PRIMARY HEALTH NETWORK

phn HUNTER NEW ENGLAND AND CENTRAL COAST

An Australian Government Initiative

Rebbeck

HNECC Palliative Care and Care for Older People

Palliative Care Needs Assessment - 28th August 2023

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Rebbeck acknowledges the traditional owners of the country on which we work and live and recognise their continuing connection to land, waters and community. We pay our respect to them and their cultures and to elders past, present and emerging.

Executive Summary

Approach and method

The Hunter New England Central Coast (HNECC) PHN undertook a palliative care rapid literature review and needs assessment to understand the current palliative care needs of the region. The purpose of these activities was to inform decisions on how to allocate the "Greater Choices for Palliative Care" funding to identify and respond to the palliative care needs of people living in the HNECC region.

The literature review identified several priority palliative care needs facing the general population and was the basis of an initial logic model. This was condensed and revised to form a series of needs hypotheses for 3 key groups of stakeholders: patients, their families/carers and clinicians.

From the needs hypotheses, a series of key lines of enquiry were developed, which subsequently informed the data collection methods.

The HNECC PHN Palliative Care and Care for Older People team conducted eight focus groups and twenty-four clinician interviews to collect qualitative data.

Quantitative data was collected from numerous sources to identify the size of the needs.

In planning the needs assessment, a series of anticipated themes were postulated.

These anticipated themes were used to conduct a thematic analysis of stakeholder consultations which recorded the frequency/severity of each theme raised.

New ideas and unanticipated themes were documented.

The quantitative data were subsequently assessed for evidence in support of or against the anticipated themes.

The profile of the local population in relation to palliative care needs was analysed from multiple sources. Demographic data from the Palliative Care Outcome Collaboration and LUMOS revealed:

- A relatively even mix of male and female service users.
- The majority of service users were aged over 65.
- Between 0.7-1.3% of patients using palliative care services at Gosford and Central Coast services identified as having Aboriginal and/or Torres Strait Islander origins.
- Most of the service users were born in Australia and spoke English as their preferred language.
- A slightly greater proportion of service users had a malignant diagnosis compared to a non-malignant diagnosis. Lung cancer was the greatest principal diagnosis within the malignant group, while 'other non-malignancy' was the most common non malignant diagnosis. The data source did not define what was meant by this diagnostic term.

Executive Summary

Findings and recommendations

Two methods were used to assess the findings:

1. Triangulation matrix
2. Prioritisation score

The triangulation matrix was used to assess the level of support that was shown in the qualitative and quantitative data gathered in the needs assessment.

A greater triangulation score corresponds to a greater level of evidence in support of the need.

The following table describes the score and the number of needs that were given this score in the needs assessment.

Further information about how individual data sources were assessed and how the triangulation score was calculated is available in appendix 2.

Score	Description of score	Number of needs
3	Strong support	6
2	Moderate support	10
1	Limited support	0
0	Contradicted or no support	1

Executive Summary

The prioritisation score was calculated based on the size of the need, the severity of the need and the addressability of the need. The addressability score was produced by the HNECC PHN Palliative Care and Care for Older People team who rated their ability to respond to the need.

The prioritisation score identified the following as the top priority needs for each of the stakeholder groups:

Patients:

1. Patients who require palliative care (in particular those with non-malignant disease or dementia diagnoses) can experience prolonged symptoms and suffering due to delayed referrals and interventions

2. Patients with low health literacy experience greater difficulties understanding and processing information, poorer health outcomes, quality of life and experience of care

3. Patients (including those from First Nation communities) receiving palliative care do not have cultural or religious rituals around dying and death acknowledged

4. Vulnerable patients including migrants and people facing financial /housing instability are less able to access palliative care

Clinicians:

1. Nurses have difficulty providing optimal care due to challenges in accessing quality information, resources and timely prescriptions

2. Palliative care clinicians experience compassion fatigue and burnout caring for patients who are end of life

Family and Carers:

1. Family and carers lack support following a bereavement and some individuals (particularly those aged 80+) are at increased risk of suicide following a bereavement

2. Carers and family members lack education regarding their role in patient care and identifying signs of end of life

Summary findings

Summary findings

Patients

8 Needs investigated

- 2 strongly supported
- 6 moderately supported

Priority needs

Patients experience:

- Increased suffering secondary to delayed interventions and referrals.
- Challenges accessing easy-to-understand information
- Challenges in receiving culturally appropriate care
- Housing and financial instability can make it challenging to access palliative care

Family and Carers

3 Needs investigated

- 1 strongly supported
- 2 moderately supported

Priority needs

Families and carers experience:

- Challenges accessing support generally and following a bereavement
- Difficulties understanding their role and signs of dying

Clinicians

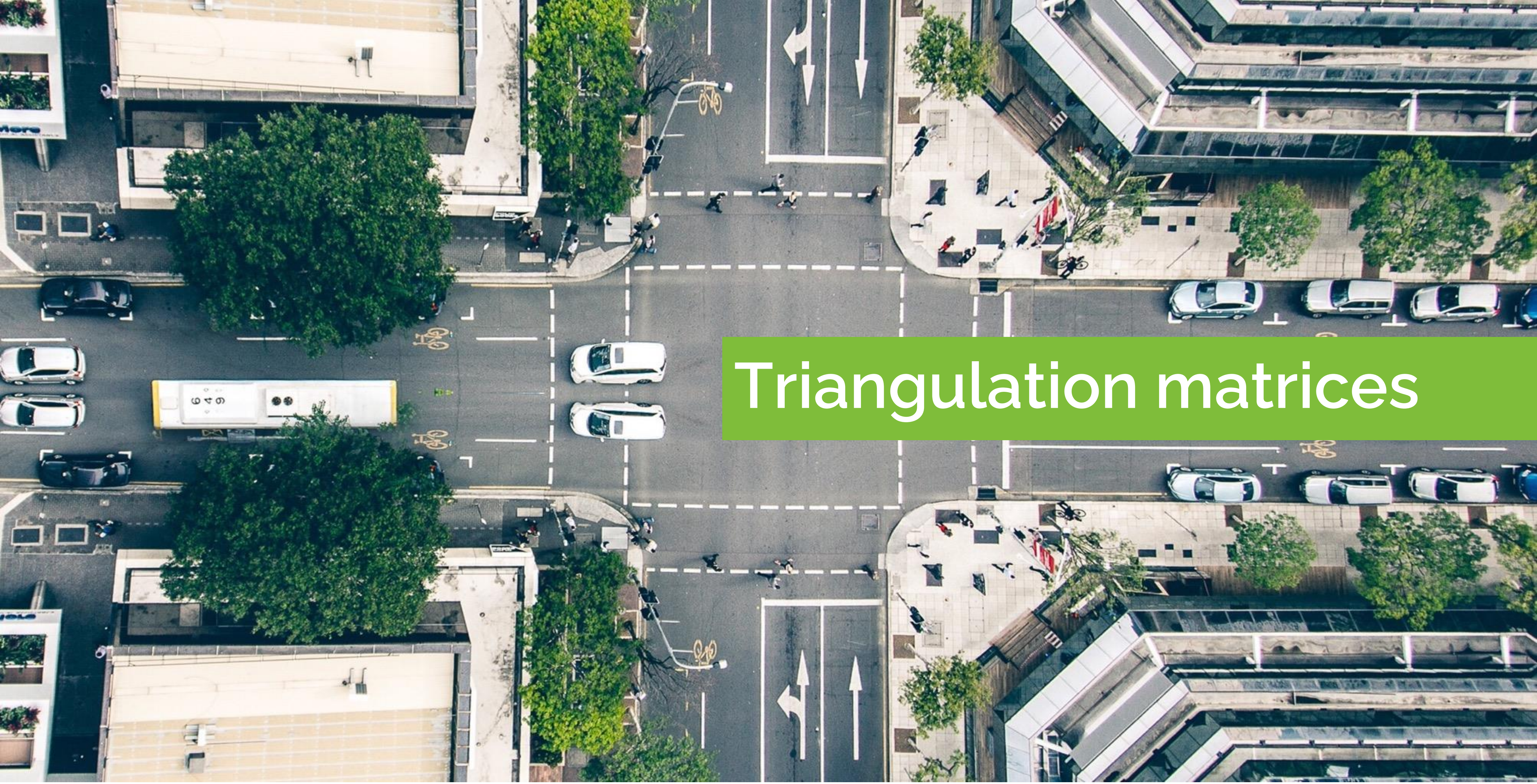
6 Needs investigated

- 3 strongly supported
- 2 moderately supported
- 1 contradicted

Priority needs

Clinicians experience:

- Difficulties in providing optimal care due to challenges accessing medication and education
- Compassion fatigue and burnout



Triangulation matrices

Triangulation and prioritisation results - Patients 1/2

Need		Action statement	Triangulation result		Prioritisation result
PC P1	Patients who require palliative care (in particular those with non-malignant or dementia diagnoses) can experience prolonged symptoms and suffering due to delayed referrals and interventions	Improve timely referrals and interventions for patients who require palliative care (in particular those with non-malignant or dementia diagnoses)	**2**	**Moderate support**	**169**
PC P2	Patients with low health literacy experience greater difficulties understanding and processing information, poorer health outcomes, quality of life and experience of care	Increase the health literacy of palliative care patients to improve health outcomes, quality of life and experience of care	**2**	**Moderate support**	**137.5**
PC P3	Patients (including those from First Nation communities) receiving palliative care do not have cultural or religious rituals around dying and death acknowledged	Improve health professional understanding of the importance of palliative patient access to cultural and religious rituals around dying and death, increasing ability for patients to participate in these rituals	**2**	**Moderate support**	**132**
PC P4	Vulnerable patients including migrants and people facing financial /housing instability are less able to access palliative care	Improve access to palliative care for patients facing financial and housing instability and for patients from migrant backgrounds	**2**	**Moderate support**	**132**

Triangulation and prioritisation results - Patients 2/2

Need		Action statement	Triangulation result		Prioritisation result
PC P5	Patients with life limiting illness experience increased suffering because of suboptimal symptom management and difficulties accessing services	Improve symptom management and access to services for patients with life limiting illness	**2**	**Moderate support**	**130**
PC P6	Patients with life limiting illness have poor management of palliative care symptoms and support during out of hours	Improve the quality of symptom management and support for palliative care patients during out of hours	**3**	**Strong support**	**108**
PC P7	Patients do not feel empowered to own their palliative care and end of life journey or maintain their independence	Increase empowerment and independence for palliative care patients	**3**	**Strong support**	**85.5**
PC P8	Rural patients have greater distance to travel and fewer services available for SPCS	Improve accessibility to SPCS for rural patients	**2**	**Moderate support**	**78**

Triangulation and prioritisation results - Family and Carers

Need		Action statement	Triangulation result		Prioritisation result
PC FC1	Family and carers lack support following a bereavement, and some individuals (particularly those aged 80+) are at increased risk of suicide following a bereavement	Increase support for family and carers of a palliative patient following a bereavement and reduce their risk of suicide (particularly those aged 80+)	**3**	**Strong support**	**182**
PC FC2	Carers and family members lack education regarding their role in patient care and identifying signs of end of life	Educate carers and family members on their role in patient care and how to identify signs of end of life	**2**	**Moderate support**	**143**
PC FC3	Family members are not regularly involved in decision-making and planning of care	Increase involvement of family members regularly in decision making and planning of care	**2**	**Moderate support**	**104.5**

Triangulation and prioritisation results - Clinicians 1/2

Need		Action statement	Triangulation result		Prioritisation result
PC C1	Nurses have difficulty providing optimal care due to challenges in accessing quality information, resources and timely prescriptions	Improve access to quality information, resources and timely prescriptions for nurses	**3**	**Strong support**	**143**
PC C2	Palliative care clinicians experience compassion fatigue and burnout caring for palliative patients	Support clinicians to identify and manage compassion fatigue and burnout when caring for patients at end of life	**3**	**Strong support**	**140**
PC C3	Palliative care clinicians lack clarity regarding their respective roles and are unable to provide continuity of care or communicate ongoing needs to other clinicians as patients move to other care settings	Support clinicians to clearly understand their role in palliative care to enable a seamless transition for patients between care settings (hospital, community, RACF)	**3**	**Strong support**	**137.5**
PC C4	GPs are unable to refer patients for beds in hospital and RACFs	Support and advocate for GPs to be able to refer patients for beds in hospitals and RACFs	**2**	**Moderate support**	**125**
PC C5	Clinicians are unable to acknowledge and support family, cultural and religious rituals when providing palliative care, end of life and death	Enable clinicians to acknowledge and support family, cultural and religious rituals when providing palliative care, end of life and death	**2**	**Moderate support**	**75**

Triangulation and prioritisation results - Clinicians 2/2

Need		Action statement	Triangulation result		Prioritisation result
PC C6	Physicians and GPs have difficulty identifying patients who are deteriorating towards death	N/A - Excluded from logic model	**0**	**Mostly contradicted**	N/A Excluded from prioritisation

There was not sufficient evidence to support clinician need PC C6.

Physicians and GPs are generally able to identify patients who are deteriorating towards death with 79% of clinicians responding in the survey that they were very confident or somewhat confident.

This was highest with General Practices/Medical specialists and nurses/nurse practitioners. Allied Health clinicians were the least confident, and in support of moving more care to the home, Allied Health professionals may benefit from further education on this area so they are able to recognise the signs of deterioration and escalate to the appropriate clinician.

Given that there was generally contradictory evidence, **this need will be removed from the logic model.**

Findings against each need

Patient Need 1: Patients who require palliative care (in particular those with non-malignant or dementia diagnoses) can experience prolonged symptoms and suffering due to delayed referrals and interventions

Identified need	Discussion of evidence	Data sources
Patients who require palliative care (in particular those with non malignant or dementia diagnoses) can experience prolonged symptoms and suffering due to delayed referrals and interventions PC P1	**Palliative care patients experience delays in accessing care**, according to comments raised in clinician and consumer surveys, as well as focus groups and interviews. The consumer survey detected that **43% of respondents felt that palliative care referrals and interventions were not made in a timely manner, while 35% felt they were.** Stakeholder engagement provides **some examples of cases in which dementia, non-malignant and younger patients did not have adequate access to palliative care services**. A patient who has dementia raised concerns that '**palliative care commences too late and too close to the end of life".** In addition, they commented, "with our often limited ability to communicate in later stages of disease, our pain and anguish is often unrecognised as such, but seen rather as "behavioural issues" and thus are disadvantaged in accessing palliative care". Although specific disease examples were not raised frequently, these comments provide a valuable insight into how certain patient groups may experience difficulties accessing palliative care, which in turn may lead to delayed access to symptom control and increased suffering. PCOC shows a **greater proportion of patients with malignant disease compared to non malignant disease are accessing palliative care services**. Data was not available to provide insights into the difference in referral times and length of symptoms in relation to specific illnesses, and this may be an area for further research.	• LHD referral data extract • LUMOS Palliative care SRG 2021 extract • No comparative data for disease type • Interviews • Focus groups • Consumer survey • PCOC **Prioritisation score: 169**

Patient Need 2: Patients with low health literacy experience greater difficulties understanding and processing information, poorer health outcomes, quality of life and experience of care

Identified need	Discussion of evidence	Data sources
Patients with low health literacy experience greater difficulties understanding and processing information, poorer health outcomes, quality of life and experience of care PC P2	Health literacy was identified by consumers and clinicians as an issue affecting patient outcomes and experience of care. Health literacy was raised as a concern frequently in clinician interviews and in focus groups. Participants identified that health literacy can impact patient autonomy, and lead to adverse outcomes. Health literacy levels were frequently identified as being a barrier to accessing palliative care. Specific examples were provided in which patients with **poorer health literacy experienced worse deaths.** It was raised that patients with **worse levels of cognition** and understanding of their condition lack insight and are **unable to advocate for themselves.** Patients with **poor health literacy are less likely to ask for help.** The consumer survey showed a mix of feedback about palliative care information being accessible in an easy-to-understand language. 32-48% felt that information was available and accessible. However**, 25-39% felt that information was not easily accessible in an easy-to-understand language**. This shows that there is still a large and significant proportion of consumers who identified health literacy as an issue.	• Interviews • Focus groups • Consumer survey **Prioritisation score: 137.5**

Patient Need 3: Patients (including those from First Nation communities) receiving palliative care do not have cultural or religious rituals around dying and death acknowledged

Identified need	Discussion of evidence	Data sources
Patients (including those from First Nation communities) receiving palliative care do not have cultural or religious rituals around death and dying acknowledged PC P3	**Patients receiving palliative care experience variable inclusion of cultural and religious elements according to feedback from focus groups and interviews**. Clinicians frequently identified that they ask patients about spiritual needs, but explained that it can be challenging to complete rituals. **Barriers to receiving cultural or religious rituals include a lack of time and misalignment of clinician and patient cultural beliefs.** **Multiple clinicians commented that they had little experience in caring for palliative patients from culturally diverse backgrounds and therefore could only provide limited insights into this need.** Just over half of the consumers surveyed felt their cultural needs and rituals were acknowledged or included during their palliative care journey. However, **15% responded that their cultural needs were not acknowledged** and 31% responding that this is not applicable to them. While there are mixed and contrasting findings, the overall impression is that patients have their culture and religion acknowledged, but incorporating rituals into care plans can be more challenging. Palliative care services and clinicians should be able to provide for cultural rituals for every patient which is currently not occurring due to available time and resources.	• PCOC • Focus groups • Interviews • Consumer survey • Clinician survey **Prioritisation score: 132**

Patient Need 4: Vulnerable patients, including migrants and people facing financial/housing instability are less able to access palliative care

Identified need	Discussion of evidence	Data sources
Vulnerable patients, including migrants and people facing financial/housing instability are less able to access palliative care PC P4	Some patients are less able to access palliative care because of funding issues. **Funding issues were viewed as a barrier to accessing palliative care** based on 6 comments raised by participants in the focus group and 4 comments raised within the clinician interviews. Clinicians identified **specific patient groups who face funding issues**. This included **patients in RACFs** or **those who are on NDIS**. Accessing equipment and packages of care were areas of care that were highlighted as being related to funding issues. Accessing and applying for financial support for palliative care was raised as an issue in comments made by consumers in the survey. Clinicians commented more generally that the palliative care system is underfunded. **Homelessness was identified as a barrier by one clinician, but no other comments regarding housing instability or migrant populations were made**.	• Focus groups • Interviews • Clinician survey • Consumer survey

"Would be great to have a mechanism to overcome some of the equipment/funding barriers."
(Focus group)

Prioritisation score: 132

Patient Need 5: Patients with life-limiting illness experience increased suffering because of suboptimal symptom management and difficulties accessing services

Identified need	Discussion of evidence	Data sources
Patients with life limiting illness experience increased suffering because of suboptimal symptom management and difficulties accessing services PC P5	**The clinician survey revealed over 30% of clinicians, did not believe they were able to provide optimal palliative care with the current services available**. More specifically, **39% of respondents from Allied Health felt unable to provide optimal palliative care** with current available services. If clinicians are unable to provide optimal care, it could be inferred that patients with life-limiting illnesses will experience increased suffering as a result of this. Community feedback from stakeholder interviews and focus groups frequently **raised issues of access to palliative care**. Interview feedback highlighted that **symptoms can be affected by medication compliance and patient health literacy.** Survey feedback from consumers reveals specific examples of how patients with a life limiting illness experience increased suffering. This includes **delays to medication administration, delays to accessing services and lack of out of hours care.**	• Interviews • Focus groups • Clinician survey • Consumer survey

Prioritisation score: 130

Patient Need 6: Patients with life-limiting illness have poor management of palliative care symptoms and support during out of hours

Identified need	Discussion of evidence	Data sources
Patients with life-limiting illness have poor management of palliative care symptoms and support during out of hours PC P6	Access to after-hours care appears to be the greatest issues with **less than 3% of consumers responding that there was adequate access after business hours**. Similarly, free text comments in surveys completed by consumers and clinicians highlighted that there was a lack of after-hours care and support. From stakeholder consultation, **six participants across the interviews and focus groups raised concerns about the lack of access to after-hours palliative care services**. With a lack of readily available support at this time, patients are less likely to be able to escalate their concerns regarding symptom management. In turn this may result in patients having poor management of their symptoms or having to seek out help from alternative services such as Accident & Emergency.	• Consumer survey • Clinician survey • Interviews • Focus groups

Prioritisation score: 108

Patient Need 7: Patients do not feel empowered to own their palliative care and end-of-life journey or maintain their independence

Identified need	Discussion of evidence	Data sources
Patients do not feel empowered to own their palliative care and end of life journey and maintain their independence PC P7	Patient **autonomy was frequently raised as an issue in focus groups.** Interview and focus group participants commented **that patients lack knowledge/health literacy and time to make decisions.** Life-limiting illness impacts patients' ability to complete activities of daily living because of loss of physical function. In addition, Clinicians identified that **disease progression, burden of treatment and symptoms also impact independence.** As a result they become increasingly dependent on others for transport, medication, personal care and financial support. The data shows that patients have high levels of dependence on others for assistance with bed mobility, toileting, transfer and eating. Similarly **the majority of patients had Australia-Modified Karnofsky Performance Status scores which showed a significantly decreased ability to perform activities of daily living.** On the other hand, **63.7% of consumers agreed or strongly agreed that independence had been enabled as long as possible**. This contrasts dramatically with the clinicians views of patient independence as described above.	• Focus groups • Interviews • Consumer survey • PCOC **Prioritisation score: 85.5**

Patient Need 8: Rural patients have greater distance to travel and fewer services available for SPCS

Identified need	Discussion of evidence	Data sources
Rural patients have greater distance to travel and fewer services available for SPCS PC P8	Patients living in rural locations have impaired access to palliative care services**. Focus groups and interviews both highlighted a lack of services in rural locations**. No comments regarding how far patients have to travel to access care were made. **Lack of support for rural palliative patients was raised as an issue in both consumer and clinician survey feedback.** **SeNT data revealed that metropolitan areas have an increased proportion of palliative care referrals (for their population size) compared to more rural areas.** These findings may suggest that there is a lack of specialist services to refer, or a lack of knowledge of referral pathways in rural areas.	• Interviews • Focus groups • Consumer survey • Clinician survey • SeNT data

Prioritisation score: 78

Family and Carer Need 1: Families and carers lack support following a bereavement and some individuals (particularly those aged 80+) are at increased risk of suicide following a bereavement

Identified need	Discussion of evidence	Data sources
Families and carers lack support following a bereavement and some individuals (particularly those aged 80+) are at increased risk of suicide following a bereavement PC FC1	Families and carers' lack of support was generally identified in both interviews and focus groups. **Six comments from focus groups identified that counselling and bereavement services could not support the needs of carers and their families**. The main issues identified with this were a lack of services to refer to or the long waiting times. Clinician interviews identified mixed evidence on the level of support available to families and carers. Approximately **20 comments were raised that the access to carer/family support was poor,** while only 12 commented that the access to support was good. Some clinicians commented that patients' families in RACFs have more of a challenge accessing support. Another issue identified was that clinicians find it challenging enabling carers/families to access support when the family or carer are not under their care. **A lack of suicide prevention for carers was highlighted as an issue within one clinician interview**. Bereavement and counselling services were not offered to either the patient, family or carer in almost 40% of respondents in the consumer survey. Overall, feedback indicates that better support and services for bereavement and counselling must be made available to families and carers.	• Consumer survey • Focus groups • Interviews **Prioritisation score: 182**

Family and Carer Need 2: Carers and family members lack education regarding their role in patient care and identifying signs of end of life

Identified need	Discussion of evidence	Data sources
Carers and family members lack education regarding their role in patient care and identifying signs of end of life PC FC2	**Carers and family struggle to identify signs of deterioration, according to approx. 5 comments raised in clinician interviews**. Some clinicians commented that carers can identify the signs of dying, but do not know how to respond to this. Carer/family member's understanding of their role is variable based on feedback from the clinician interviews. In terms of their involvement in care, 4 concerns were raised regarding carers 'taking too much on', which can lead to carer stress and burnout. Family and carers frequently raised concerns about their ability to deliver care at home in the consumer survey. Lack of education, support and resources were the main concerns raised. For just under a third of respondents in the consumer survey, palliative care information and educational material were considered inaccessible and difficult to understand.	• Interviews • Consumer survey **Prioritisation score: 143**

Family and Carer Need 3: Family members are not regularly involved in decision-making and planning of care

Identified need	Discussion of evidence	Data sources
Family members are not regularly involved in decision-making and planning of care PC FC3	**There is mixed and conflicting feedback about how involved family members are in decision-making and planning of care:** - Clinicians report that they actively encourage family participation and try to get them involved from the beginning of the palliative care journey. - Family members are not regularly involved in decision-making, according to feedback from a community focus group, where comments in support of this need were made 3 times. - Family and carers were involved in care planning and decision making for 73% of respondents to the consumer survey. This was not the case for **15% of respondents who reported being somewhat uninvolved or not involved at all.** This was raised as an emotive issue when family and carers were either very involved or uninvolved. This suggests that family involvement, or lack thereof, in decision making and care planning can have significant impact on the family and carer experience during the care of their loved one. While the overall impression is that there is support for this need from the perspective of family members, it is also important to recognise that family involvement in decision making/care planning may go against the wishes of the patient. Therefore as much as some family members may wish to be more regularly involved, where this goes against the wishes of patients, then this must be respected.	• Consumer survey • Interviews • Focus groups **Prioritisation score: 104.5**

Clinician Need 1: Nurses have difficulty providing optimal care due to challenges in accessing quality information, resources and timely prescriptions

Identified need	Discussion of evidence	Data sources
Nurses have difficulty providing optimal care due to challenges in accessing quality information, resources and timely prescriptions PC C1	Greater education and training for nurses and care assistants to be able to escalate concerns and provide care in the home and the community was raised frequently in the clinician survey as a barrier to delivering optimal care to patients. The clinician survey also revealed that **19% of Nurse/Nurse Practitioners felt they were unable to access quality information and resources to fulfil their role.** In addition, **16% of nurses felt unable to administer appropriate medications to palliative care patients when it is needed**. Barriers raised that prevent achieving this include staff resources and lack of access to medications in community settings.	• Clinician survey • Consumer survey

> *"Implement the use of Nurse Practitioners into Residential Aged Care so end of life can be managed in a more timely and effective manner"*
> (Clinician survey)

Prioritisation score: 143

Clinician Need 2: Palliative care clinicians experience compassion fatigue and burnout caring for palliative patients

Identified need	Discussion of evidence	Data sources
Palliative care clinicians experience compassion fatigue and burnout caring for palliative patients PC C2	Clinicians are experiencing compassion fatigue and burnout according to feedback from clinician interviews and focus groups. When examining whether clinicians are experiencing compassion fatigue and burnout, the interviews detected that **almost 90% of comments made on this subject supported this need**. The interviews were conducted with GPs, palliative care physicians/specialists, Clinical Nurse Consultant, Nurse Practitioner, mental health clinicians, physiotherapists, occupational therapists and social workers. Multiple comments were made during interviews that compassion fatigue and burnout were **secondary to the general health system pressures**. At the same time, others did specify that the **distressing and emotional nature of palliative care work was contributing to burnout**. One of these clinicians felt they were not suffering from compassion fatigue because of the meaning they got out of their work, while another praised the supportive team and use of reflective practice. Generally, there is **mixed awareness of local palliative care professional support networks** based on clinician survey feedback**. For the Allied Health respondents, only 16% were aware of any local palliative care professional support networks**. There was a large proportion of respondents who did not respond (33-47%). The lack of response could be inferred as meaning participants were not aware.	• Focus groups • Interviews • Clinician survey **Prioritisation score: 140**

Clinician Need 3: Palliative care clinicians lack clarity regarding their respective roles and are unable to provide continuity of care or communicate ongoing needs to other clinicians as patients move to other care settings

Identified need	Discussion of evidence	Data sources
Palliative care clinicians lack clarity regarding their respective roles and are unable to provide continuity of care or communicate ongoing needs to other clinicians as patients move to other care settings PC C3	Issues with continuity of care and communication between services was frequently raised within focus groups. **Comments which supported that there is poor continuity of care and communication between services featured approximately 23 times**. Concerns regarding clinician's level of palliative care knowledge and lack of access to education were raised as areas needed to improve so that clinicians can fulfil their role. Similarly, the clinician interviews identified problems with communication between services and continuity of care frequently. **Over 50% of comments made about communication between services viewed it as an issue**. The main issues regarding communication and continuity were a **lack of handovers from acute to community facilities and too much dependence on phone calls for communication. Enablers of good communication were also raised, and includes: good referral pathways and the utilisation of communication methods such as email.** Most clinicians feel that current communication and referral pathways are effective when patients move between palliative care settings/providers, with 37-63% of clinicians commenting that referral pathways and communication when patients move between settings is somewhat effective or very effective. However, **30% of clinicians responded that communication and referral pathways is somewhat ineffective/ineffective, which represents a significant proportion of clinicians viewing this as an issue**.	• Focus groups • Interviews • Clinician survey **Prioritisation score: 137.5**

Clinician Need 4: GPs are unable to refer patients for beds in hospital and RACFs

Identified need	Discussion of evidence	Data sources
GPs are unable to refer patients for beds in hospital and RACFs PC C4	While survey data does not specifically identify if GPs are unable to refer patients for beds in hospitals or RACFs, it did identify that **25% of clinicians were unaware of services that offer in-patient palliative care beds or the number of places available**. 22.7% were aware of available services and the number of places, while 52.3% were aware of services available but not the number of places available. Of the clinicians, Allied Health had the highest unawareness about the availability of the services. **3 clinicians commented in the survey that they would like to have more hospices to refer to.** SeNT data revealed that metropolitan areas had an increased proportion of referrals to palliative services compared to their population area. On the other hand, more rural areas, had a low proportion of referrals compared to their population. This may suggest that there is **a lack of specialist services to refer to in rural areas, or a lack of knowledge of referral pathways in these areas.**	• Clinician survey • SeNT data **Prioritisation score: 125**

Clinician Need 5: Clinicians are unable to acknowledge and support family, cultural and religious rituals when providing palliative care, end of life and death

Identified need	Discussion of evidence	Data sources
Clinicians are unable to acknowledge and support family, cultural and religious rituals when providing palliative care, end of life and death PC C5	Over 50% of clinicians felt they were very confident or somewhat confident in delivering culturally safe/appropriate palliative care to persons from culturally and/or linguistically diverse backgrounds, according to clinician survey feedback. However**, 13-40% of clinicians responded that they were somewhat unconfident to unconfident, with Allied Health workers having the highest proportion having these confidence levels (40%)** In the interviews, multiple **clinicians commented that they ask about spiritual needs but find the practicalities of incorporating rituals more of a challenge**. **Multiple clinicians commented on lacking experience caring for patient's from culturally diverse backgrounds.** Similarly, within focus groups, there was mixed feedback. Overall, there **was a greater number of comments (approximately 58%) that clinicians struggled to support cultural and religious elements when providing care**. The main perceived barriers for this were time constraints and misalignment of clinicians and patient cultural/religious views. Enabling patients to 'return to Country' was raised as an issue by two participants.	• Interviews • Focus groups • Clinician survey **Prioritisation score: 75**

Clinician Need 6: Physicians and GPs have difficulty identifying patients who are deteriorating towards death

Identified need	Discussion of evidence	Data sources
Physicians and GPs have difficulty identifying patients who are deteriorating towards death PC C6	Physicians and GPs are generally able to identify patients who are deteriorating towards death. **79% of clinicians identified that they were very confident or somewhat confident in identifying signs of dying**. **General Practices/Medical specialists and nurses/nurse practitioners have the highest confidence level at 90% and 89%**, **respectively**. Allied health professionals were the least confidence in identifying signs of dying. Within palliative care, allied health care professionals main role is in helping patients maintain their independence during the palliative care journey. As patients approach the end of their life, the scope of allied health professionals work often diminishes. Therefore, while allied health have less of a role during the final stages of life, it is important that they are able to identify signs of deterioration so that they can escalate to the appropriate clinicians to ensure timely access to care and symptom management. In support of a move toward enabling patients to die in the home, it is worth considering improving the confidence of allied health care professionals in identifying signs of deterioration so they can escalate to the right person at the right time.	• Clinician survey **Prioritisation score: 95**

Recommendations*

*The PHN acknowledges the implementation of recommendations are dependent upon current, ongoing and future funding streams.

Recommendations for patients

Patients

Patients who require palliative care (in particular those with non-malignant or dementia diagnoses) can experience prolonged symptoms and suffering due to delayed referrals and interventions

Improving timely access to referrals and interventions is an area of improvement the PHN should consider focusing on. Potential activities which may best address this need include:

- Creating MDT Case conferencing meetings, including GPs and inpatient palliative care teams. This could be piloted within a smaller hospital and focus on a specific condition, e.g. patients with Dementia.
- The PHN could collaborate with the Care Finder Program and allied health providers to add palliative care education into service delivery.
- Organise GP educational activities to improve timing of referrals and knowledge of condition specific palliative care experiences and symptoms. This may involve talks from condition specific speakers, E.g. Dementia, MND, Cancer.
- Educational activities for patients should aim to improve self advocacy so that they can access referrals at the right time
- National PHN Collaborative advocacy for palliative care specific MBS item numbers.

Patients with low health literacy experience greater difficulties understanding and processing information, poorer health outcomes, quality of life and experience of care

The PHN could implement a number of educational activities or interventions to empower patients about death and dying. Activities may include the following:

- Patient education resources about how to advocate for yourself to clinicians. This may include social media campaigns, link to care finder/assertive outreach or community education forums.
- Commissioning or scholarships for primary care health professionals to support priority population groups.
- Delivering targeted education and resources for patients with poor health and death literacy, this may include arranging speakers at awareness events, or supporting existing community initiatives.

Recommendations for patients

Patients

Patients (including those from First Nation communities) receiving palliative care do not have cultural or religious rituals around death and dying acknowledged

The PHN should consider the following activities to support the inclusion of cultural and religious practices during the palliative journey:

- Developing communication pathways between inpatient and community teams to ensure details about cultural and religious needs is handed over.
- Commissioning end of life multicultural liaison officers to support the inclusion of cultural and religious rituals in the community.
- Creating inclusive, multicultural resource packs about the palliative care journey.
- Collaborate with other services and providers to develop end of life support and resources.
- Develop First Nations specific compassionate communities.

Vulnerable patients including migrants and people facing financial /housing instability are less able to access palliative care

To address this need, the PHN should consider focusing it's efforts on helping these population groups to navigate the palliative care system. This may involve the following activities:

- Promoting death literacy through community activities and initiatives. This will aim to educate patients on what to expect and advanced care planning.
- Commissioning or providing scholarships for primary care health professionals may help this demographic approach and navigate their palliative care journey.
- Collaborating with relevant service providers to ensure they include palliative care education for service delivery.

Recommendations for families and carers

Families and carers

Families and carers lack support following a bereavement and some individuals (particularly those aged 80+) are at increased risk of suicide following a bereavement

Many of the strategies and activities which would help to address this need involve providing education to clinicians and providers, as well as developing resources/activities to support families and carers. The PHN may consider the following activities to address this need:

- Promote existing information detailing the available grief and bereavement services currently in the area to educate primary care providers on where they can refer families and carers to.
- Provide GPs, community service providers and volunteers with education on suicide risk and bereavement, with a specific emphasis on how this may manifest in the elderly.
- Educate the community on death literacy through the development and support of existing community initiatives, peer to peer support and education programs.

Carers and family members lack education regarding their role in patient care and identifying signs of end of life

To address this need, our focus is on empowering families and carers through support and education. The PHN may select some of the following activities to improve families/carers understanding of their role and confidence in identifying signs of end of life:

- Develop educational materials for families and carers. Topics to be covered may include: manual handling, working with volunteers, identifying signs of end of life, the role of ambulance services, etc.
- Engage with existing volunteer groups to enhance volunteer group networks.
- Promote the compassionate communities movement across HNECC region.
- Consider enhancing existing services to support family and carers who have concerns for a deteriorating patient at home, particularly during out of hours.

Recommendations for clinicians

Clinicians

Nurses have difficulty providing optimal care due to challenges in accessing quality information, resources and timely prescriptions

The PHN could address this need by considering the following activities:

- Collaborating with the Pharmaceutical Society of Australia to create a community pharmacy project which aims to streamline communication pathways across inpatient and community settings. This would help to enable safe and timely access to medications when patients are discharged with a limited supply.
- Creation of MDT discharge meetings with GP present to ensure ongoing medication review, future prescription planning and confirmation of drug availability in the community.
- Collaboration with the Local Health Districts to review and develop more robust medication prescription and administration pathways for patients who move from the inpatient setting to primary care. This would involve specialists, GPs, nurses and community pharmacists.

Palliative care clinicians experience compassion fatigue and burnout caring for patients who are end of life

To support staff experiencing burnout and compassion fatigue, the PHN should consider the following activities:

- Promotion of self care strategies in primary care, e.g. Employee Access Program.
- Providing education and self care strategies to aged care workers who provide palliative care support to patients and families.
- Delivering skills training to build resilience in the workplace (e.g. for frontline care workers) exposed to death and dying. This may include debriefing sessions, boundary setting, etc.

Appendices

Appendix 1 - Limitations and considerations

- The sample size of participants in focus groups, interviews and surveys may not reflect all opinions of the greater community. As the participants have chosen to engage with the project, it could be argued that these individuals are already engaging with palliative care, and therefore it is possible that the data may not be fully representative.
- There was limited access to localised quantitative data to confirm the size of some needs. Further collection and analysis of palliative care quantitative data for the region will allow for continued and greater understanding of the needs.
- The quantity of qualitative data is variable across different needs.
- Due to the emotional nature of the activity, there was limited consultation directly with patients. While a breadth of data was collected, further consultation with ethics approval with specific stakeholder groups, may be valuable in the future for specific service or intervention planning.

Appendix 2 - Triangulation Matrix Methodology

1. To calculate the triangulation score, **each data source was evaluated for the following**:

- The frequency that the need was raised as an issue,
- The presence and frequency of contradictory evidence
- Whether the proportion of evidence in support of the need met a subjective threshold of significance

2. Where **evidence in support of the need was detected**, a score from 0-4 was assigned for **each source of evidence**

Source score	Meaning
0	Not raised at all
1	Raised infrequently
2	Raised on multiple occasions or via multiple sources
3	Raised frequently
4	Raised frequently as a high priority

3. Next, we considered the **number of data sources** where evidence in support of the need was detected, and their respective score and calculated an **overall score**

Overall score	Description of score
0	Contradicted or no support
1	Limited support
2	Moderate support
3	Strong support

Appendix 2 - Triangulation Matrix - Patients 1/2

Hypothesis		Data to support need profile	Stakeholder consultation	Triangulation result
PC P1	Patients who require palliative care (in particular those with non malignant or dementia diagnoses) can experience prolonged symptoms and suffering due to delayed referrals and interventions	PCOC - 1	Clinician survey - 1 Consumer survey - 3 Focus groups - 1	**2**
PC P2	Patients with low health literacy experience greater difficulties understanding and processing information, poorer health outcomes, quality of life and experience of care	Consumer survey - 2	Interviews - 2 Focus groups - 1	**2**
PC P3	Patients (including those from First Nation communities) receiving palliative care do not have cultural or religious rituals around dying and death acknowledged	Consumer survey - 1 Clinician survey - 2	Interviews - 2 Focus groups - 2	**2**
PC P4	Vulnerable patients including migrants and people facing financial /housing instability are less able to access palliative care	0	Interviews - 1 Focus groups - 2 Clinician survey - 1 Consumer survey - 1	**2**
PC P5	Patients with life limiting illness experience increased suffering because of suboptimal symptom management and difficulties accessing services	PCOC - 3	Focus groups - 2 Interviews - 2 Consumer survey - 1 Clinician survey - 2	**2**

Appendix 2 - Triangulation Matrix - Patients 2/2

Hypothesis		Data to support need profile	Stakeholder consultation	Triangulation result
PC P6	Patients with life limiting illness have poor management of palliative care symptoms and support during out of hours	Consumer survey - 4	Clinician survey - 1 Consumer survey - 4 Focus groups - 1 Interviews - 2	**3**
PC P7	Patients do not feel empowered to own their palliative care and end of life journey or maintain their independence	PCOC - 4 Consumer survey - 1	Focus groups - 2 Interviews - 4	**3**
PC P8	Rural patients have greater distance to travel and fewer services available for SPCS	SeNT data - 2	Interviews - 2 Focus groups - 2 Consumer survey - 2 Clinician survey - 1	**2**

Appendix 2 - Triangulation Matrix - Family and Carers

Hypothesis		Data to support need profile	Stakeholder consultation	Triangulation result
PC FC1	Family and carers lack support following a bereavement, and some individuals (particularly those aged 80+) are at increased risk of suicide following a bereavement	Consumer survey - 3	Focus groups -2 Interviews - 2	**3**
PC FC2	Carers and family members lack education regarding their role in patient care and identifying signs of end of life	Consumer survey - 2	Interviews - 2 Consumer survey - 2	**2**
PC FC3	Family members are not regularly involved in decision-making and planning of care	Consumer survey - 1	Focus groups - 1 Interviews - 1 Consumer survey - 4	**2**

Appendix 2 - Triangulation Matrix - Clinicians

Hypothesis		Data to support need profile	Stakeholder consultation	Triangulation result
PC C1	Nurses have difficulty providing optimal care due to challenges in accessing quality information, resources and timely prescriptions	Clinician survey - 3	Clinician survey - 2 Consumer survey - 3	**3**
PC C2	Palliative care clinicians experience compassion fatigue and burnout caring for palliative patients	Clinician survey - 2	Focus groups - 4 Interviews - 4	**3**
PC C3	Palliative care clinicians lack clarity regarding their respective roles and are unable to provide continuity of care or communicate ongoing needs to other clinicians as patients move to other care settings	Clinician survey - 2	Focus groups - 4 Interviews - 4	**3**
PC C4	GPs are unable to refer patients for beds in hospital and RACFs	SeNT data - 1 Clinician survey - 3	Clinician survey - 1	**2**
PC C5	Clinicians are unable to acknowledge and support family, cultural and religious rituals when providing palliative care, end of life and death	Clinician survey - 2	Interviews - 2 Focus groups - 2	**2**
PC C6	Physicians and GPs have difficulty identifying patients who are deteriorating towards death	Clinician survey - 1	0	**1**

Appendix 3 - Prioritisation scoring method (1/2)

For each need with a triangulation score ≥ 2, we calculated the size of the need, the severity of the need and the addressability of the need

Rating	Size of the need in the population	Severity of the need in the population	How addressable is the need by the PHN
Guidance	% of the population with the health need	Does it require immediate attention? Is there public demand? What is the impact on quality of life?	Determine the effectiveness of interventions made by the PHN to address the need
9 or 10	>25%	Very serious	Completely in control of HNECC PHN Need completely addressed
7 or 8	10% – 24.9%	Relatively serious	Completely in control of HNECC PHN and Need addressed substantially, or Substantially in control of HNECC PHN and Need addressed completely
5 or 6	1% – 9.9%	Serious	Moderately in control of HNECC and Need addressed substantially, or Substantially in control of HNECC PHN and Need addressed moderately
3 or 4	0.1% – 0.9%	Moderately serious	Somewhat in control of HNECC PHN and Need addressed moderately, or Moderately in control of HNECC PHN and Need addressed somewhat
1 or 2	0.01% – 0.09%	Relatively not serious	Not in control of HNECC PHN and Need addressed somewhat, or, Somewhat in control of HNECC PHN and Need not addressed
0	< 0.01%	Not serious	Unable to address need

Source: NACCHO guide to prioritisation techniques

Appendix 3 - Prioritisation scoring method (2/2)

Scoring for size and severity was completed by Rebbeck project team using data collected in the palliative care needs assessment. Addressability scoring was completed by the HNECC PHN Palliative Care.

The scores were entered into the calculation below to determine whether it was a prioritised need. The higher the score, the more the need should be prioritised.

Prioritisation Score = [A+(2xB)] x C

A = Size of need
B = Severity of need
C = Addressability score

Source: NACCHO guide to prioritisation techniques

Appendix 4 - Revised logic model (Patient 1/3)

Needs	Input	Activities	Outputs	Provider experiences	Client experiences	Short term outcomes	Medium term outcomes	Long term outcomes
P1 - Patients who require palliative care (in particular those with non malignant or dementia diagnoses) can experience prolonged symptoms and suffering due to delayed referrals and interventions	GP, palliative care specialist, nurse practitioner, allied health, family and community	Screening patients, needs round / palliative care case conferencing / palliative care case management, GP education and retraining for identifying early triggers	Increased early referrals for dementia and non malignant patients education and training course, clinician resources	Clinicians avoid distress by preventing unnecessary suffering and improving their quality of life	Patient suffering and decline is acknowledged early and they experience less pain and/or slower decline	Patients are aware of their palliative care needs and feel supported	Improved symptom management of disease and more effective palliative care interventions	Reduction in distress and deterioration caused by preventable hospitalisation and improved quality of end of life care
P2 - Patients with low health literacy experience greater difficulties understanding and processing information, poorer health outcomes, quality of life and experience of care	Patients, family, clinicians	Language interpreter services, health literacy interventions, foreign language telehealth service	Public health culturally specific messaging, patients understand health information, patients can make informed decisions	Clinicians are confident their patients are making informed decisions about their care	Patients feel empowered through understanding health information	Patients are not overwhelmed by technical or medical information and feel comfortable understanding the information involved in their illness and care	Patients feel confident when making decisions throughout their life limiting illness	Patients experience greater autonomy and improved health outcomes, quality of life and experience of care throughout their life limiting illness
P3 - Patients (including those from First nation communities) receiving palliative care do not have cultural or religious rituals around dying and death acknowledged	AMS, GP, palliative care specialist, nurse practitioner, care assistants, allied health, family, patient, culturally appropriate educational resources	Collaboration with AMS, inclusive conversations with patients and communities, care planning, advance care planning	Care plans and advance care plans that include cultural and community input, Dying to Talk conversation starters, culturally appropriate educational resources	Clinicians feel empowered to deliver personalised care when patients are vulnerable and suffering	Patients are comforted by their religious and cultural practices as they experience life limiting illness and death	Patients experience less distress and discrimination by having their medical care align with their psychological, cultural and spiritual care	Patients' symptoms, pain and death are experienced according to their cultural and religious beliefs. Increased engagement with care providers	Palliative care, death and dying are seen as normal parts of life and human experience

Appendix 4 - Revised logic model (Patient 2/3)

Needs	Input	Activities	Outputs	Provider experiences	Client experiences	Short term outcomes	Medium term outcomes	Long term outcomes
P4 - Patients facing financial and housing instability and patients from migrant backgrounds are less able to access palliative care	Social services, Centrelink, patients, migration agents, NGOs, Medicare	Review of funding for housing and care, migrant, support services, translation and interpreter services, family and domestic violence services, review of funding for specialist services	Available public / affordable housing, palliative care delivered safely in the home, vulnerable populations receiving health messaging and information, patients referred to social services, patients can afford the care they need	Clinicians and carers feel safe and less distress at their patients safety by knowing care can be delivered regardless of their financial / housing situation	Patients and their families do not feel disadvantaged based on their housing or financial status	Patients feel less disadvantaged when receiving care based on their immigration, housing status or financial status	Patients experience greater safety at home where they can receive care, and their care is not limited by income or finances	Greater equity in the delivery of palliative care for vulnerable, low income populations
P5 - Patients with life limiting illness experience increased suffering because of suboptimal symptom management and difficulties accessing services	GP, palliative care specialist, nurse practitioner, care assistant, family, allied health	Palliative care needs round / palliative care case conferencing / palliative care case management, care planning, advance care (end of life) planning, GP case conferencing	Palliative care plans, advance care plans, referrals, pharmaceutical scripts, medication, NP Led and GP supported care models	Clinicians feel able to provide appropriate and timely care to patients who are suffering	Patients feel cared for and that their pain and quality of life needs are met	Less pain and greater comfort for patients during palliative care	Greater quality of life through palliative care journey	Patients suffering is reduced or eliminated during their illness and death
P6 - Patients with life limiting illness have poor management of palliative care symptoms and support during out of hours	GP, palliative care specialist, nurse practitioner, allied health, aboriginal health worker, care assistant, pharmacist, family	After hours services, telehealth services	Care is delivered at the time of need	Clinicians are satisfied that patients are receiving optimal care at the time it is required. Staff or carers are less stressed during palliative care episodes that occur out of hours	Patients are comforted by the availability of optimal care regardless of the time of need	Patients avoid distress by receiving care where they are, when they need it	Less pain and greater comfort in out of hours periods	Reduction in distress and deterioration caused by preventable hospitalisation. Reduced decline in patient condition during out of hours periods

Appendix 4 - Revised logic model (Patient 3/3)

Needs	Input	Activities	Outputs	Provider experiences	Client experiences	Short term outcomes	Medium term outcomes	Long term outcomes
P7 - Patients do not feel empowered to own their palliative care and end of life journey and maintain their independence	Patients, GP, palliative care specialist, nurse practitioners, aboriginal health worker, allied health, death doula, family, patient, community	Care planning (involving patient and family input), advance care planning, counselling, education, assistance to develop strategies for managing ADLs	Palliative care plans, advance care plans, referrals, pharmaceutical scripts, medication (targeting patient's wishes)	Clinicians feel satisfaction because they are able to deliver personalised care to patients which incorporates the patient and family values, and helps the patient to maintain their independence	Patients feel empowered to take control of their experience and maintain their independence. Patients do not feel like they are a burden on their family	Patients are comforted knowing they retain autonomy, independence and choice over the palliative care and end of life experience	Patient undertake meaningful tasks and activities throughout their illness and feel empowered to make choices	Patients are able to experience end of life and death according to their wishes and maintain some degree of independence up until the end of life
P8 - Rural patients have greater distance to travel and fewer services available for SPCS	Rural GP, rural palliative care specialist, rural nurse practitioner, allied health, rural care assistants, family, telehealth equipment	Rural palliative care services	Resources for rural clinicians, SPCS referrals for rural patients	Clinicians do not feel limited by patient rurality and geographic distance when providing care	Rural patients do not feel disadvantages due to their rurality and geographic location	Patients experience less distress by experiencing care closer to home and in their community	Decreased pain and increased comfort due to reduced travel	Greater equity in the delivery of palliative care regardless of geographic location or rurality

Appendix 4 - Revised logic model (Families and Carers 1/1)

Needs	Input	Activities	Outputs	Provider experiences	Client experiences	Short term outcomes	Medium term outcomes	Long term outcomes
FC 1 - Family and carers lack support following a bereavement and some individuals (particularly those aged 80+) are at increased risk of suicide following a bereavement	Counsellor, psychologist, GP, family, patients	Systematic pre bereavement planning, counselling services, community support programs	Bereavement plans, mental health plans, counselling sessions, grief and bereavement plans, crisis support mental health plans, Dying to Talk conversation starters	Clinicians experience less distress when witnessing family grief	Family members experience less distress and despair when loved ones pass. Family members feel supported and a greater sense of social connectedness	Family and carers experience less distress during patient's end of life	Family and carers are supported and feel less distress during the death of loved one, and reduced suicidality	Death and bereavement are seen as normal parts of life and human experience
FC2 - Carers and family members lack education regarding their role in patient care and identifying signs of the end of life	GP, palliative care specialist, nurse practitioner, allied health, care assistants, family	Education, care planning involving family	Health information resources, training sessions, care plans	Clinicians feel satisfaction by empowering family with knowledge to provide care and comfort for patients	Family members are confident that they are providing appropriate and sufficient care and support for patients	Family and carers feel empowered to be part of the patients' care	Family and carers feel less distress during the patient's symptoms and pain. Patients feel less distressed and more understood by family and carers	Palliative care, death and dying are seen as and experienced as a part of a family's social journey and responsibility
FC3 - Family members are not regularly involved in decision making and planning of care	GP, palliative care specialist, nurse practitioner, allied health, care assistants, family, patients	Family meetings, care planning involving family if appropriate	Care plans including family input if appropriate. Care decisions that include family if appropriate. Regular and informative meetings between health professionals and family if appropriate	Clinicians are confident that family wishes are being incorporated into patient care	If appropriate, family feel their wishes are being acknowledged when decisions are made and are able to advocate for patients during care and death in a timely manner	Family and carers feel less distress, more included and more connected by contributing to decisions in patients' palliative and end of life care and death if appropriate	Family and carers feel they are better able to support and provide care	Palliative care, death and dying are seen as and experienced as part of a family's social journey and responsibility

Appendix 4 - Revised logic model (Clinicians 1/3)

Needs	Input	Activities	Outputs	Provider experiences	Client experiences	Short term outcomes	Medium term outcomes	Long term outcomes
C1 - Nurses have difficulty providing optimal care due to challenges in accessing quality information, resources and timely prescriptions	GP, palliative care specialist, nurse practitioner, care assistants	Case conferencing, education, training, telehealth services	Care plans include defined roles, practical resources for nurses and support from GPs. Nurses and care assistants can provide appropriate care for patients when it is needed including some medications, reduction in unnecessary hospitalisations	Nurses feel confident in their roles, responsibilities and duties in providing palliative care	Patients feel safe within the nurses care	Nurses feel less distress about being limited in the level of care they can provide	Nurses and care assistant feel less distress as they are able to reduce the pain and suffering of their patients	Nurses, care staff and patients experience less distress and deterioration caused by preventable hospitalisations and improved quality of end of life care
C2 - Palliative care clinicians experience compassion fatigue and burnout caring for patients are end of life	Counsellor, psychologist, GP, nurse practitioner, palliative care specialist, allied health practitioners, care assistant	Training, employee assistance programs, counselling services, community of practice to support across different settings	Emotional, physical and mental support plans for clinicians. Clinicians are able to care compassionately for patients without experiencing burnout	Clinicians feel more confident in providing palliative care for all patients	Patients feel their needs are better met if clinicians are more confident	Clinicians feel less exhausted and distressed are able to care compassionately for patients without experiencing burnout	Clinicians are psychologically, emotionally and physically healthier	Clinicians experience greater job satisfaction and are able to remain in their role longer

Appendix 4 - Revised logic model (Clinicians 2/3)

Needs	**Input**	**Activities**	**Outputs**	**Provider experiences**	**Client experiences**	**Short term outcomes**	**Medium term outcomes**	**Long term outcomes**
C3 - Palliative care clinicians lack clarity regarding their respective roles in patient care and they are unable provide continuity of care or communicate ongoing needs to other clinicians as patients move to other care settings (hospital, community, RACF)	Counsellor, psychologist, GP, nurse practitioner, palliative care specialist, allied health practitioners, care assistance	Tailored GP interventions, case conferencing, education, collaboration and communication between services and care providers, advance care planning training, adoption of digital health solutions and MHR for transitions of care	Care plans including defined roles, practical resources for clinicians, documented referral pathways, contact information. Clinicians are able to effectively communicate when patient care moves between providers or settings, and their role in the patient's care	Palliative care clinicians experience greater confidence in their role providing palliative care	Patients experience greater confidence when seeing different clinicians in different settings	Specialist palliative care clinicians feel less frustration when care is moved to different settings or to other clinicians because they are more able to communicate patient needs and have greater awareness of their role	Specialists are comfortable and confident that their patients will receive a seamless transition of palliative care and feel confident to communicate their role	Clinicians and patients experience less distress and deterioration caused by preventable hospitalisations and improved quality of end of life care. Clinicians have no doubts about their role within palliative care
C4 - GPs are unable to refer patients for beds in hospital and RACFs	GP, palliative care, funding bodies	Education, communication between services, training for GPs	Practical resources for GPs, contact details/resources and referral pathways, increased availability of palliative care beds GPs can find appropriate beds to refer patients who need inpatient palliative and end of life care	GPs feel less distress and frustration because they are able to find beds for patients who need them	Patients are relieved that their GP is able to find appropriate care facilities for them when they are required	GPs experience less frustrations and despair because beds are available for patients when they are needed	GPs feel confident that they can provide the appropriate level of care in the appropriate seeing when it is required	GPs no longer have hesitation or reservation about being able to provide optimal palliative and end of life care for their patients

Appendix 4 - Revised logic model (Clinicians 3/3)

Needs	Input	Activities	Outputs	Provider experiences	Client experiences	Short term outcomes	Medium term outcomes	Long term outcomes
C5 - Clinicians are unable to acknowledge and support family, cultural and religious rituals when providing palliative care, end of life and death	GP, palliative care specialist, nurse practitioner, allied health, family and patient	Education, care planning involving family, develop relationships and linkages with culturally diverse and appropriate advocacy groups	Care plan including cultural and religious practices, advance care plans including cultural and religious practices. Clinicians provide care in culturally appropriate settings and incorporate practices and rituals into provision of care	Clinicians feel satisfaction at being able to deliver personalised care to patients	Patients and family members feel confidence that clinicians are incorporating religious and rural practices into their care and death	Clinicians feel greater confidence in their ability to provide care to patients	Clinicians experience less distress and greater comfort by witnessing patients experience cultural and religious practices thought their illness and death	Religion and culture are seen as an integral part of palliative care, death and dying

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