NSW Regional HEALTH PARTNERS

CENTRE FOR INNOVATION IN REGIONAL HEALTH

End of Life Care in a sample of Regional and Rural NSW – what is the current situation and what are the problems?

A white paper developed to support the work of NSW Regional Health Partners

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Foreword

NSW Regional Health Partners is an NHMRC Accredited Centre for Innovation in Regional Health. Our objective is to make appreciable improvements in patient outcomes and experience by translating evidence into practice. Supporting translational research into end of life care is a major priority for our next two years. Our end of life initiative will also include communication work to encourage discussion and advance understanding.

We are committed to best practice in research and in research commissioning, which includes the use of evidence syntheses. There are many systematic reviews available about the evidence underpinning specific clinical aspects of end of life and palliative care. However, this white paper has been designed to help a range of readers get a concise overview of major issues. Research evidence from the academic literature with a focus on rural Australian research is combined with information about local and state initiatives and the views of clinicians, consumers and managers who we surveyed. (Consumer views from the 2017 Statewide NSW Palliative Care Forums were also incorporated.)

I'd like to very much thank Tonelle Handley for the comprehensive and balanced approach she took in researching and writing; the clinicians and managers who took time to inform us about their services and future plans; and, also all those that answered the survey – identifying areas of need and proposing ideas for improvement and research. Hopefully, we can match the passion of those who responded to the survey by supporting translational research into end of life care that will make a lasting difference.

Changes in our population structure and advances in medical care have resulted in a growing need for end of life care and the overall messages of this paper are confronting. Many people are ill prepared for death. Formal acknowledgement that a patient is dying occurs late and limits the opportunity for planning or provision of palliative care. Services are more limited for patients who are not dying from cancer and those who live rurally.

The perceived need for 'more' end of life and palliative care is not currently well supported by evidence about where the best return on investment is. Managers face difficult and competing resource requests. How do they decide between requests to support dying at home with equipment versus recruitment of specialised staff such as palliative care physicians and grief counsellors versus dedicated hospital beds? They have little evidence available to help with decision making. Additionally, current funding models seem to be impeding improvement initiatives from sustaining and becoming established parts of the system of care. There seems opportunity for research modelling the effects of possible funding changes that might better enable policy makers manage growing demand, including in residential aged care. There is a plethora of freely available web-based education and clinical tools, yet respondents called for more training. There is little evidence to demonstrate that these tools are routinely being used and are improving patient outcomes. A lack of clarity seems to exist about whose responsibility ensuring good care for the dying is; what kind of education different staff need; and, whose job is it to provide the education, and when.

I look forward to the full development of the initiative. It will acknowledge the extensive work already occurring in this area, and encourage consumers, community, clinicians, researchers, managers and policy makers to work together to address existing barriers and improve patient outcomes.

Professor Christine Jorm | Director
NSW Regional Health Partners

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Abbreviations

ACP	Advance Care Plans
ACD	Advance Care Directive
ABS	Australian Bureau of Statistics
ACI	Agency for Clinical Innovation
PCOC	Palliative Care Outcomes Collaboration
ICU	Intensive Care Unit
CPR	Cardiopulmonary resuscitation
HNE	Hunter New England
LHD	Local Health District
JHCH	John Hunter Children's Hospital

Introduction

This paper provides a concise summary of the important end of life issues for northern regional and rural NSW. Definitions are important in this field and community confusion can lead to patients rejecting offers of help. Thus, the paper begins with definitions.
A rapid review search strategy was implemented, with the broad search terms "palliative care" and "end of life" initially entered into major databases (PubMed, PsychINFO, Embase) to search Australian literature. Where relevant Australian research papers were found, their citations and reference lists were also searched. Grey literature was obtained from key informants and through search engines.
The results of the literature review are presented under three headings:

- The demographics of death
- What else do we know about the provision of end of life care
- Australian rural literature

This is followed by collation of major NSW state-wide initiatives and details on the services provided for end of life and also the improvement activities underway in the region. The final section contains the results from a survey: identification of gaps and ideas for improvement and research contributed by clinicians, consumers and managers from three Local Health Districts. While this paper provides syntheses of bodies of knowledge and some conclusions, its purpose is to provide a resource for the decisions and actions of others – in particular, researchers and managers. To undertake meaningful priority setting would require a formal engagement process with much larger groups (including regional and rural communities) – thus there has deliberately been no attempt to produce overall conclusions (as they would merely be pseudo-priorities).

Defining the Important Concepts

End of Life

The NSW Agency for Clinical Innovation uses the term "end of life" to refer to the "period of time when a person is living with an advanced, progressive life-limiting illness".[1] Rather than attempting to predict *when* a person is going to die, they suggest that it is more useful to *identify those who will likely die* within the next year, and that these individuals may benefit from end of life care. "End of life care" describes the care provided by all health professionals to individuals who are nearing the end of life.[1] The Australian Commission on Safety and Quality in Health Care describes end-of-life care services as including 'physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff' provided to people who are "likely to die within the next 12 months" as well as their families and carers.[2]

Palliative care

"Palliative care" refers to specialist services provided by palliative care professionals, often in an interdisciplinary team whose primary focus of work is people nearing the end of life.[1] The World Health Organization definition of palliative care has an emphasis on affirming life and encouraging meaningful engagement, by "improving the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".[3]

Although the terms "end of life care" and "palliative care" are often used interchangeably, they refer to different services targeted towards different groups of people.[4] End of life care generally refers to care provided to people "approaching the end of life"; that is, during the 12 months prior to death, including to people who are likely to die in the short-term.[2] Palliative care may be delivered over a much longer period of time to patients with life-limiting illnesses, and depending on the nature of the illness, the type and level of care may vary over time.[2]

Advance Care Planning

Patients' preferences for care may be documented in an advance care plan. An advance care plan outlines a patient's wishes regarding medical treatment or goals of care in the case that they become unable to communicate or to make decisions. Advance Care Plans (ACP) may be completed at any time, not just when a person becomes ill. They make take the form of a conversation with a person who will be responsible for their care (such as a family member, friend, or doctor), a letter, or an entry into a patient's medical record. This may be an ongoing process, with preferences being updated as a patient's condition changes.[5] An Advance Care Directive (ACD) is an advance care plan that has been formally recorded and has legal status.[6]

The demographics of death

Who dies?

In Australia, there were 160,000 deaths recorded in 2017 (ABS, 2018). It is estimated that between 50 to 90 per cent of those who die may benefit from end of life care, [7 8] indicating that 80,000-144,000 people may have benefited from such care in the past year. This figure is expected to rise considerably in the coming years, as Australia's population is increasing, and the age structure is also changing dramatically.[4] While the current proportion of Australians aged over 65 is approximately 15% (3.7 million people), this is expected to rise as high as 19% (5.7 million people) in 2031, and 25% (12 million people) by 2066.[9] Many of these people will die from chronic diseases, however improvements in medical treatments enable people to live longer with such conditions, meaning that there will be an increase in demand for end of life care is that unlikely to be met by current services and systems. For example, the top five leading causes of death in 2017 were ischemic heart disease, dementia, cerebrovascular disease, chronic lower respiratory diseases, and cancer of the trachea, bronchus, and lung;[10] each of these conditions are ongoing and progressive, and patients may benefit from palliative or end of life care for a considerable period prior to their death.

In 2017, the median age of death was 78.9 years for males and 85.0 years for females, an increase of approximately 1.5 years since 2007 for both genders.[10] However, it is estimated that Australians aged 65 or over can expect to live at least half of their remaining life with an ongoing illness or disability,[11] indicating a potential need for palliative care amongst a considerable proportion of the older population.

Where do they die?

End of life care is provided in a range of settings across Australia, including public and private hospitals, residential and community aged care services, and general practices. Services are also available to deliver end of life care to individuals in their homes.[4] According to the Australian Institute of Health and Welfare, information about Australians' preferred place of death, actual place of death, and the end of life care they receive is fragmented, raising questions about its completeness and accuracy.[4] However, the majority of people will die in one of three locations: aged care services, admitted patient care, and palliative care (hospice) services.

Eighty percent of all deaths occur in hospitals or residential aged care facilities.[12] This appears to conflict with people's preferred place of death, with 70-80% of people indicating that they wish to die at home.[13] Several factors may contribute to this discrepancy. Firstly, the necessary resources may not be available to enable an individual to die in their home. Many palliative care services experience under-resourcing for both staff and equipment, especially in rural and remote areas. This may limit the availability of home visits to provide necessary medical care, administration of medications, and etc., as well as restricting access to equipment such as electric beds and sling lifters. Caring for a patient in the home may also place a considerable burden on informal caregivers, and as a result may not be a feasible option. Research by Burns

and colleagues found that about half of informal carers report that caring for a loved one nearing the end of life was worse, or much worse, than they expected.[14] This was especially so for those providing full-time rather than intermittent or occasional care.

In addition to these barriers, families and carers are not always aware of the patient's preferred place of death, and also as people approach the end of their life they may change their mind about their preferred place of death, as the reality of the situation may be different to their expectations. For example, Agar and colleagues found that 28% of patients utilising a palliative care service changed their preferred place of care, and 32% changed their preferred place of death, as the time of death became closer.[15] While 87% of patients initially preferred to be cared for at home, this decreased to 71% over a period of approximately three months. The same trend was observed for preferred place of death, with 41% of patients initially wishing to die at home, decreasing to 35% of patients as death became more imminent.[15] This study also highlighted an interesting issue that while home was the preferred location of care for the majority of patients in the lead-up to their death, less than half wished to die at home. Conversely, Aoun and colleagues found among patients with terminal cancer who lived alone, only approximately one-third wished to be cared for at home.[16] However, among this sample, the preference for home as a location for death was higher at 49%. Similarly, Waller et al., reported that less than half of terminal cancer patients wish to be cared for at home.[17]

Taken together, these findings suggest that preferences for place of care and place of death differ, may vary depending on diagnosis and personal circumstances, and are likely to change over time. Waller et al. also report that only 41% of patients discussed their preferred place of death with their carer and 7% discussed it with their doctor, although 87% wanted their doctor to ask them their preference.[17] Even when the preferred place of death is known, only approximately half of people are able to die in their preferred location.[4 15 16]

What do we know about their death?

The majority of deaths in Australia occur in hospitals, and are somewhat expected, often being the result of ongoing chronic conditions. However, little formal planning is occurring in advance.

An audit of 200 deaths in John Hunter Hospital in Newcastle, New South Wales, showed that the majority of patients (81%) were living at home prior to their admission, with 12% residing in a residential aged care facility. Almost half of patients (48%) had no previous hospital admissions during the previous 12 months, with 28% having 1-2 admissions, and only 6% having more than 5 admissions. A small proportion (13%) had a written advanced care plan or advanced health directive prior to the admission in which they died. During their admission 61% discussed their preferences for care, and 72% discussed a resuscitation plan. This audit included 50 patients from each of four categories: patient died on an in-patient ward, hospital admission 4 to 48 hours; patient died on an in-patient ward, hospital admission more than 48 hours; patient died in ICU,

hospital admission 4 to 48 hours; patient died in ICU, hospital admission more than 48 hours.[18]

An audit conducted across five regional and rural hospitals in Western Australia documented 90 consecutive deaths.[19] This audit found that the majority of patients (58%) were admitted via the emergency department, and 73% were admitted for three or more days prior to their death. In about two-thirds of cases (64%), patients were referred to palliative care during or prior to their admission, with 31% receiving a clear diagnosis during their admission that they were dying. Only 10% of patients had a formal advance care plan, 29% had an informal advance care plan, and 30% had documented their preferred place of death. Over one-fifth (22%) were deemed to have no decision-making capacity at the time of their admission.

A study conducted in Alice Springs hospital in the Northern Territory documented 73 deaths, with 83% of patients receiving a diagnosis that they were dying.[20] However, in one-third of cases the diagnosis was made on the day of, or the day before, the patient's death, and on average was made six days prior to death. In about half of cases, chronic complex conditions were the cause of death. About half (48%) of patients had been admitted to intensive care during their previous hospital admission. Two-thirds (68%) were referred to palliative care during their hospital admission, and 88% had 'not for resuscitation' orders documented. The majority (85%) were deemed to be "comfortable" at their time of death.

In conclusion, it seems that formal acknowledgement that a patient is dying occurs late and limits the opportunity for planning or provision of palliative care. While palliative care provision and end of life discussions did occur for many patients in the period immediately prior to their death, the opportunity for patients to benefit from this was limited due to the late occurrence of referrals to the palliative care team, and late identification that the patient was dying.

What else do we know about the provision of end of life care?

Palliative care has multiple benefits at both patient and service level

For patients, palliative care has been associated with enhanced quality of life and management of symptoms including pain and anxiety, while also relieving caregiver burden.[1] At a service level, palliative care leads to greater efficiency in the health system, by avoiding or reducing hospital admissions, treatments, and procedures, while also being less resource-intensive and costly than inpatient services. Research suggests that the quality of palliative care in Australia is high. According to data collected by the Palliative Care Outcomes Collaboration (PCOC), the vast majority of patients who receive care from a specialist palliative care service begin receiving this care on the day of, or the day following their referral, and that in most cases patients are having their needs, such as pain management, met to their satisfaction.[21] However, consistent measures of patient experience of care do not currently exist in Australia, and such measures generally differ across service providers.[4] The nationally funded palliative care outcomes collaborative is a registry based at the University of Wollongong collects and reports on a detailed series of measures, but its coverage is limited.

There are recognised gaps in services to support those nearing the end of life

These include difficulties accessing care from general practitioners (especially after hours), limited access to care for people living in rural and remote areas, difficulties accessing federally funded services, and limitations in the care provided by specialist palliative care services.[1] It has been reported that many people find the end of life care system difficult to navigate.[2] While some end of life care services (including aged care) are subsidised by the federal government, other services are delivered at the state or territory level. They therefore differ in the level of government investment, service delivery practices, and the demographic and geographical profiles they are required to cater for.[4] A series of workshops held by NSW Health in 2017 with consumers, health sector representatives, and academics led to recognition of several key issues. The workshop in Newcastle identified the following as essential to the effective delivery of palliative care: ensuring sufficient local resources are available (including capacity building among the current palliative care workforce and providing training for specialist and generalist nurses); equity of access (including equity of access to medications, equipment, and services); and models and approaches to palliative care (including culturally sensitive care, and better integration of services).[22] Similar themes were noted in the workshop held in Tamworth, with an additional emphasis on the importance of GP involvement, open communication, and patient- and family-centred care.[23]

The current system can prevent people from dying in their preferred place

This includes the limited availability of services in rural and remote areas, a lack of after-hours advice and support, limited incentives for general practitioners to provide home visits, lack of adequate support to provide quality palliative care in aged care facilities,

and a lack of coordination between hospitals and community-based services. Dying in hospital has been associated with multiple negative outcomes, including potentially unwanted aggressive treatment, poorer management of symptoms, and underuse or late use of palliative care.[24 25] A recent systematic review found that 70% of presentations to a hospital emergency department during the last month of life led to a hospital admission, which is often both distressing for patients, and increases the chances of an in-hospital death.[26 27] Several studies have shown that community-based palliative care is effective in reducing emergency department presentations and hospital admissions, as well as shorter admission times.[28 29] However, many vulnerable groups, including those residing in rural and remote areas, or those with complex conditions such as dementia, are less likely to have access to such services.[28]

Staff lack training

A particular gap has been identified around the inadequate access to education, training, and ongoing professional development for staff, including new staff members, specialists, and primary care providers. The workshop held by NSW Health with consumers, health sector representatives, and academics in Newcastle identified the importance of specialised staff and a well-trained workforce as part of an effective palliative care service.[22] This includes the provision of specialised training for staff working in palliative care, as well as the availability of ongoing training for nurses to maintain specialised skills. This was identified as something that would be particularly beneficial in areas where there are no specialised palliative care services, and as something that would generally make palliative care less "doctor dependent." The workshop held in Tamworth also noted that upskilling GPs would also be beneficial, including further education, as well as access to specialist clinicians to provide advice and guidance.[23]

Care givers don't initiate end of life discussions with patients

The quality of end of life care is often impacted by a lack of information about patient preferences. End of life discussions generally do not occur until a patient's condition has deteriorated and they are nearing death, meaning that important decisions about care are often made by patients and their families while they are under considerable distress.[4] Processes for formalising preferences for care, such as advance care plans and advance care directives, are available, however it is estimated that only 14% of Australians have completed an advance care plan.[30] It has been suggested that completing these processes before an illness occurs, or a patient's condition deteriorates, will lead to a higher likelihood of patients' preferences for care being met, hence improving their experiences of end of life care.[4]

Despite the availability of guidelines and conceptual frameworks, end of life discussions are often not initiated by healthcare professionals. Factors that contribute to this underutilisation include the emotional burden these conversations entail, low confidence among health workers, and differing goals among members of the care team.[31] A recent study among 181 nurses employed in acute or critical care wards showed relatively low knowledge around advance care planning practices, with only 10% of nurses having prepared an advance care directive.[32] Advance care planning has

also been described as "paradoxically rewarding" by clinicians, because it empowers patients and leads to better outcomes, yet may also cause clinicians to feel emotionally vulnerable and/or distressed.[33] Although training programs are available and are recommended for new staff, it is also recognised that experience may be more beneficial than education.[31 34]

There is limited evidence to support strategies to improve end of life care

A recent review of research studies aiming to improve end of life processes or outcomes revealed mixed findings.[35] The majority (82%) of studies which aimed to improve processes (such as end of life discussions or documentation) showed evidence of success. These studies predominantly aimed to increase the use of advance care plans, advance care directives, and CPR orders. Palliative care consultations,[36 37] and staff-facilitated advance care planning conversations,[38-40] were both shown to lead to an increase in formalised advance care plans. Less intensive interventions, such as providing patients with written information or showing them a short video, also led to an increase in patients clarifying their preferences.[41 42] However, there was less evidence for the success of strategies aiming to improve outcomes, with only 43% of studies positively influencing the patient experience. Consultation with a palliative care team in particular was associated with improved patient outcomes, including longer hospice stays, [36] and decreased physical and psychological symptoms.[37 43] However, of the 18 studies reviewed, only one was conducted in Australia, and hence the conclusions may not be locally relevant.

The Australian Institute of Health and Welfare has provided a range of suggestions for improving end of life care in Australia.[4] These include suggestions encouraging Australians to have conversations about their preferences for their care and place of death, and providing information to the community about end of life care services. Recommendations for staff include greater training and better integration of end of life services across the health sector. Obtaining greater understanding of the barriers to accessing end of life care has been identified as an important future goal, together with more consistent data collection to better inform strategies.

The funding of end of life care is problematic

Internationally, funders have struggled to define optimal payment models for palliative care.[44] Home-based palliative care is cost saving, but in many systems those savings are not realised by the funders of services (e.g. when an acute health system funds programs that keep patients out of hospital but their own funding is activity based).[45] Duckett has comprehensively explored the range of desirable funding model directions for palliative care.[44] Activity measures for palliative care are available from the Australian palliative care sub-classification,[46] but Spanish and German researchers have developed a more fine-grained assessment of complexity in palliative care.[47] Duckett's review suggests that more fine-grained measurement (enabling a measure of activity) will not be a sufficient solution for ensuring care is high quality and improves patient outcomes.[44]

Australian rural literature

In Australia, approximately one-third of people reside in rural or remote areas. Rural areas are typically characterised by an older age profile, and often experience poorer health outcomes, including higher rates of chronic illness, higher death rates, and a lower life expectancy, as well as lower access to services.[48] There are recognised gaps in the provision of end of life care to rural and remote residents. As regions become more remote, access to end of life services becomes more limited, with many rural and remote areas of NSW having no access to specialist palliative care physicians or services.[1 49] Access to palliative care services for rural and remote patients and carers has been identified as an area in particular need of focused research.[50]

Rural and remote residents are much less likely to die at home

A study in regional north Queensland found that compared with the 23.4% of palliative care patients in metropolitan areas dying at home, only 11.6% of rural residents, and 0% of remote residents did so.[51] Home deaths were more common among people who were younger, married, and had the involvement of a community nurse (data recalculated by Rainsford et al.[52]). However, a similar study in South Australia found a smaller difference, with 18.1% of rural residents dying at home, compared with 20% or urban residents. Urban residents were, however, more likely to die in a hospice (16.2%) than rural residents (7.9%), due to their limited availability outside of major urban centres.[14] A similar trend was observed in a study by Foreman et al. which found that a hospice setting was the preferred place of death for 11.4% of urban residents, compared with only 6.2% of rural residents, which again may reflect a reluctance to leave the local community if hospice services are not available in rural areas.[53] Considering that one aim of palliative care is to enable people to die in their preferred location, the benefits of palliative care services appear to be less prominent in rural and remote locations. However, it has been noted that insufficient information exists to define what a "good death" means for rural residents, and it is inappropriate to generalise the preferences of urban residents to rural populations.[54] It is also important to acknowledge that rural and remote areas are highly heterogeneous, and the characteristics and needs of rural communities often differ greatly.

Services are less available in rural areas

Factors that may contribute to the lower proportion of home deaths in rural areas include the lower availability of home-based services, the lack of 24-hour care, and delays in service provision.[55] Informal caregivers often have difficulties caring for the patient in their home, particularly related to administering medications, manual handling, and managing their own psychological wellbeing and burnout related to being responsible for these demanding tasks.[55] In cases where manual handling tasks such as moving the patient or using equipment become too difficult, or the administration of medication is too complicated, informal carers may request hospital admission for the patient. In addition, as the end of life approaches, caring for patients may become more complex, as symptoms often worsen or new symptoms appear. As conditions deteriorate, these symptoms may become too difficult or complex for informal carers to

manage in the home environment, and hence may result in hospital admission. Greater support for informal caregivers in the home environment may therefore lead to fewer hospital admissions and fewer deaths in hospitals in rural and remote areas.

Remote residents have special problems

Across Australia, less than 1% of people in residential aged care are residing in remote or very remote regions, with the vast majority of these services being located in major cities or inner/outer regional areas.[56] Remote residents who require residential aged care are therefore often required to move to a more urbanised area to access these services. The need to travel or relocate to receive adequate care contributes additional hardship in what is an often already distressing situation. There is some evidence that, given many remote residents' deep connection to their home and community, and a preference to die in the area of their home, remote individuals may choose to remain in their home community rather than relocate, even when this means receiving sub-optimal end of life care. Approaches such as providing telephone or videophone support to rural and remote families have been shown to reduce the isolation felt by many informal carers caring for a family member at home,[57-59] as well as extending the outreach of palliative care workers.[60]

The evidence available about what works in rural Australia is limited

A 2003 review by Evans and colleagues reported little published work and most focused on identifying problems with the delivery of care, rather than evaluating strategies to improve and expand services.[61] A 2009 review by Robinson and colleagues had similar findings, concluding that there was not a sufficient body of evidence to guide policy or practice, suggesting the need for co-ordinated research programs to inform policy and service development.[62] More recently, Bakitas and colleagues found that options to improve care such as increased training for rural health professionals, telehealth, and partnerships between academics and rural communities, remain largely unevaluated.[63]

The National Rural Health Alliance has identified that an understanding of palliative care should be part of initial training and ongoing professional development for health care professionals working in rural and remote regions.[64] Several trials have been undertaken to investigate the impact of training rural and remote health workers in palliative care. Reymond et al. evaluated a series of face-to-face workshops delivered by a specialist palliative care team to 149 primary care workers in rural far north Queensland.[65] More recently, Ray et al. delivered professional education via videoconference to 101 rural health practitioners across north Queensland.[66] Both of these studies reported positive outcomes, indicating that these training methods are feasible and acceptable to rural health workers. However, outcomes only related to health workers' self-rated confidence and knowledge in working in palliative care, and whether training had any impact on patients' experience of care was not evaluated. Additionally, the follow-up periods were short (three months and immediately after training, respectively), so it is also unknown whether this training had any lasting impact on the participants. An international review of palliative care educational interventions for primary care physicians by Alvarez and Agra concluded that this area has received

little research attention, and that the majority of study designs to date have been poor.[67]

There is evidence that rural and remote residents may receive poorer quality information about their illness and treatment. In a study of patients with advanced cancer who were receiving palliative care, those in rural areas were less likely to understand that their treatment was non-curative, with one-fifth of rural patients believing that their illness was not life-threatening.[68] Six months after entering palliative care, patients' understanding of their condition had improved, however it was noted that misunderstandings such as these can lead to excessive optimism and may impact on decision making as patients and their families may make decisions based on incorrect beliefs.

End of life care for Indigenous Australians needs special attention

Indigenous people have been identified as a priority population for palliative care, given their higher mortality rates and disproportionate burden of disease compared to non-Indigenous people. Despite this, Indigenous people are among the least likely to access or receive palliative care, although comprehensive data on the rates of access is not currently available. The Australian Government has expressed a desire to reduce disparities in Indigenous health outcomes through campaigns such as Close the Gap. In addition, non-government organisations including Palliative Care Australia (Program of Experience in the Palliative Approach (PEPA)), the Palliative Care Outcomes Collaboration (PCOC), and Cancer Australia have developed Indigenous-specific end of life initiatives.[69] However, significant challenges still remain.

A comprehensive model of care for working with Indigenous Australians was proposed by McGrath and Holewa consisting of seven principals to guide palliative care service delivery.[70] These principals include equity of access; autonomy/empowerment of patients; trust; humane, non-judgmental care; seamless care by a multidisciplinary team of health professionals and community-based organisation; emphasis on living rather than dying; and cultural respect. However, to date no evaluation of this model has been undertaken.

Challenges in the provision of end of life care for Indigenous Australians include the lack of culturally appropriate service options available. Indigenous Australians have a strong preference to be cared for and to die at home.[69] For an Indigenous Australian to die "in country" is of considerable cultural significance, [71] and they often express a fear of dying away from their home and community.[72] [73] Relocation for care is associated with considerable fear and discomfort for Indigenous Australians; this includes feelings of disempowerment associated with leaving family and community networks.[72] Indigenous people are often uncomfortable in metropolitan settings, particularly when they are receiving (sometimes invasive) treatments in an unfamiliar setting away from their family and community. Despite this, there is some evidence that when Indigenous Australians do receive palliative care, they are more likely than non-Indigenous people to receive this care as an inpatient, rather than in the home.[74] There is a need to engage with Indigenous communities and families before designing or implementing palliative

care programs, as well as a need to improve training for staff to increase their skills and awareness before working with these communities.[69] Building relationships with community, and involving family in any decision making processes, as well as including Indigenous staff where possible, is essential to gain the confidence of Indigenous patients.[69]

Alongside cultural challenges, it has been reported that there is a general lack of awareness among Indigenous patients of palliative services available and how to access them.[71] In addition, there is often a misperception of what palliative services entail, with Indigenous patients tending to associate palliative care with death and end of life care, rather than the broader spectrum of services available (pain relief, psychosocial support, etc.[71]). Education for Indigenous communities around the broad focus of palliative services may improve attitudes towards, and uptake of care.[69]

In addition, factors such as geographical isolation contribute to the lack of care. Indigenous communities are often located a considerable distance from services, making them difficult for patients to attend. While mobile palliative care units exist, many of these visit remote communities infrequently, and where homes are geographically isolated, access may be restricted.[71]

State-wide initiatives and their evidence/research opportunities

Expert informants identified the following initiatives/resources. It was difficult to get any sense of how well used they are by clinicians in the area.
Please note:

1. We apologise for any inadvertent omissions from this list, but these were the programs nominated by our key expert informants
2. While evaluations that are not publicly available may exist, we assumed that any high-quality evidence of initiative effectiveness and impact will have been provided on the relevant initiative websites

Initiative name	**Description**	**Evidence? Evaluation?**
The Palliative Care Bridge	NSW-wide palliative care education program delivered by the HammondCare consortium. Website providing educational videos to health professionals working in palliative care.	No current evidence of evaluation
The Advance Project	A practical, evidence-based toolkit of screening and assessment tools and a training package specifically designed to support Australian general practices to implement a team-based approach to initiating advance care planning (ACP) and palliative care into everyday clinical practice.	Has received positive feedback from workshop attendees, but no formal evaluation
ACI Last Days of Life Toolkit	Provides tools and resources to support staff to ensure all dying patients are recognised early, receive optimal symptom control, have their social, spiritual and cultural needs addressed, that both patients and families/carers are involved in decision making, and that bereavement support occurs. Toolkit has been integrated into health facilities across each sector of HNE LHD. Evaluation of uptake is currently underway. Also being modified for use in Residential Aged Care Facilities (RACFs).	Tools for evaluation are provided by the Clinical Excellence Commission, but are focused on the toolkit and staff experiences, not patient outcomes

ACI Palliative and End of Life Care Blueprint	A flexible guide for health services to meet the needs of people approaching and reaching the end of life, their families and carers. The Blueprint can be implemented across all settings of care – acute, subacute, aged and community spanning across public, private, not-for-profit and community sectors.	A list of ten intended outcomes of the blueprint is available, but no current evidence that these have been evaluated
Specialist Palliative Care Telehealth Outreach Model	Uses available Telehealth technology to facilitate consultation between palliative care medical officers at the Calvary Mater Newcastle and patients, families, and local GPs and/or palliative care practitioners at the patient's home or in a local clinic facility. Model currently expanding to allow specialist palliative care allied health practitioners to provide consultation and support to colleagues and residents in RACFs across HNE.	No current evidence of evaluation
Clinical Excellence Commission – End of life Program	The End of Life program aims to introduce a state-wide approach to end-of-life care in NSW. This incorporates excellent symptom control, a prompt for communication to address social, spiritual and cultural needs as well as bereavement support for families and carers. This includes the introduction of the AMBER care bundle, a State-wide mortality review process and ACI Last Days of Life Toolkit.	No current evidence of evaluation

Services provided and activities underway in the region

Hunter New England Local Health District

The Hunter New England Local Health District (HNE LHD) has a population of 938,595 people, which is approximately 12% of the population of NSW. Geographically, this district is one of the largest in NSW, covering an area of approximately 131,785km.^{2} The district is unique in NSW in that in encompasses a major metropolitan centre, several large regional centres, many smaller rural centres, and a small number of remote communities within its borders. It also has a large Aboriginal population of approximately 52,990 people, making up 5.7% of the HNE LHD population, compared with the state average of 3%. Overall, the HNE LHD population is experiencing considerable growth and ageing, with the population expanding at the fifth-fastest rate of any LHD in NSW, and the fastest outside of Sydney.

In the 12-month period from March 2017 to March 2018, there were 3,485 deaths in acute facilities. Data relating to deaths in other settings, including private hospitals, residential aged care facilities, or at home, is difficult to obtain and hence cannot be reported.

It is important to note that the majority of data available related to palliative care in the HNE LHD relates to acute care facilities, and staff whose designated role is palliative care. Information relating to staff and services outside of those scope is difficult to obtain, and data are not readily available.

The palliative care services in the HNE LHD are based on the principle that a fully integrated and comprehensive network of services working collaboratively to provide community and inpatient care is most effective. The core aims of initiatives in this district are to ensure equitable, coordinated and adequately resourced palliative and end of life care services to the people of the HNE district, and to ensure consistent practice and reduce variation in palliative and end of life service provision. There are two major palliative care services in the HNE LHD; the Calvary Mater Newcastle Palliative Care Service and Mercy Hospice, and the Paediatric Palliative Care service. The Palliative Care Service works locally in the Newcastle region to provide consultation to other public and private hospitals, community outreach, and support to residential aged care facilities. More widely, it provides outreach to the regional centres within the district, and supports community palliative care services throughout HNE. The Paediatric Palliative Care Service, based at the John Hunter Children's Hospital (JHCH) in Newcastle, provides support to patients and families across HNE and Northern NSW. This service uses telehealth to enable equity of access to services across regional and remote areas. It is linked to the NSW Paediatric Palliative Care program, along with the Children's Hospital at Westmead and Sydney Children's Hospital at Randwick.

In addition to these major service centres, additional palliative care service centres (with specialist palliative care clinicians) are located in Tamworth, Maitland, Taree, and Cessnock/Kurri Kurri/Singleton. There are also small services across the district, which are mostly led by nursing staff. Some regional and remote areas in the HNE LHD have little or no access to palliative care services. Recruitment and retention are particularly challenging in these areas.

Across the LHD, there are 31 beds for adults requiring palliative care (17 in Newcastle, 6 in Tamworth, 6 in Manning base hospital, 2 in Armidale), and 6 paediatric beds (3 JHCH, 1 Tamworth, 1 Manning base hospital, 1 Maitland). Additionally, the Silver Chain Care End of Life Care Packages, funded by NSW Health, provide home-based nursing care and phone support within a limited number of geographical areas, primarily in the Newcastle and Maitland areas.

District initiatives and projects

There have been numerous initiatives to enhance the care of the dying patient and their family/carers across the District. Examples of these initiatives include:

- Development of HealthPathways: Care in the last 12 months of life – includes four pathways for health professionals to access that provide evidence based practice on clinical care
    - Advance Care Planning
    - Bereavement
    - Care of the Imminently Dying
    - Palliative Care
- Trialling the Last Days of Life Toolkit at 3 sites in the District in 2016
- The Development of the MyNetCare resource by the Hunter Alliance
- Establishment of the End of Life Care, Nurse Practitioner role at the JHH in 2016
- Establishment of the Renal Supportive Care Service at the JHH in 2015
- The "Virtual Hospice Program" at Maitland
- Utilisation of home-based video conferencing by the Paediatric Palliative Care Service
- "Into the Dreaming" program: Multi-pronged HNE-wide plan for Closing the Gap with the aim to encourage uptake of palliative and end of life care services for Aboriginal people and their communities
- Participation in national and state collaboratives for palliative care research
- Palliative care education for health professionals and university students
- Standardising approaches to clinical care and symptom management across HNE
- The ACE program – focused on RACFs
- "Let's Start Talking" communication skills workshops connected with Health Councils

- "It's Now or Never" communication skills workshop (500 HNELHD staff have attended)
- Agency for Clinical Innovation's Program "Living Well in Multipurpose Services"
- HAPENN – Hunter Area Palliative Education Nurses Network
- HAPCN – Hunter Aged Palliative Care Network

Priorities

A range of priorities for the LHD to improve patient outcomes have been identified. These include:

- Improving support and education for the generalist workforce providing care to patients and their families at the end of life
- Developing an effective and sustainable model for supportive care of patients with end-stage non-malignant disease
- Expanding the effective use of telehealth solutions to maximise equity to access specialist palliative care clinicians
- Support for development of an on-site palliative care consultancy service at JHH
- Improving access to allied health professionals specialising in palliative and end of life care
- Recruitment and retention is an ongoing issue, especially in rural and remote areas
- Succession planning and staff retention needs further development and strategies to ensure workforce requirements into the future
- Improving and developing appropriate models for ATSI end of life care in the district

Central Coast Local Health District

The Central Coast Local Health District (CCLHD) has a population of approximately 328,000 people, including an Aboriginal and/or Torres Strait Islander population of 3.8%. People aged 65 and over account for 20.9% of the district's population, and the median age of the district is 42 years, four years older than both the NSW and Australian median of 38.

The CCLHD has a level 2 palliative care service. This service does not include any hospice or inpatient facilities, but provides a specialist palliative care community nursing service. The district is divided into six geographical areas, each with a dedicated palliative care community nurse who provides services such as symptom advice and home visits as needed. The nursing service is supported by two full-time staff specialist and a part-time occupational therapist.

The CCLHD has two major hospitals, located in Gosford and Wyong. Each of these hospitals offers a palliative care consult service. The consult team at Gosford includes a full-time staff specialist, registrar, and nurse practitioner, and a part-time clinical nurse

specialist. The consult team at Wyong also includes a full-time staff specialist and registrar, with a nursing position currently undergoing recruitment.

Both the community and consult services operate five days a week, with a nurse on-call seven days a week for the community service, and a staff specialist on-call for community nurse support on weekends. Additional funding from the NSW government has been recently received, with an aim to use this funding to recruit an additional staff specialist to increase on-call capabilities.

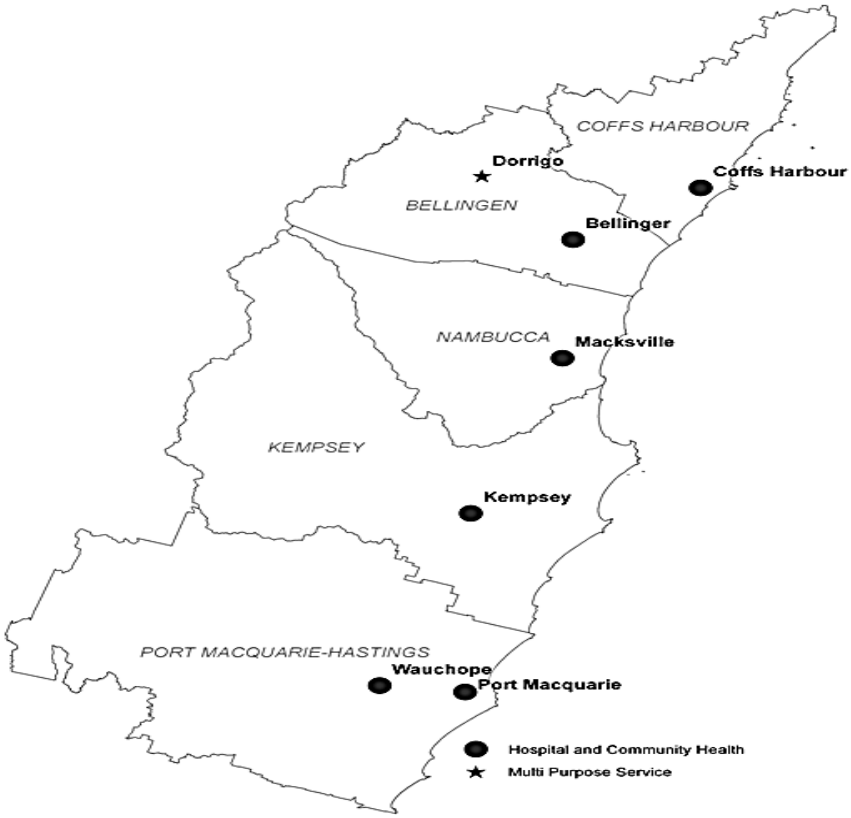
District initiatives and projects

The district is currently implementing the Palliative Care Residential Care Outreach Service (PCROS). This is a commonwealth-funded initiative that provides funding for a full-time clinical nurse specialist and a part-time social worker to oversee palliative care in local residential aged care facilities. This includes upskilling residential aged care staff to provide improved palliative care. This initiative has been partially evaluated, and an application has been lodged for further funding.

Mid North Coast LHD

The Mid North Coast Local Health District (MNCLHD) covers an area of 11,335 square kilometres extending form Port Macquarie Hastings Local Government Area in the south to Coffs Harbour Local Government Area in the north. The Mid North Coast has an increasing ageing population and a higher than average Aboriginal population. There is a total population within the district of 207,490 people.

The district has two regional base hospitals at Coffs Harbour and Port Macquarie, and four smaller regional hospitals at Bellingen, Macksville, Kempsey, and Wauchope, as well as a multi-purpose centre in Dorrigo.



The district is divided into two networks; the Coffs Clinical Network (comprising Coffs Harbour, Bellingen, and Macksville hospitals, and Dorrigo multi-purpose centre), and the Hastings/Macleay Clinical Network (comprising Port Macquarie, Kempsey, and Wauchope hospitals). These networks are similar in terms of the size of population they service.

Coffs Harbour base hospital comprises 300 beds (which will increase when current renovations are completed). It has two palliative care specialists, one of whom was recently recruited; these specialists service the entire Coffs Clinical Network and provide consultation-liaison services. The hospital receives approximately 550 new palliative-care related admissions per year, which has increased from approximately 120 admissions per year four years ago, due to a range of quality improvements, including improvements in the identification of patients who may benefit from palliative care services. There are approximately 110 deaths in the hospital each year. The hospital has a multidisciplinary team dedicated to palliative care, including a registrar, nursing staff, and part-time allied health professionals including an occupational therapist, social worker, speech therapist, and dietician. This team services the whole hospital, with referrals from the emergency department, intensive care unit, medical and surgical wards. A major aim of this team is to provide patients with greater choice about their care. The palliative care unit is available five days per week, and is available by telephone on weekends.

Patients within the Coffs Clinical Network also have access to an inpatient palliative care unit in Bellingen, with six dedicated palliative care beds based in Bellingen hospital. This has increased from two dedicated beds four years ago. Approximately 240 patients are seen through this unit each year, with a 60% discharge rate. This service is well-resourced, with a CNC specialist in palliative care, and a range of allied health professionals. Palliative rehabilitation is also available with the allied health team. This area has a newly appointed staff specialist, who is supported by generalist staff who receive access to the LHD's rural generalist training program to provide them with palliative care skills. The generalist community team in Bellingen also provide outreach and consultancy services if needed.

Macksville hospital hosts a smaller palliative care service with a clinical nurse coordinator, registered nurse, and part-time social worker, which is available 7 days a week. It provides in-reach to the hospital and limited in-reach to local residential aged care facilities.

Within the Hastings/Macleay Clinical Network, there are 2 designated palliative care beds at Kempsey Hospital and 8 palliative care beds at Wauchope Palliative Care Unit. Care is provided by nurse practitioners, with no staff specialist currently employed. While there is funding available for a staff specialist, difficulties with recruitment have led to this position remaining vacant at present. Support for families is also provided by a part-time bereavement counsellor, and local general practitioners provide clinical governance. Overall this network is quite fragmented, with a different line manager in each area.

The LHD has two consumer reference groups (one in the Coffs Clinical Network and one in the Hastings/Macleay Clinical Network) that work with the Primary Health Network and Local Health District, as well as a community engagement sub-committee. The sub-committee reports directly to the board of the Local Health District to provide advice and feedback on factors such as the Local Health District's performance in engaging with the community (including different cultural and indigenous groups, refugee populations, and those from a non-English speaking background), whether services are meeting the community's needs, and whether patients' experiences with services are positive.

District initiatives and projects

- Patient-reported outcomes are currently collected from all sites. Data collection, including patient outcomes, will be standardised across the LHD in 2019, to improve the quality of data to inform future service delivery, patient needs, etc.
- Weekly medical education is currently provided for nurse practitioners, registrars and consultants. This education is frequently attended by clinicians from surrounding areas including Lismore and Grafton, who often face difficulties maintaining their own education programs due to low numbers.
- A research grant has been secured to trial telehealth for palliative care in patient homes, allowing patients to receive telehealth consultations with a palliative care

specialist. This trial will evaluate patient reported outcomes, acceptability, and effectiveness.
- Renal supportive care medical clinics are currently being set up, and are due to begin in February 2019

Priorities

Recruitment and retention in this region is an ongoing challenge. Implementing rural generalist training locally has helped to address this issue, by equipping local generalist staff with advanced palliative care skills, reducing the need to recruit staff externally. It has been recognised that the role of sole practitioners is not sustainable.

The MNCLHD operates under the "Quality End of Life Care Framework," which has four key goals and detailed strategies for achieving these. These goals include:

- Planning for care at end of life (advance care planning)
- Supporting patient preferred treatment options
- Carer support
- Providing quality care at end of life

A gap analysis exploring the quality of care for patients in acute hospital services nearing the end of life was completed in 2017. This has been the basis for the development of improvement work in the MNCLHD. Two areas were consistently identified: the need for ongoing education for clinicians and consumers to ensure quality end of life care, and the need for improvements in advance care planning. In summary, the recommendations from this gap analysis include:

- Promote a district wide approach to End of Life Care/Palliative Care to enable standardised practice in both the Hastings/Macleay and Coffs Clinical Networks
- Develop a strategic workforce plan to enhance specialist palliative care staffing-medical, nursing and allied health
- Invest in education to all staff caring for patients at end of life, promoting a person centred approach to end of life that is in keeping with patient and family wishes.
- Actively promote the use of advanced care planning in partnership with primary Health Care Networks, Residential Aged Care Facilities, General Practitioners and Ambulance. Educate staff, patients and families on the importance of advanced care planning to enable patient wishes to guide care at end of life.
- Implement into the medical record correct terminology associated with consent and end of life care decision-making e.g. "Person Responsible", "Substitute Decision Maker"
- Shift the current focus from active and sometimes futile treatment at end of life by empowering and educating staff to have open and honest conversations with patients and families regarding treatment limitations
- Offer bereavement support to all families and carers of patients who died in MNCLHD hospitals.

Results of survey on local end of life priorities

Between December 2018 and January 2019, a survey was disseminated to consumers, clinicians, managers, and researchers across the Hunter New England, Central Coast, and Mid North Coast Local Health Districts, assessing their views on priorities for end of life research. Respondents were asked to identify any unmet needs relating to end of life care in their area, as well as ideas for strategies or research projects to improve end of life care.

In total 195 people began the survey, with 121 people completing the question relating to unmet needs and/or the question about research projects. This included 68 clinicians, 23 managers, 11 researchers, and 3 consumers, as well as 16 people who identified themselves in more than one role. The majority of respondents were associated with the Hunter New England Local Health District, followed by the Mid North Coast and Central Coast Local Health Districts. Respondents also represented local neighbourhood groups, universities, councils, and state and federal government.

All responses were read by two trained researchers and then the major themes agreed.

1. Need for more staff training

There was an identified need among survey respondents for better education and training in a range of areas.

Medication management was a specific area where more education was requested, by both clinicians and managers:

> "Train doctors in dying so they don't withhold medications because the four hours is not up" – *Manager 22, HNELHD*

> "Education for end of life pain management for GPs and other health professionals especially in rural areas" – *Clinician 50, HNELHD*

It was noted that pain relief for patients is often inadequate, and that this leads to unnecessary suffering. In particular, challenges with community pharmacies were identified:

> "From personal experience, it is difficult to get appropriate pain relief at the concentrations required via community pharmacies …My mother was in end stage 5 bowel cancer with metastases to brain, lungs and liver. In the last two days of her life, she was in constant pain. Her physician prescribed high dose pain relief for her, however the pharmacist would not dispense due to the dose. Dose checked with the medical officer, and then had to be ordered in from a neighbouring

town. My mother died before the pain relief arrived" – *Manager 11, HNELHD*

"The need for adequate pain relief and counselling for patients. Phone calls to patients to see how they are from palliative care outreach are often commented on by patients as not an effective way to assess patients' coping with pain, or the progression of health decline" – *Clinician 22, HNELHD*

"Availability of appropriate medications in a timely manner from community pharmacies at end of life" – *Clinician 34, HNELHD*

Multiple respondents indicated that **improving clinicians' ability to identify when a patient is nearing the end of life** and communicate this to patients and their families would be beneficial for all – including clinicians. Examples of these responses include:

"I think perhaps the greatest need continues to be for health staff developing the clinical skills needed in recognising when a patient is dying." – *Clinician 33, HNELHD*

"Identification of patients with non-malignant disease who may be in the last 12 months of life and initiation of an approach to care that allows exploration of patient's goals of care and a systematic approach to treatment of symptoms and other issues" – *Clinician 87, HNELHD*

It was recognised that the failure to identify patients nearing the end of life contributed to poorer outcomes for patients, including inappropriate care:

"Early identification of those patients who are at end of life does not occur - we therefore do not tailor their care appropriately so go on to receive the same treatment protocols (e.g. surgery, resuscitation) as those not at end of life…." – *Researcher/Clinician/Manager 1, HNELHD*

Respondents claimed recognition that patients are near the end of their life was something that is not part of routine clinician education:

"Much, much more education needed here. There was none whatsoever in my medical degree, and so far as I know none now in most medical programs. There was also none in my Royal Australasian College of Physicians training." – *Clinician 85, HNELHD*

2. Need for improved communication

Communication was identified as an important area where better education and training may lead to improved outcomes. Better communication between clinicians and patients and their families was raised by multiple respondents as something that would improve the patient experience:

> "If conversations that were open and honest were occurring with patients and their carers and families in the weeks preceding the death, it would allow the dying process to be a much smoother transition and allow time to prepare emotionally, spiritually and psychologically. It needs to be explained in simple terms, not medical jargon. Death audits in this area indicate these conversations are being left too late or sometimes not happening. I believe every family deserves … a family conference with the senior treating doctor and relevant staff so they can voice any concerns and be validated." – *Clinician 33, HNELHD*

> "We don't do end of life care as well as we could. I struggle with doctors trying to encourage full intervention for 85-90+ year old patients who are not independent and have no rehabilitation prospects. I wish more doctors would talk to elderly patients AND their family members about what they want to achieve with their medical care" – *Clinician 35, HNELHD/HMRI*

> "Communication with patients and families earlier on in admission regarding their wishes." – *Clinician 88, HNELHD*

In addition, improving communication *between* clinicians was also identified as an important goal:

> "Collaboration between oncology medical and palliative care medical staff more closely to support and improve patient quality of life." – *Clinician 93, MNCLHD*

Under-use or poor use of advance care planning was identified by clinicians and managers across all LHDs as an important issue affecting patient outcomes. In many cases this was thought to be due to hesitancy among clinicians to have end of life discussions with their patients and families:

> "Medical teams seem to struggle with having a frank and open conversation regarding death and dying. They are afraid to suggest treatment is futile. Noticed more with junior doctors and registrars" – *Clinician 4, HNELHD*

"Specialties unwilling or not skilled to have end of life discussions with patients and their families" – *Clinician 10, MNCLHD*

"Poor knowledge about use and completion of advance care plans (ACP) and advance care directives (ACD) by front line staff, especially in the emergency department (who frequently ask "Is there an advance care directive?" before assessing the patient and have the perception that an ACD equates to no admission to hospital) and intensive care unit staff (who act upon the view that ACDs or resuscitation plans completed during crises are valid for the future)." – *Clinician 31, CCLHD*

"ACP uptake and completion rates are lower than desired. [Need to] improve clinical communication skills in critical care, intensive care and emergency department re: end of life discussions" – *Researcher 2, UNE*

"Lack of ACP by specialist teams and primary care resulting from lack of identification of patients that are at risk of dying within the next year. Palliative care are often reviewing people in the last weeks or days or hours of life, often in acute hospitals with no planning. A potential solution is education/training in ACP and ACP clinics that facilitate ACP for patients who have been identified as potentially in their last year of life." *Researcher/Clinician/Manager 3, HNELHD*

The importance of providing involving GPs and the need for early discussions with patients and their families was also noted:

"Bigger influence from GPs regarding ACP to enable end of life wishes be met before it's too late" – *Clinician 20, HNELHD*

"End of life discussions are not happening and advanced care directives are not being discussed with clients early enough. Families need to also be aware of the decisions that are being made." – *Manager 5, HNELHD*

"Lack of end of life care planning as standard practice, need to increase awareness for consumers to understand the importance of developing a plan. Some aversion to discussing this among consumers" – *Manager 4, HNELHD*

The absence of planning leads to poorer outcomes for patients:

"So often you see family members pushing patients to have more treatment when this may not offer the best quality of life." – *Clinician 95, MNCLHD*

3. Need for better co-ordination of care

Existing palliative care services were identified as disjointed and difficult to navigate for patients, with a need to attend a range of different services to receive holistic care:

> "Disjointed management between different service providers. For example as a consumer caring for someone with terminal cancer I had to attempt to linkup GP, oncologist, residential service, home care etc. as they were all different providers." – *Consumer 9, HNELHD/CCLHD/MNCLHD*

> "Greater overlap between acute medical services and palliative care, so that the 'crossover' does not seem such a gulf to patients, as well as greater access to palliative care in the community - even the best staffed services are largely nursing-based and therefore do not easily provide advice on analgesia etc." – *Clinician 85, HNELHD*

> "What palliative care services offer is very limited. Families would benefit from a holistic service instead of having multiple services try and meet their needs e.g. NGO for personal care, community nurse for wound care, palliative care for pain medication." – *Clinician 6, HNELHD*

4. Requests for more physical resources

Requests for increased numbers of dedicated staff were common, including many requests simply for 'more' specialist services, community palliative care services, outpatient clinics, and allied health services:

> "Specialist medical care for patients in hospital - currently being attended by locums, medical physicians" – *Clinician 90, MNCLHD*

> "Currently there is a lack of Medical Governance, Social Work and Occupational Therapy in the Community Palliative Care setting … I would like to see a universally recognized Palliative Care Plan/Card including Advanced Care Directives and death wishes that Community workers, Ambulance workers and inpatient setting including the emergency department recognizes." – *Manager 21, MNCLHD*

> "More resources for local palliative care- especially trained staff." – *Consumer 8, HNELHD*

> "Lack of Community Palliative Care Services. The services we have are excellent, but they are under-resourced and under-staffed" – *Clinician 89, MNCLHD*

"MNCLHD requires more social work and bereavement support" – *Clinician 93, MNCLHD*

"Clinical psychologist input and presence in the cancer centre" – *Clinician 106 MNCLHD*

"Rotation of palliative care trainees to MNCLHD" – *Clinician 106 MNCLHD*

Limited support for dying at home was also generally identified, with deficiencies noted in the availability of staffing and equipment:

"Need access to Palliative care specialist. Clinical nurse consultant service is also limited. Community health service works Monday to Friday, and is unable to support dying at home" – *Manager 15, HNELHD*

"Support for patients who wish to die at home. Adequate staffing for nursing care and medical advice at the end of life for symptom control." – *Researcher/Clinician 1, HNELHD*

"There is a lack of electric beds, alternating air mattresses, sling lifters and pressure care cushions… I have seen firsthand the impact that this lack of equipment has had on our ability to optimally meet the needs of clients requiring end of life care in the community. It has caused delayed discharge home, and undue stress to family and clients, and sub-standard care of clients in the home (e.g. sleeping, bed bath, pad change and catheter care all on a three seater lounge as no electric bed available). Currently, clients are required to arrange someone (family or friends) to collect one of the few electric beds and alternating air mattresses from palliative care community nursing. These require a ute at smallest for collection and there is a large manual handling risk to the family/friend collecting the equipment." – *Clinician 80, HNELHD*

"Access to services (particularly afterhours/nights and weekends) in rural areas. Limited clinicians trained in palliative care. Huge areas to cover (geographically). Limited choices for patients/clients who wish to die at home - no syringe driver changes on weekends for example - very limiting. Carer support lacking." – *Clinician 86, HNELHD*

"Dying in hospital is the one thing that few of us wish to do. While the local hospital staff are wonderful, it is impersonal. The ability to die at home would be lovely, but often this is not possible." – *Manager 24, HNELHD*

Specific needs by location; in the case of **Hunter New England (HNE) LHD** there were some very specific requests for improved services at the John Hunter Hospital (JHH):

> "Social work service, knowledge of anticipatory grief and counselling skills are under-utilised in JHH" – *Clinician 44, HNELHD*

> "Need to develop palliative and end of life care at John Hunter Hospital, especially models of care for chronic disease as opposed to oncology, e.g. heart failure, COPD, etc." – *Researcher/Clinician 2, HNELHD/HMRI*

> "A lack of proper rooming in facilities for family in acute care wards in JHH. Uncomfortable for families who are staying. Single rooms are really small and crowded. Family have to leave the room to eat and shower. Nowhere for anyone to sleep over. Lack of privacy for relatives. Need to look at the paediatric palliative care rooms and copy them. Have at least one on each ward for dying patients and their families to stay in." – *Clinician 26, HNELHD*

There were concerns that funding was not distributed evenly across the HNE LHD:

> "The major unmet need in Newcastle is getting the funding out of the Mater to service the rest of the District. Mater palliative care patients when sick are encouraged by Mater staff to get admitted under general medicine at Belmont and JHH where there is not the support. The general physicians do an excellent job but think if we are going to fund palliative care in the District it needs to service the whole District." – *Researcher/Consumer/Clinician/Manager 1, HNELHD/UON/HMRI/government*

HNE respondents also felt that services were centralised in the Newcastle area, and that more distant areas of the LHD are under-serviced:

> "Clients who live in the Westlakes area (South of the Fennel Bay bridge) are serviced by Westlakes Palliative Care Service. This service does not have a dedicated equipment pool. They are able to access limited equipment from Hunter Equipment Service but do not have the same equipment available as the Mater outreach team." – *Clinician 18, HNELHD*

> "There are significant barriers for end of life care equipment for clients in Maitland/ Cessnock/ Kurri areas. We can't get access to beds, hoists, power lift chairs, and every agency tries to state that it's not their responsibility. There is limited allied health support for palliative care in Lower Hunter- it has to come from other teams where the specialist training in pall care is not provided." – *Clinician/Manager 1, HNELHD*

"A hospice or palliative care ward at The Maitland Hospital plus extra funding for Social Work to make this a fulltime position within the Maitland/Dungog/Cessnock areas." – *Manager 8, HNELHD*

"Manning Rural Referral Hospital requires special training of all critical care, ED and ward staff in appropriate pain management. Additionally, staff working in critical areas should have access to the Pain Medication Protocol used widely from Port Macquarie through the north coast health districts... I have seen too many avoidable patients suffering pain." – *Clinician 81, HNELHD*

It was similarly suggested by **Mid North Coast LHD** respondents that some of their more rural areas were under-resourced:

"Specialist palliative care medical team in Kempsey district hospital, surrounding Residential Aged Care Facilities and community." – *Clinician 70, MNCLHD*

"Increasing palliative care activity for Kempsey area - needs are increasing, staff and services are not" – *Clinician 90, MNCLHD*

"Inadequate services to assist in the care of a person at home at end of life. The process to obtain services is long, arduous and often unsuccessful. There is a lack of local facilities to care for a person at the end of their life if they cannot be managed at home" – *Clinician 53, MNCLHD*

The limited availability of services on weekends was identified:

"In hospital have CNS (Clinical Nurse Specialist) palliative care Monday to Friday (40 hours per week), patients are often delayed from receiving timely care and conversation after hours and on weekends" – *Clinician 90, MNCLHD*

In the **Central Coast LHD**, the lack of a hospice facility was noted by several managers:

"Hospice required for the Central Coast- a place with inpatient beds, education, training and support for family carers and a wellness centre for patients, families and carers." – *Manager 9, CCLHD*

"On the Central Coast there are no options, other than an acute hospital bed, for people that don't want to die at home or in a nursing home. While Palliative Care support does exist in the community it is often not

comprehensive enough to provide the full scope of support needed in the last days of life…" – *Manager 10, CCLHD/HNECC PHN*

5. Specific needs by patient group

Finally, some of the needs identified related to specific patient groups. A large proportion of these comments related to **residential aged care facilities** (RACFs), and the need for increased end of life care in these facilities, particularly from respondents in the Mid North Coast region:

> "End of life (EOL) care in RACFs could be improved by facilities having specialist palliative care nurse practitioner position. The nurse practitioner could cover several RACFs and would improve medication and symptom management for the EOL period." – *Manager 26, MNCLHD*

> "Aged Care is a huge area of need. The Palliative Provision in many of our aged care facilities is sub-standard at best. We need a permanent presence within these facilities to oversee the care and construct care plans, facilitate family discussions etc." – *Clinician 62, MNCLHD*

> "The inability to provide EOL care for people requesting to die in hospital when their timeframe is difficult to prognose - they are forced to accept and seek residential care where their increasing needs are difficult to meet, medical and specialist nursing assessment and care is minimal, [this] increases distress and anxiety and takes time away from their loved ones" – *Clinician 90, MNCLHD*

In addition, the provision of community services for **younger patients** nearing the end of life were recognised at being limited:

> Home help for patients under 65 who wish to stay at home to die and need support services to do so" – *Clinician 41, HNELHD*

Services for different **cultural and disadvantaged groups** were identified as an area of need:

> "Better engagement and/or education for culturally and linguistically diverse/non-English speaking background CALD/NESB community groups to address end of life care options" – *Clinician 13, HNELHD*

> "Aboriginal Torres Strait Islander Palliative Care services" – *Researcher/Clinician 4, HNELHD/UON*

"Ensuring excellent care for all patients at the end of life in the location of choice - particularly in rural and remote areas, for indigenous patients and for patients in disadvantaged groups including the homeless, mentally ill and incarcerated." – *Clinician 87, HNELHD*

Finally, improved services were requested for patients with specific diagnoses:

"End of Life Care and Palliative Care for people with dementia" – *Manager 29, HNELHD*

"Palliative care services are often not able to take end stage respiratory disease and end stage heart failure clients" – *Clinician 76, CCLHD*
"Development of a supportive care model to provide care to patients with liver failure and liver cancer" – *Clinician 16, HNELHD*

Palliative Care in the antenatal period (for prenatally diagnosed life threatening conditions) and for families of babies that are stillborn or die in the first hour or so after birth." – *Clinician 87, HNELHD*

6. Areas proposed for research

Many respondents proposed service improvements or training rather than research. There was also felt to be a need to undertake a substantial amount of scoping research to better understand patient, family and carer experience and also the function of current services. Some research and projects already underway were nominated.

Idea	Suggested by
Local scoping/exploratory research	
• Identifying culturally appropriate measures for our multicultural community	Titus Alias (HNELHD)
• Patient and carer preferences for services and how they are accessed.	
• Data review of Kempsey palliative care presentations, admissions, ward transfer of care and patient, family and carer needs and wishes met and unmet	Joanne Pierce (MNCLHD)
• Looking at care needs of COPD and heart failure clients at end of life.	Gail Eadie (CCLHD)
• An interview study of a sample of older persons, using a fairly unstructured process to explore their concerns then structured interviews based on the findings followed by an intervention project targeted at evaluating interventions arising from the interview results.	Chris Sharpley (UNE)
• Quantifying the issue of end of life care for disadvantaged groups	Sharon Ryan (HNELHD)

• Role of general practice/primary care in rural palliative care	David Perkins (UON)
• What are the bereavement needs of families who live in regional and rural NSW, who have experienced the death of a child?	Sharon Ryan (HNELHD)
• Why are medical professionals reluctant to refer to palliative care early in disease trajectory?	Sally Laurie (HNELHD)
• Evaluation of existing collaboration between John Hunter Children's Hospital Paediatric Palliative Care Service and the Maternal Foetal Medicine clinic at John Hunter Hospital	Sharon Ryan (HNELHD)
• Survey into community needs re hospice, expansion of pall care services in our area	Jo Smith (MNCLHD)
• Is there a satisfaction difference between families who access bereavement support via the telephone/telehealth compared to those families who access the support face to face?	
• Evaluating all health palliative care services and resourcing them equally	
• Patients' experiences and acceptability of non-government organisations partnering with health to deliver palliative care services	
• Review families' experiences of organ donation	
• Identify patients at end of life having futile medical interventions	
• Needs analysis	
Training, education, awareness	
• Disseminate information/education on recognition of the patient whom is near the end of life to medical providers	Fiona Day (HNELHD)
• Upskill the specialist workforce to deliver and support uncomplicated end of life care. Innovative ways of incorporating Allied Health support in End of Life, particularly at home. Upskill specialists/craft groups in how to have difficult conversations regarding treatment choices at end of life.	Rachel Sheather-Reid (HNELHD)
• Wellbeing program for rural nursing home/health staff.	
• Work with Primary Health Care Networks and provide specialist training, support and supervision by appropriate staff from Health districts working in an integrated fashion.	David Perkins (UON)
• Nurse Practitioner led models working in partnership with RACFs	Teresa Howarth (MNCLHD)
• 1. Palliative care multidisciplinary team (MDT) with oncology attendance. 2. Palliative care MDT meeting. 3. Palliative care physician recruitment OR palliative care rotation for advanced trainee.	Renee Duvenage (MNCLHD)
• Normalising ACP among the people with chronic diseases in acute and community settings.	Se Ok Ohr (HNELHD)
• Training community nurses/community workers to be ACP facilitators and make ACP discussions their routine tasks.	Se Ok Ohr (HNELHD)
• Use of service rounding at RACFs to assist staff identify imminently dying residents and activate resources and supports to ensure comprehensive care	Sharon Ryan (HNELHD)
• Advance care planning. It is important to get family members and other carers on the same page	Constance Dimity Pond (UON)
• Advance Care Plan facilitators in primary care	
Interventional research	

• A project based on UK research (Sara Booth/ Cambridge Breathlessness Intervention Service), which is being replicated by an OT/Physio/SW at David Berry Hospital (small rural palliative care unit in Southern NSW) with good results. It would be good to trial with a range of ages (paediatrics to elderly) and could utilise telehealth to support in-home education +/- upskill of local therapists.	Madelon Scully (HNELHD)
• Telehealth for palliative care patients whilst at home: measuring patient outcomes, effectiveness and acceptability. MNCLHD pilot to start soon.	Daniel Curley (MNCLHD)
• Trialling packages for supporting dying at home.	Angie Newton (HNELHD)
• Trialling 7 day a week service across Tablelands Sector (support, clinical expertise, access to syringe drivers, etc.)	Angie Newton (HNELHD)
• Evaluation of a renal supportive care type model in selected patient groups (e.g. end stage liver disease)	Sharon Ryan (HNELHD)
• Expand previously trialled model for psycho-oncology clinical supervision via telehealth	Sharon Ryan (HNELHD)
• Non-Pharmacological Strategies for Breathlessness: An Allied Health Model'. It could include anyone who identifies with a symptom of breathlessness. Interventions include facial cooling, energy conservation, breathing techniques, light exercise, positioning education, anxiety/stress reduction techniques	Sharon Ryan (HNELHD)
• The PAUSE (Plan Assess Understand Survival after Stroke) project could readily be scaled to other conditions beyond stroke	Di Marsden (HNELHD)
• Develop and validate a liver condition specific Integrated Palliative care Outcomes Scale (IPOS) tool. Develop an electronic version of the tool which could be completed at home or in the clinic wait room prior to clinic review to enable clinicians, allied health services such as social work, dieticians, +/- Palliative care +/- Drug and Alcohol services to deliver informed patient care targeted to the individual (and family member needs)	Suresh Sharma (HNELHD)

• Formal carcinoma-unknown-primary services have been established in very high-volume centres but an area-wide resource may be able to address this problem in Australia; a Suspected Malignancy: Advice, Recognition and Triage resource. A SMART system to assist and advise people with suspected cancer and Health Care Professionals (HCPs) caring for people in whom they suspect systemic malignancy might have two systems; one to enable HCPs to follow a diagnostic pathway, and a complementary system to engage, enable and empower patients to self-triage and escalate care and access further services. An example might include:
  • HCP System: 1. When a clinical presentation that prompts an USS or CXR finds evidence of suspected metastatic cancer, the radiology service might flag the existence of a SMART pathway to the HCP who ordered the imaging test; this would also enable radiology to offer an expedited biopsy; histology (+/- flow cytometry) is requested and reported 2. Existing HealthPathways website will be used. 3. Accurate referral expedited to the appropriate medical or radiation oncology or haematology service.
  • Patient system: A smart device viewable webapp that helps patients 'self-triage' based on their symptoms, functional ability and dynamic changes thereof. Based on the CMN CANcierge project due to launch February 2019. Management of systemic cancer would be enabled.
	Craig Gedye (HNELHD)

• Efficacy of normalisation of Advance Care Planning (ACP) for people with chronic diseases in acute and community settings. The preliminary outcomes suggest that; 1. The intervention proposed in this project have addressed those challenges in each step from the perspectives of patients, families and health care professionals. 2. ACP process is normalised in admission process which can be transferred and scaled to any wards, sites or settings including rural/regional areas. 3. The tested model can be transferred and scaled in non-government home care providers. 4. Proposed RN ACP facilitators (RN level 3) are not a privileged or specialised personnel (e.g. CNC, medical specialist) but should be available at other wards, sites and settings and should be cost effective. 5. The training package is comprehensive and accessible at any wards, sites and settings across NSW.	Sarah Jeong (UON)
• The flagship project in the UK is called Integrate My Care based at the Royal Marsden in London. In Newcastle we have a project called MyNetCare, which is a more patient focused web-based tool for recording interventions and preferences. Todd Tobin at the Calvary Mater Newcastle leads this project. Ambulance callouts have fallen by 55% in the patients enrolled in this programme.	Peter Saul (HNELHD)
• Renal supportive care model – ACI. Current work not completed but will help in future (one year).	
Resource utilisation focus/dying at home	
• Health economic analysis of palliative care services - community, hospice, private, nil	James Lynam (HNELHD)
• Resource utilisation study comparing dying at home to dying in hospital.	Nick Zdenkowski (UON)
• A project around caring at home for people in rural/remote areas	Sally Laurie (HNELHD)
Other research	
• Community wellbeing collaborative research	David Perkins (UON)
• Therapeutic drug monitoring	James Lynam (HNELHD)
• Develop an Aboriginal Centred Palliative Care blueprint to guide mainstream service integration, delivery and evaluation in the Hunter New England Local Health District.	Tony O'Brien (UON)
• Drug stability and compatibility studies. Talks between Hospice pharmacy and Professor Jennifer Schneider at University Newcastle are underway.	
• Alerts and linkage in Electronic Medical Record re: ACP	
• Research better methods for direct communication with GPs e.g. apps.	

7. Responder Cautions

Some respondents' experiences had made them wary about project work in this area:

> "There have been a number of initiatives but once the project finishes the ability to deliver the support … Sustainability needs to be the focus rather than repeated projects that come and go." – *Manager 30, MNCLHD*

It was noted that promotion of ACDs had been a project in the MNCLHD but the funding was not continued. Survey of medical records demonstrated a low rate of ACD in the records of palliative, aged or chronic care clients.

Again, from the MNCLHD the difficulties experienced with trying to sustainably improved end of life care in Residential Aged Care Facilities (RACFs) were noted:

> "There have been numerous projects around palliative care in RACFs in this area over the last 20 years. However, when the project is completed or funding withdrawn the level of interaction between the RACF and the palliative care team reduces. This is in part due to the inability of the palliative care service to meet the demand of the RACFs and also due to staff turnover in RACFs [which means] … the education and skills they acquired during the project are lost. It may also reflect the lack of attention to both the scalability and sustainability of these projects in the initial planning/ implementation phases. These issues should form a cornerstone of subsequent project submissions." – *Manager 31, MNCLHD.*

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