP into their standard practice, ensuring that discussions begin as soon as people are enrolled into their chronic disease program. This approach has resulted in more people having their end-of-life wishes respected.

Telehealth: Another top end innovation is mobile telehealth units which can support virtual connection to Country or enable family meetings when physical return is not possible. Telehealth connection may be especially important in cases where transport delays, such as those through the Royal Flying Doctor Service or Care Flight, mean individuals may pass away before being able to return to their Country.

Palliative Care Champions: Some respondents reported that where remote or very remote locations had enough staff palliative care champions were often able to provide support and assist in people being able to die on country.

Focus group participants also reported that the Central Australian hospice is a great example of how culturally safe palliative care can be provided. Family can visit at any time without restrictions and anecdotal reports are that people feel comfortable finishing up there.

Collaborative Care: Some ACCHOs have been able to integrate some palliative care into their frail and aged home visiting service, noting that when GPs are given enough time and supported adequately, they can provide a lot of the palliative care that is needed. While this was noted to be an effective model it was also reported that this program is under resourced and therefore not able to meet the latent demand for such a service.

In other more general examples providers reported building strong relationships with community and service providers fostering collaborative approaches to palliative care. In addition, it was noted

that the tertiary sites in the NT provide useful support such as to aged care settings, where possible or consultancy by telehealth.

4.12.2. Farewell community visits

In Central Australia, Purple House has a model of care where palliative renal clients can return home for a farewell visit in a customised truck. This truck has the capacity to hold a bed, a lifter, what is needed for shower care, pillows, continence aids, medical supplies, and oxygen concentrator, tube-feeding equipment, other consumables and can travel over rough terrain while also being low enough to the ground for people towards the end-of-life to enter.

4.12.3. Communications to key community groups

COTA has a quarterly newspaper that is printed in large font size and sent out to various community hubs like Members of the Legislative Assemblies offices and libraries. There is availability to include advertisements in this newspaper specifically relevant to older people.

4.12.4. Advanced personal planning facilitator

NT PHN has successfully funded a program to support clinicians in completing APP. The activity differs from the national program in that it is more specialised and focused on the need for culturally safe conversations with and for Aboriginal and Torres Strait Islander people and communities. This program has also involved staff training and capacity building in remote areas. It is scheduled to continue until 2029 and will include work on updating the NT APP and making it more culturally appropriate.

5. Implications for implementation of GCfAHPC program the in the Northern Territory

NT PHN has determined that the most effective way to maximise the value and impact of this program in our jurisdiction is through the commissioning of service delivery by established, on-the-ground providers. These organisations possess the operational capacity, local knowledge, and specialist expertise required to respond directly to identified needs and deliver outcomes efficiently and responsibly.

In particular, prioritising providers with relevant cultural expertise ensures that services are appropriate, respectful, and responsive to the communities they support. This approach enables funding to be directed to where it is most needed, supports community-led solutions, and strengthens existing know-how rather than duplicating services. By commissioning delivery in this way, we are confident the funding will achieve meaningful and sustainable impact.

5.1. Program Goals

- improve access to the best palliative care at home
- support palliative care services in primary health and community care
- make sure Territorians get the right care, at the right time and in the right place to reduce unnecessary hospital visits
- generate and use data to improve services
- use technology to provide flexible and responsive care, including after-hours care.

5.2. Key program deliverables

Informed by the findings of the NT PHN Palliative Care Needs Assessment 2025 and aligned to the Greater Choice for At Home Palliative Care (GCfAHPC) program objectives, NT PHN will deliver the following five strategic, measurable implementation streams.

5.2.1. Commission Palliative Care Capacity-Building Services

Goal (Specific): Commission on-the-ground, culturally appropriate palliative capacity-building services in all NT regions by mid-2027.

Actions:

- Maintain existing commissioned services in Top End, Big Rivers, and East Arnhem (2025–2029).
- Procure service coverage for Central Australia and Barkly through open tender by June 2026.
- Ensure alignment of all service partner deliverables to at least one GCfAHPC program objectives.

SMART Indicators:

☑ Contracts executed covering all NT regions by 31 December 2026.

☑ Six-monthly performance reports showing milestone achievement rate.

☑ Four case-studies of successful community-based palliative capacity-building initiatives by June 2028.

Link to Greater Choice Objectives: Improves access, enhances workforce capacity, and supports place-of-choice care delivery at home.

5.2.2. Strengthen Primary Health and Community Care Capability

Goal (Specific): Build sustained capacity of primary health, aged care, and community providers to deliver safe, culturally appropriate, and integrated palliative care.

Actions:

- Collaborate with commissioned providers to deliver regular NT-wide education and on-the-job training sessions across areas including but not limited to, culturally safe communication, APP facilitation, goals of care, end-of- life issues and expectations, bereavement support and/or medication management in community – see section 4.10.1. for further details on CPD priorities.

- Promote locally relevant CPD for GPs, AHPs, allied health, nurses, ALOs, aged care and NDIS providers.
- Foster “champions” within each region to support ongoing skill transfer.

SMART Indicators:

☑ At least 300 providers trained per financial year, across ≥ 80 % of service regions.

☑ Annual pre- and post-survey respondents show a 25% improvement in confidence to put learnt concepts into practice.

☑ Enable commissioned providers to partake and/or lead Advanced Care Planning CoP (Community of Practice) or knowledge-sharing events e.g. Office of the Public Guardian and other working groups.

☑ Available national resources and education promoted via NT PHN channels.

Link to Greater Choice Objectives: Strengthens capability of the primary care system and community services.

5.2.3. Coordination and Integration of Care

Goal (Specific): Enable care coordination and integration across the NT to be visible, measurable, and routine.

Actions:

- Partake in the development of Territory-wide Coordination mechanisms that set clear referral, discharge, and digital information-sharing mechanisms.
- Ongoing updates to NT HealthPathways relevant to palliative care.
- Enable commissioned providers to partake/lead in regional integration working groups with local providers to identify system barriers, and solutions to local palliative care pathways.

SMART Indicators:

☑ Palliative care NT HealthPathways reviewed at least annually ensuring integrity and promoted as part of relevant education sessions.

☑ Evidence of improved clarity around service coordination by June 2028.

☑ Collaboration with the NT Chief Pharmacist to identify joint opportunities enhance Promotion of the National Core Community Palliative Care Medicines List by June 2027.

☑ Evidence of increased usage of My Health Record for Advanced Personal Plans by June 2029.

Link to Greater Choice Objectives: Supports seamless patient journeys and right-time, right-place care.

5.2.4. Community Awareness and Advance Personal Planning

Goal (Specific): Increase public and community understanding and completion of culturally safe Advanced Personal Plans (APPs).

Actions:

- Enable commissioned providers to co-design plain-language, culturally relevant communications campaigns (print, social media, radio, COTA newspaper advertising).
- Embed Aboriginal and Torres Strait Islander APP training in commissioned activities.
- Establish measurable engagement metrics for digital resources hosted on NT HealthPathways and local websites.

SMART Indicators:

☑ Resources made available via NT PHN channels such as website, social media, NT HealthPathways and GP liaison updates.

Link to Greater Choice Objectives: Builds community capability to plan for end-of-life care at home.

5.2.5. Continuous Evaluation and Data-Driven Improvement

Goal (Specific): Apply a robust evaluation framework that measures not only activity but also outcomes and program impact.

Actions:

- Monitor progress six-monthly using integrated KPI dashboards.
- Include longitudinal data collection to assess workforce training impact and service integration.
- Report annually on qualitative and quantitative indicators (see section 5.3).
- Feed evaluation insights into commissioned activity and future commissioning cycles.

SMART Indicators:

☑ By December 2026, establish baseline data sets and provider reporting tools.

☑ Annual report submitted to DHDA showing measurable progress across all four GCfAHPC objectives.

☑ Minimum two improvements implemented annually based on monitoring and evaluation outcomes.

Link to Greater Choice Objectives: Generates and uses data for continuous program improvement.

5.3. Monitoring and Evaluation Framework

Commissioned and in-house NT PHN activity will measure progress and success via this consolidated evaluation framework, modelled on the National Evaluation framework for the Greater Choice for At Home Palliative Care Program.

In practice, contract managers will consider the below to inform contents of reporting tools for commissioned services.

AREA	Evaluation Question	Indicators/Data sources	Timeline
Workforce, Education and Awareness	To what extent has NT PHN improved workforce capacity and confidence in delivering home-based palliative care and/or enable advanced care planning?	Pre/post-training surveys - Number of trained providers - Skill retention and application interviews	Baseline 2025, annual review
Community Awareness & Death Literacy	Are providers equipped with resources to enable patients to access to key messages in plain language that explain patients what to expect and allow family to understand how they can provide basic care to support a loved one to die at home?	- Reach metrics from awareness campaigns - Resources developed -NT HealthPathways updated with key resources	2025–2029
Coordination & Integration	Has the project contributed to fostering a culture of embedding APPs and discussions around goals of care as part of routine care such as chronic conditions management putting patient's wishes and needs at the centre of care?	- Cross-agency meeting attendance records - APP completions via My Health Record / Public Trustee - APP intake data from aged care providers - Case studies - HealthPathways usage analytics - Stakeholder satisfaction surveys	Annual
Impact and Improvement	What outcomes can be attributed to GCfAHPC implementation?- Benchmarking to baseline 2025	- Hospital data where available e.g. EOL location trends, quality of life, reduced hospitalisations, on-Country deaths, improvements on death audits	2025 baseline + 2027, 2029 reviews

AREA	Evaluation Question	Indicators/Data sources	Timeline
		- Qualitative testimony e.g. Inappropriate hospital transfers	

6. Appendices

Appendix 1: Feedback from stakeholder consultations 2023-2024

In 2023, NT PHN and NT Health undertook a series of stakeholder interviews across the Northern Territory to better understand the current strengths, challenges, and opportunities for strengthening palliative care. Consultations included general practitioners, registered nurses, clinic managers, AHWs, and representatives from ACCHOs. These interviews were designed to capture local, on-the-ground perspectives from both urban and remote health settings, with a strong emphasis on culturally safe care, workforce development, service coordination, and community engagement.

The interviews revealed the following themes:

Cultural safety and communication

- Strong need for culturally appropriate language and approaches when discussing death and dying, using terms such as “finishing up” or “passing” rather than “death.”
- Importance of early, family-centred conversations that align with Aboriginal cultural protocols, led where possible by trusted community members.
- Use of culturally relevant resources like the *‘Dying to Talk’* booklet and conversation cards, adapted to local languages and customs, to make discussions less confronting.

Workforce capacity and training

- Limited opportunities for remote staff to attend multi-day Dept of Health and Ageing Program of Experience in a Palliative Approach (PEPA) training due to backfilling and staffing constraints.
- High value placed on reverse placements (trainers visiting communities) and follow-up support to embed learning into practice.
- Need for developing local community champions to lead palliative care awareness and skill-building.
- Workforce wellbeing concerns, with calls for structured grief support, supervision, and burnout prevention strategies.

Service coordination and integration

- Limited awareness of available palliative care services, especially in remote regions.
- Need for consistent referral pathways, shared care plans, and better communication between Territory Palliative Care, ACCHOs, hospitals, and local clinics.
- Recognition of successful, locally designed models such as Groote Eylandt’s high APP uptake and Wurrumiyanga’s integrated approach.

Advance personal planning (APP) awareness, cultural barriers, and system issues

- APP uptake remains low due to cultural beliefs that discussing death can hasten it, leading to avoidance of conversations.
- Conversations often occur too late, sometimes only in the last weeks of life, reducing their impact.
- Existing tools such as the Aboriginal Advanced Care Planning booklet and 'Dying to Talk' cards are valued but under-promoted, with limited availability in local languages.
- Lack of clear, culturally safe processes for documenting and sharing APPs across services, especially in remote areas without electronic health record integration.
- Families and carers often need ongoing support to understand APPs options and navigate the legal and service systems.

Access, equity, and data gaps

- Uneven access to pain medications, equipment, and after-hours support, particularly in remote settings where services rely heavily on family care.
- Gaps in service mapping, workforce capacity data, and cultural resources make it difficult to plan and commission effectively.
- Region-specific solutions are needed to address the distinct needs of the Top End, East Arnhem, Big Rivers, Barkly, and Central Australia.

Appendix 2: Palliative Care Outcomes Collaboration

PCOC is the Palliative Care Outcomes Collaboration, a national program in Australia that uses standardized clinical assessment tools to measure and improve palliative care outcomes for patients, their families, and carers. It works by providing a common language for clinicians, enabling routine data collection, and offering feedback to services through national analysis and benchmarking to drive improvements in quality of care. The Northern Territory submits data to PCOC however reporting is only provided at a national level for NT data.

Appendix 3: Advanced personal planning in the NT

A National multicentre audit of health record data (Advance Care Planning Australia, 2021) of 4187 health records across general practices, hospitals and residential aged care facilities found that the median prevalence of advance care directives (ACDs) was low (19 %) across organisations (bmchealthservres.biomedcentral.com)[19]

The key findings from the audit include:

- Only 14% of older Australians had a statutory or common law advance care directive (ACD) for preferences of care and/or to appoint a substitute decision-maker. The prevalence across sectors was 6% in General Practice, 11% in hospitals, and 38% in residential aged care.
- When including non-ACD documentation (planning documents completed by a doctor or someone else), only 29% of older Australians had documentation to inform future medical treatment decisions and end-of-life care.
- For older Australians in residential aged care, 30% of documents were advance care plans completed by someone else (e.g., a family member or carer), with 65% of these including

life-limiting instructions and only 25% indicating that a discussion took place with the person the instructions relate to.

- Low prevalence is complicated by poor document quality, with 27% of documents missing important quality identifiers such as full name, signature, document date, and/or witnessing.
- Having a discussion about advance care planning with anyone (including a clinician), made a person three times more likely to document an advance care directive.
- An analysis of the 62 participating organisations across 100 sites, found that only 18 organisations across 29 sites had a valid (in date and referring to correct legislation) advance care planning policy

When the authors examined hospital data and adjusted for organisational characteristics, jurisdiction was associated with higher ACD prevalence, and the Northern Territory had the highest adjusted prevalence at 35.3 %[19]. New South Wales had the lowest (1.4 %). The authors cautioned that these figures are based on only one NT hospital site and uneven representation of jurisdictions, so the NT percentage should not be interpreted as a population prevalence. They suggested that the high NT figure may reflect a hospital specific program promoting advance care planning.

Appendix 4: End-of-life Directions for Aged Care

ELDAC (End-of-life Directions for Aged Care) provides information, guidance, and resources for all aged care staff to support palliative care and advance care planning. End-of-life Directions for Aged Care - ELDAC. There are 9 participating aged care homes in the NT NT - Participating Sites.

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8. Further Information

Definitions	Modified Monash Model The Modified Monash Model (MMM) is a classification system used in Australia to categorize areas based on their remoteness and population size, ranging from metropolitan to very remote locations. Regional, Very Remote, Remote: These terms have been used as defined in the Modified Monash Model. Hyper remote/ extremely isolated locations: No standard definition exists for hyper remote or extremely isolated locations. The inclusion is intended to reflect the disparity in very remote locations between states. Advanced Personal Plans Advanced Personal Plans are used in the NT to document a person's end-of-life wishes, they can be considered equivalent to Advanced Care Plans in other states. Advanced care planning is the process of developing and documenting APP or ACPs and is a process used in all states. Imprest An "imprest system" means the method by which medicines are supplied from the pharmacy department of a hospital, or by an authorised seller of poisons, to a licensed health service or the wards, theatres, departments or clinics thereof, either in containers of the original manufacturer, or repacked containers in order to establish and maintain a stock of medicines at a pre-determined level for use in such places.

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