ACKNOWLEDGEMENTS

Firstly we express sincere thanks to the large number of people involved in consultations for this project who gave willingly of their time, experience and stories so that this report can truly reflect current issues and respond by developing actions for change. In particular we thank the patients, carers and families; specialist palliative care providers; other medical specialists; primary care providers including general practitioners, as well as the range of key stakeholder organisations.

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FOREWORD

The NSW Government is committed to improving the care available to the people of NSW as they approach and reach the end of life. This Diagnostic Report is the next step in the process of building a patient-centred model for palliative and end of life care service provision in NSW. It aims to define the problems associated with the provision of such care and to better understand the root causes of those problems with a view to developing longer-term, evidence-based solutions.

The scope of these problems is broad ranging with multiple, complex and inter-related dimensions. There are no quick fixes or easy solutions to this socially complex and sensitive topic. Approaches to better understanding these problems therefore need to be incremental, collaborative and work across jurisdictions. For these reasons, palliative and end of life care can be referred to as a ‘wicked problem,’ one which goes “beyond the capacity of any one organisation to understand and respond to … and which requires innovative and comprehensive solutions that can be modified in light of experience and on-the-ground feedback.”

The development of solutions will take a staged approach, uncovering what we need to know now in order to gain a better understanding of what we need to plan for in the near future. It is a participatory process, drawing on the experience of patients, carers and family members as well as the views and experiences of specialist palliative care providers, primary care providers, other stakeholders and the growing field of evidence.

In short, this is an improvement journey that will take a sequenced approach, learning as we go, and travelling towards an end point that sees all NSW residents having access to quality care, based on assessed need as they approach and reach the end of life.
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EXECUTIVE SUMMARY

The Diagnostic Report identifies a range of issues that need to be considered in order to develop a flexible, patient-focused and evidence-based model for providing palliative and end of life care services. The model of care broadly defines the way health services are delivered.

This Report builds on the Framework for the Statewide Model for Palliative and End of Life Care Service Provision (ACI: 2013) which describes the network of services to support people approaching and reaching the end of life; minimum expected levels of accessibility of these services; and established safety and quality standards. The Framework is the “brace and girders” that support the model (Davidson et al, 2006).

The Framework also sets out the vision for the Model of Care (MoC): to ensure that all NSW residents have access to quality care based on assessed need as they approach and reach the end of their life.

This improvement journey is a challenging one and is conceptualised here as a ‘wicked problem,’ one that is socially complex and multi-factorial with solutions that have many inter-dependencies. For this reason, our journey is a staged, participatory and incremental one.

Information we gathered

The Health Economics and Analysis Team at the ACI and the Centre for Epidemiology and Evidence at the NSW Ministry of Health undertook a Fact of Death Analysis which focusses on the utilisation of inpatient services by people who died in 2011–2012 and were hospitalised in their last year of life. This research helps us to better understand the demand for care to people as they approach and reach the end of life. The highlights of the Fact of Death Analysis and the results of our consultations with primary care, specialist palliative care and residential aged care sectors are contained in Section 3. What did we discover?

Section 2. What do we know? includes key learnings from other sources:

• NSW Government Plan to increase access to palliative care 2012–2016;
• Clinical Excellence Commission’s 2013 Care for the Dying in NSW report;
• The Australian Commission on Safety and Quality in Health Care’s 2013 Safety and Quality of End-of-life Care in Acute Hospitals;
• NSW Ministry of Health’s Advance Care Planning for Quality Care at End of Life: Action Plan 2013–2018; and
• Australian Institute of Health and Welfare’s Palliative Care Services in Australia 2013 report.
Our sources

Understanding a diagnostic evaluation is a complex task which involves collaboration across NSW communities and with inter-sectoral service providers that collectively have the capacity to improve the patient journey.

This Report summarises the results of a comprehensive evidence gathering process. Since the publication of the Framework, the ACI, under the leadership of the ACI Palliative Care Network Executive has consulted over 1,200 stakeholders, including:

- Patients, families, carers and volunteers;
- Primary care providers including general practitioners, residential aged care facility staff, community nurses, medical specialists, hospital staff, Aboriginal health workers;
- Non-government and community agencies;
- Specialist palliative care providers;
- End of life governance committees in Local Health Districts;
- Planners, managers, researchers.

What we learned

The findings of the diagnostic process have been synthesized into a number of key learnings that have been drawn from all consultation sources. They are broadly grouped into twelve key learnings that describe:

1. People’s needs change

The needs of the patient, family and carer during their end of life journey vary over time and care setting. Services need to be responsive, coordinated and flexible in meeting these changing needs.

2. Geography matters

People living in rural and remote areas experience additional barriers to receiving quality care at the end of life and rely on local, innovative strategies to help overcome these.

3. There are gaps in the reach of specialist palliative care services

Gaps in specialist palliative care services inhibit the reach of care to people with complex needs as well as limiting the support available to primary care providers.

4. Many people fall through the gaps

Care to people approaching and reaching the end of life is often fragmented and under-utilised by identified population groups or clinical cohorts. These include but are not limited to:

- Aboriginal people;
- People under the age of 65;
- People who live alone;
- People of culturally and linguistically diverse backgrounds;
- People with non-cancer diagnoses;
- People living with Dementia.

5. Not every patient journey is the same

Current patient journeys are often poorly coordinated. This is particularly true for people with advanced chronic disease who have multiple comorbidities and a much slower and more unpredictable trajectory of functional decline.

6. Hospitals are the ‘default’ carers for many people

People in their last year of life make intense use of admitted acute hospital services including unplanned emergency admissions. Lack of advance care planning for admitted patients inhibits timely and coordinated care for people approaching and reaching the end of life.
7. There is unwarranted variation in clinical care
There are numerous factors that impact on reported unwarranted variation in clinical care. These include a lack of agreed and standardised clinical assessment tools and referral practices; insufficient resourcing, capability and workforce.

8. People want care to be provided as close to home as possible
Although most patients prefer to be cared for as close to home as possible, services required to provide such care are limited and often inflexible.

9. General practitioners and residential aged care providers experience a unique range of structural barriers that limit their capacity to provide palliative and end of life care
A range of structural barriers were identified that reduce the capacity of primary care providers (including GPs) and residential aged care facilities to provide optimal care to people approaching and reaching the end of life. For GPs these include an escalating demand to provide increasingly complex and at times, time consuming care. For residential aged care facilities these include inadequate staffing ratios, limited access to specialist palliative care expertise, limited access to GPs with skills and knowledge in providing PEoLC, limited access to a range of allied health services and inadequate training and other workforce development opportunities.

10. Community denial and discomfort of death and dying can block access to appropriate care at the end of life
Patients, families and some health providers are often reluctant to agree to referral to specialist palliative care services or to initiate end of life discussions. The stigma associated with death and dying along with often unrealistic expectations of modern medicine can make preparing for death less likely and this mitigates against a healthy approach to death and a peaceful death in many cases.

11. Language can be confusing
Palliative care means different things to different people. This range of definitions and conceptual understandings inhibit the ability develop an integrated approach to care – one that crosses jurisdictions.

12. Leadership and collaboration is needed
For significant improvements to be made, strong leadership and collaborative action across jurisdictions including public, private, community sectors and individuals needs to occur.

Illustrating our findings using Lynn’s trajectories of functional decline
A key component of this diagnostic work has been to focus on the journeys and care needs of people approaching and reaching the end of life, their families and carers. Using the well-established Trajectories of Functional Decline developed by Joanne Lynn and David Adamson (Lynn and Adamson, 2003)\(^2\), quotes from our consultations have been plotted along the three common trajectories of cancer, organ failure and poor function with long-term functional decline (associated commonly with dementia and frailty).

These figures (Figures 1–4) aim to put into context the various perspectives of those interviewed as well as the diverse and changing care needs of people as they approach and reach the end of life, over time. The figures also help to demonstrate the need for different forms of care coordination required at different points in time.
Figures 1-4: Trajectories of functional decline at End of Life
(adapted from Lynn J and Adamson D 2003.)

Trajectory 1: Rapid decline over a few weeks or months before death; mostly cancer

“Dad was diagnosed in April. For 12 months he was okay but then he deteriorated. The pain got to Dad in the end.”

“Seeing someone earlier on helps prevent crisis calls later on – ensuring home is suitable to manage.”
(Palliative Care Specialist)

“Very few GPs would do any home visits and that that had a huge impact on what we can achieve.”
(Rural Specialist Palliative Care Nurse)

“The community nurses came. We had a lot of medication for each possible thing. The home care during this time was very good.”
(Family Member)

“There’s a lack of 24-hour care in the community to allow people to die at home. Services tend to operate 8am-5pm Monday to Friday.”
(Rural Community Nurse)

“In the last week they put the catheter in so I could administer his medications. They wrote down all the details and I added notes to help me. It was very important they could lay that out for me – because when you’re in shock you’re going on raw feelings.”
(Carer)
Trajectory 2: Organ failure due primarily to chronic illness

"We’re not always in the loop when shared care is with other medical specialists and GPs, so communication is a big problem." (Rural Palliative Care Specialist)

"Patients with chronic heart failure and respiratory disease miss out. It’s hard to know when to change to a palliative approach. They fall through the cracks because we don’t know whether they’re going to live for 3 days or 3 years." (Rural Discharge Planner)

"Discharge planning is so important. It should start when people walk through the door of the hospital." (Metro Palliative Care Specialist)

"Don’t know if referrals have changed, but patients are sicker, referred later and more complex." (Rural Palliative Care Specialist)

"Our acute hospitals need to become more dying friendly. Many hospital clinicians do not know what they do not know about safe, high quality end of life care." (Metro Specialist Palliative Care Nurse)

"Bereavement counselling closes the loop for family members." (Intensivist)

Trajectory 3: Poor function with long-term slow decline; mostly dementia and frailty

"It starts the day they come in. Firstly, opening up the conversation even though it’s a difficult time. The conversation has to start straight away. We talk about their life, their stories, their history... which are then coordinated into our care plans." (Rural RACF)

"People with Motor Neurone Disease don’t spend a lot of time in hospital. The need is in the community. That’s where the emphasis of need is." (MND Stakeholder)

"There are delays because services are often siloed in the community – they work well within their teams but not often across their silos." (Rural Community Nurse)

“People entering Residential Aged Care Facilities have increasingly complex and acute care needs".

"A practical difficulty is being able to provide palliative care medications in some of the facility settings." (Genecitian)

"They got me the bed, walker, shower stool and oxygen – things I wouldn’t have been able to arrange myself. Without the specialist palliative care service I don’t know how you’d get all this." (Patient at home)

“We couldn’t leave Mum in the room. She had to be moved right away – before the other residents awake. I would have liked to have some time with her right after she died.” (Family member of an RACF resident)
Next stage

This Diagnostic phase has identified key challenges in the provision of care to people approaching and reaching the end of life. By identifying and refining the ways in which we describe these – in light of the breadth of evidence gathered – the Model of Care development process then looks towards describing the ways in which end of life journeys can be improved. The findings of this Diagnostic Report provide ACI with the basis on which to develop solutions and a Model of Care that directly address the core problems that have been identified.
THE MISSING PIECE – COMMUNICATION

It was bad enough that Gary was feeling the pain of only just understanding that his beloved wife was imminently dying. His pain was further exacerbated by learning too late that his best intentions in providing care only created more discomfort and conflict for the love of his life.

I witness this scenario every week. Perhaps I should be used to it, but despite my 33 years of working in end of life care and education, it still pains me to hear the familiar lament. “If I had only known.” In these situations, no one alerts the patient and family to the signs that death was approaching. No one tells them that it was time to replace a push for treatment with a push for comfort care. No one explains the natural course of the disease and the dying process. No one tells them how to respond to the expected changes to assure comfort and obtain closure.

When facing the end of life, we are naturally scared. Our problem is that too many of our decisions are based on this fear, or on lack of information or misinformation, which often results in devastating physical, emotional and financial consequences for the patient and family alike.

We can and must do a better job.

Tani Bahti, RN, CT CHPN

VISION

To ensure that all NSW residents have access to quality care based on assessed need as they approach and reach the end of life.
KEY DEFINITIONAL CONCEPTS

Language and terminology around palliative care has evolved and is still evolving as systems of care mature and engage a wider group of people with an interest in improving care for people who are either approaching or reaching the end of life, or experiencing distress associated with a life-limiting illness. We understand that there are considerable differences in the way that these terms are used and that many of the currently used terms have different meanings for different people. Terms that are useful for one purpose may not be well understood in a different context. To ensure that readers are clear on the meaning of these terms as they are used in this report the following definitions are provided:

End of life
The term ‘end of life’ refers to the period of time when a person is living with an advanced, progressive, life-limiting illness. Estimating when someone will die is very difficult. It is more useful to identify those for whom increasing disability and illness will lead to their death sometime in the next year.

End of life care
The term ‘end of life care’ describes care provided to people approaching the end of life by all health professionals, regardless of where they work in the health and aged care systems. End of life care is an integral component of aged care services, medical and surgical care, management of chronic and complex illness, intensive care, accident and emergency care and paediatrics amongst others. All health professionals should be competent to provide care to people who are approaching the end of their life or dying.

Palliative care
The term ‘palliative care’ describes designated specialist services provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with people approaching the end of life.
THE NSW AGENCY FOR CLINICAL INNOVATION (ACI)

The Agency for Clinical Innovation (ACI) is the lead agency in NSW for promoting innovation, engaging clinicians and designing and implementing new models of care. The ACI’s clinical networks provide a framework for clinicians and consumers to meet across regional and service boundaries with a mandate to drive improvements in care through innovation in clinical practice.

ACI clinical networks engage clinicians and community members to design and support implementation of models of care which spread best practice across the NSW health system and meet the needs of patients, their carers and families. The networks work across metropolitan and rural NSW in partnership with local health districts, specialty networks, researchers and non-government organisations to identify innovations that improve health services. The networks also provide expert advice to the NSW Government and Ministry of Health to improve patient care, address inequities in access and reduce avoidable hospital admissions.

ACI Palliative Care Network

The ACI Palliative Care Network draws together the expertise of specialist and primary care clinicians, service managers, consumers and researchers across all care settings where people may receive care as they approach the end of their life. Its purpose is to drive continuous improvement in palliative and end of life care for all people approaching and reaching the end of their life in NSW, their families and carers. Supported by the ACI, this Diagnostic Report and the upcoming Model of Care is led by the ACI Palliative Care Network Executive and significantly informed by Network members.

The Network was established in 2012 and by February 2014 had almost 400 members. The ACI is the lead agency for promoting innovation, engaging clinicians and designing and implementing new models of care. It works closely with the Ministry of Health, Bureau of Health Information, Clinical Excellence Commission, Health Education and Training Institute, NSW Kids and Families and the Cancer Institute NSW.
1. CONTEXT

1.1. A holistic approach to a ‘wicked’ problem

The challenge of developing systems to make sure that ‘all people have equitable access to quality care, based on their assessed needs as they approach and reach the end of life’ is complex. It could be described as a ‘wicked’ problem, or in other words:

- The problem is socially complex with no clear solution.
- It involves multiple factors and many interdependencies.
- There are differing perspectives on the nature of the underlying issues and problems.
- Simplistic solutions can have unforeseen and disappointing consequences.
- The problem does not sit conveniently within the responsibility of any one organisation.

There are no quick fixes for ‘wicked’ problems. The Agency for Clinical Innovation (ACI) recognises the benefits of collaboration and the need to engage with many dispersed stakeholders to gain a broader perspective on the inter-related issues that impact on the patient journey. Taking a systemic, multifactorial and staged approach will be pivotal to developing a model of care. In many cases it will be in “the interactions between a multiplicity of factors and processes (rather than the factors and processes themselves) that the answer is to be found.”

1.2. Our approach to the diagnostic

Methodology

A multi-method approach was taken comprising the following 5 streams of enquiry:

1. A ‘Fact of death’ analysis conducted by the Health Economics and Analysis Team at the ACI
2. Commissioned consultations with a range of primary care and residential aged care facilities including general practitioners across NSW (n=489)
3. ACI state-wide consultations with specialist palliative care providers, primary care providers, patients, families, carers and other key stakeholders (n=583)
4. Consultations with rural chronic disease and specialist palliative care clinicians at the Dying to Know: Integrating Palliative Approaches to Chronic and Life Limiting Illness conference in Dubbo, September 2013. Consultations occurred using the Automated Response System allowing for real-time, anonymous responses to multiple choice questions. (n=137)
5. The Annual Palliative Care Network Forum in November 2013 aimed in part to verify the research (Fact of Death Analysis) and key themes arising from the range of consultations that occurred. (n=123)

Consultations were undertaken on both a one-to-one and group basis. Interview questions can be found at Appendix 3.

The findings of these distinct investigations have been distilled into an integrated set of key learnings. In doing so, the Diagnostic Report identifies the ‘root causes’ of the limitations and challenges in the current service system so that strategies can be tailored to effectively address the core issues.

This will inform the development of a Model of Care (MoC) that broadly defines the essential characteristics of care, services and best practice approaches. The intention is to provide the right care, at the right time, by the right team and in the right place.
The diagnostic phase has identified and prioritised the issues that require attention in the MoC. It is a key stage in the ACI process for developing a MoC, as illustrated in Figure 5. This has been done by:

1. Drawing on the recent work of expert sources that highlight the challenges and enablers of quality care
2. Distilling the themes that emerged from ACI’s extensive consultations with service providers and carers
3. Analysing the findings of the Fact of Death Analysis: Analysis of admitted patients in the NSW Public Hospital system.

1.3. Our partners

These key partners have broadened our perspective on the patient’s journey, and understanding of what needs to change:

- Patients, their families and carers
- Primary care providers, including general practitioners, nurses, allied health professionals, community workers and staff in residential aged care
- Other medical specialists who provide end of life care, but whose substantive work is not in palliative care, including oncologists, geriatricians, staff in intensive care and emergency departments
- Palliative care service providers who provide care for patients with complex or unstable symptoms or meet other high level needs associated with end of life care. Care may be episodic or part of ongoing partnerships with primary care providers including other medical specialists.
- Networked palliative care service providers who have the capacity to provide coordinated or sustained palliative and end of life care. This includes formalised partnerships, consultative arrangements and pop-up models, particularly for those living in rural or regional areas.
1.4. Core principles

The patient-centred approach

The Diagnostic Report builds on The Framework for the Statewide Model for Palliative and End of Life Care Service Provision, 2012 (‘The Framework’) which sets out the principles, service definitions, priority action areas and structural arrangements that are needed to achieve the vision for PEoLC.

The Framework is built on the patient centred approach and reflects a set of core principles:

<table>
<thead>
<tr>
<th>Principle</th>
<th>What it means</th>
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<tbody>
<tr>
<td>1. Patient and family centred care</td>
<td>Care is delivered in accordance with the wishes of the patient and family.</td>
</tr>
<tr>
<td>2. Population and needs based care</td>
<td>Services are planned, based on population distribution. Disparities in health status between different population groups and clinical cohorts are addressed. Networked care is provided on the basis of assessed patient and carer needs.</td>
</tr>
<tr>
<td>3. Care as close to home as possible</td>
<td>All people approaching the end of their life in NSW should be able to access care as close to their home as possible.</td>
</tr>
<tr>
<td>4. Accessible</td>
<td>People approaching the end of their life have access to local primary care, needs based access to level one specialist palliative care services and networked access to Level 2 or 3 services based on assessed need.</td>
</tr>
<tr>
<td>5. Equitable</td>
<td>Needs based care is accessible, regardless of age, diagnosis, geography or culture.</td>
</tr>
<tr>
<td>6. Integrated</td>
<td>Primary services, specialist acute services and specialist palliative care services are integrated to enable seamless patient transfer based on needs assessment and clear referral and access protocols.</td>
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</table>
| 7. Safe and effective | Care meets the Australian Safety and Quality Goals for Health Care:  
  - people receive health care without experiencing preventable harm;  
  - people receive appropriate evidence-based care;  
  - there are effective partnerships between consumers and healthcare providers and organisations at all levels of healthcare provision, planning and evaluation. |
A networked approach to services

People have many different needs during the course of an end of life journey. They frequently need a network of personal, practical and health-related supports and services. The Framework describes the strong links needed among specialist palliative care providers and primary care providers including support care and the community. Their key responsibilities are outlined and describe how services are coordinated to respond to the needs of the individual and their families/carers. Drawing from the Palliative Care Australia (2005) population based approach to service development, the figure illustrates how services respond to the hierarchy of patient, primary carer and family needs and attempts to align services to most appropriately, effectively and efficiently meet those needs. (ref PCA 2005) (Figure 6)

Figure 6: A networked approach for the care of people approaching and reaching the end of life in NSW

Source: Adapted from the Framework for Palliative Care Service Planning (PCA, 2005).
2. WHAT DO WE ALREADY KNOW?

The stakeholder consultations, the data analysis and the review of the work of others have generated some consistent findings about the causes of current difficulties that people experience in accessing quality support and care as they approach and reach the end of their lives.

2.1. Social and economic context

The significance of social and economic changes cannot be over-estimated in the development of the Model of Care. An effective, equitable and sustainable model for PEoLC services will need to take these realities into account:

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<tr>
<td><strong>1. Escalating demand</strong></td>
<td>The total number of deaths each year is expected to more than double in NSW by 2058. As the population ages, more people will require social, aged and health services and supports. As people live longer, their care needs will be increasingly complex.</td>
</tr>
<tr>
<td><strong>2. Economic context</strong></td>
<td>Health expenditure is expected to increase 7-fold by 2049-50, and by 12-fold for people aged over 85. At the same time, there will be fewer people in the workforce available and a proportionally lower tax base to fund and support increasing demand.</td>
</tr>
<tr>
<td><strong>3. Concurrent pressures on health, aged and social care systems</strong></td>
<td>More people will end their lives in residential aged care in the future. People enter aged care later in life and have more acute, complex health problems than in the past.</td>
</tr>
<tr>
<td><strong>4. Workforce capacity</strong></td>
<td>The capacity to provide care to people approaching and reaching end of life will depend on the availability of suitably trained primary and specialist palliative care providers including GPs and community support workers.</td>
</tr>
<tr>
<td><strong>5. Access in regional, rural and remote communities</strong></td>
<td>Current difficulties in equitably delivering PEoLC in remote, regional and rural areas will be compounded by the ageing of these communities. Innovative, flexible arrangements will be required.</td>
</tr>
<tr>
<td><strong>6. Particular population groups or communities</strong></td>
<td>The needs of particular groups, including people with dementia, children and adolescents, Aboriginal people, and those from different cultural and linguistic backgrounds will need to be addressed in the MoC.</td>
</tr>
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2.2. What can we learn from others?

Recent publications that are particular relevant and can contribute to the diagnostic process include:

3. **Safety and Quality of End-of-life Care in Acute Hospital**, Australian Commission on Safety and Quality in Health Care 2013.
2.2.1. Commitments for change: NSW Government Plan

NSW Health recognises the need to improve PEoLC services and to increase access to quality care. Additional funds have been committed to:

1. Expand community-based palliative care services, especially in rural areas and for special needs populations.
2. Integrate primary care and specialist palliative care across the state.
3. Expand support for families and carers.
4. Extend capacity of palliative care services.

This entails building new models of care, new partnerships and linkages between the sectors that provide palliative and end of life care, and also links to people living with a life-limiting condition, their families and carers.

What an improved MoC should deliver

The NSW Plan defines what is required from an improved MoC:

<table>
<thead>
<tr>
<th>Patient centred</th>
<th>Multidisciplinary approach to PEoLC involving family members, carers and other care providers.</th>
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<tbody>
<tr>
<td>Partnerships</td>
<td>• Formalised links between community-based and specialist PEoLC.</td>
</tr>
<tr>
<td></td>
<td>• Across sectors: government, non-government and community agencies (eg carer respite, home care, equipment and transport).</td>
</tr>
<tr>
<td>Communication between care settings</td>
<td>• Clinical networks: assessment, case management and coordination between care settings.</td>
</tr>
<tr>
<td></td>
<td>• Easy to navigate processes to transfer people from acute to PEoLC, with patients and carers informed and involved in decisions.</td>
</tr>
<tr>
<td>Community based services</td>
<td>Community-based services extended, especially in rural areas and for special needs populations.</td>
</tr>
<tr>
<td>24 hour support</td>
<td>Capacity or networked to provide after-hours support and advice.</td>
</tr>
<tr>
<td>Rural and remote</td>
<td>MoC responds to the needs of people in rural and remote areas.</td>
</tr>
<tr>
<td>Cultural relevance</td>
<td>Services tailored to address cultural needs.</td>
</tr>
<tr>
<td>Aboriginal communities</td>
<td>Partnerships between Specialist Palliative Care Services and Aboriginal health and community services.</td>
</tr>
<tr>
<td>CALD</td>
<td>Partnerships between Specialist Palliative Care Services and CALD health and community services.</td>
</tr>
<tr>
<td>Innovative solutions</td>
<td>Use of technology to share information: telehealth and e-health.</td>
</tr>
<tr>
<td>Evidence-base</td>
<td>Data-drive approaches to clinical practice improvement. Partnerships with research to ensure evidence base.</td>
</tr>
<tr>
<td>Standards</td>
<td>National Standards guide service development.</td>
</tr>
</tbody>
</table>
2.2.2. Care for the dying in NSW, 2013

The Clinical Excellence Commission identified end of life care as a major theme for NSW public organisations to examine as part of the 2012 Quality Assessment Process. The Care for the Dying report was based on the findings of multi-level online self-assessments, onsite verification visits, feedback and reporting which involved 1,513 respondents from 1,130 clinical units in 17 LHDs, Ambulance Service and the Justice Health and Forensic Mental Health Network.

Quality Systems Assessment of acute care highlights issues to be addressed by the MoC:

<table>
<thead>
<tr>
<th>Lack of performance monitoring</th>
<th>There is minimal examination of the quality of care provided to patients dying in acute care facilities. A third of clinical units reported that they did not monitor any performance measure relating to end of life care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delay identifying anticipated deaths</td>
<td>More than a third of clinical units do not routinely identify patients who are likely to die in the next 6-12 months. This leads to delays in advance care planning, has implications for families and patients’ capacity for informed decision making around treatment.</td>
</tr>
</tbody>
</table>
| Communication | Clinical units say the most challenging issues are related to communication:  
  • Incomplete documentation in medical records (59%).  
  • Staff members not feeling comfortable initiating the conversation with the patient, family or carer (53%).  
  • Poor communication between staff and family or carers (31%). |
| Lack of standard systems | There is a lack of a standardised approach to ensure all dying patients benefit from a consistent approach to care, including:  
  • excellent symptom control;  
  • communication about social, spiritual and cultural needs; and  
  • bereavement support for families and carers. |
| Guidelines and protocols | Clinical services need policy makers to provide standardised, evidence-based protocols, guidelines, pathways and training. |

‘The QSA work was excellent – it’s been really useful in establishing some baseline end of life data.’
—Key Stakeholder
2.2.3. End of Life Care in acute hospitals

The Australian Commission on Safety and Quality in Health Care undertook scoping and preliminary consultation work to identify the key factors affecting the quality of end of life care in acute hospitals. Major issues identified included:

<table>
<thead>
<tr>
<th>Single focus on cure</th>
<th>Acute care focusses on diagnosis, treatment, cure and discharge rather than end-of-life care. Deaths are evaluated in terms of unexpectedness and potential preventability, rather than on quality of end of life care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Physicians often delay or lack the capacity to communicate with patients and families about the goals of care, limitations on treatment, terminal care or psychosocial and spiritual needs.</td>
</tr>
<tr>
<td>Pain management</td>
<td>Control of symptoms and pain is suboptimal.</td>
</tr>
<tr>
<td>‘Out-sourcing’ death</td>
<td>End-of-life care is ‘out-sourced’ to the medical emergency team, the palliative care team or the intensive care team, even when a death could have been anticipated. Care may then be provided by strangers and in urgent circumstances.</td>
</tr>
<tr>
<td>Lack of holistic approaches</td>
<td>Junior physicians are often responsible for care but lack experience in end of life care. They delay contacting senior staff even when a patient has complex needs. Care is often focussed on a single organ or disease group, instead of a holistic approach.</td>
</tr>
<tr>
<td>Advance care planning</td>
<td>Advance care directives aren’t widely used. Many are poorly documented or unavailable when a patient presents to emergency</td>
</tr>
<tr>
<td>Few options</td>
<td>There are limited supports and options for end of life care in non-acute settings.</td>
</tr>
</tbody>
</table>
2.2.4. Advance care planning action plan, 2013-2018

“Advance Care Planning involves thinking, discussing and documenting. It generally involves ongoing conversations between patients, their families and their treating health professionals introduced gradually over a period of time. These conversations enable planning ahead for potential deterioration in future health when that person becomes unable to make decisions about their own treatment and care. It involves eliciting that person’s choices, wishes and values and how these affect preferences for care and goals of treatment.”

The Action Plan provides the way forward for NSW Health implementing advance care planning in the NSW public health system over the next 5 years. It also identifies strategic partnerships with other government agencies and sectors to improve this aspect of planning for end of life care in primary, acute and aged care settings.

The Action Plan specifies action required from the PEOtLC system and from the MoC in particular:

<table>
<thead>
<tr>
<th>Model of Care</th>
<th>Advance Care Planning needs to be incorporated into the MoC for chronic disease self-management and decision making from diagnosis through to end stage clinical management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dying at home and in RACFs</td>
<td>New models of PEOtLC Service Provision are needed to increase community services to support dying at home, including in residential aged care facilities.</td>
</tr>
<tr>
<td>Communication systems</td>
<td>Advance Care Planning information needs to follow the person as they transfer between clinical settings. Systems are needed at admission, clinical handovers, for medical records and electronic health records.</td>
</tr>
<tr>
<td>Clinical leadership</td>
<td>Specialty-agreed clinical triggers are needed to promote Advance Care Planning. Quality indicators for care of the dying are needed</td>
</tr>
<tr>
<td>Evidence base</td>
<td>Accurate, detailed data are needed on subsets of patients in acute care (intensive care, high dependency units, emergency departments), residential aged care and homes. Enhanced audits of patients’ records can provide information on the extent to which a death was expected and how it was managed.</td>
</tr>
<tr>
<td>Cross learning partnerships</td>
<td>Links between primary, acute, community health services and residential aged care to support service improvement.</td>
</tr>
</tbody>
</table>

‘As well as the cultural challenges in not discussing dying and death, this is an area that is complicated by ethics and law that are also not well understood.’

—Key stakeholder
2.2.5. **AIHW report on specialist workforce capacity**

There is widespread concern about the limited availability of the specialist palliative care workforce, especially in rural and regional areas.

**Specialist Palliative Medicine Physicians**

AIHW’s Palliative Care Services in Australia 2013 used the Medical Labour Force Surveys 2010 and 2011 to estimate the capacity of the specialist palliative medical workforce:

- Specialist palliative medicine physicians represent only 0.4% of all employed medical practitioners in Australia.
- There were 39 specialist palliative care physicians registered as working in NSW.\(^{14}\)
- This represents 0.5 FTE per 100,000 population.
- More than half (57%) are female. Their average age was 51.
- Almost 9 out of 10 (86%) worked mainly in major cities.

**Specialist Palliative Care Nurses**

AIHW’s report Palliative Care Services in Australia 2012 used the AIHW Nursing and Midwifery Labour Force Survey 2011 to estimate the capacity of the specialist palliative nursing workforce:

- 2% of all employed nurses in Australia work principally in specialist palliative care nursing.\(^{15}\)
- There were 1,383 specialist palliative care nurses working in NSW in 2009.
- NSW has a lower rate of specialist palliative care nurses (17 per 100,000 population) compared to the national rate (21 FTE per 100,000).
- The supply of specialist palliative care nurses has been decreasing nationally.
- The specialist palliative care nursing workforce is aging. Nurses working in palliative care are slightly older (47 years) than the general nursing workforce (44 years).
- Nationally, nurses are concentrated in Inner Regional areas (26 FTE per 100,000) and spread most thinly in remote and very remote areas (12 FTE per 100,000).
MALCOLM’S STORY: MISSED OPPORTUNITIES, MISSING CONNECTIONS

Malcolm, a 63 year old male was admitted to hospital following an extended period of shortness of breath, weakness and poor appetite. He was diagnosed with advanced disease that was impacting on his heart and lungs. Malcolm and his wife Anna were shocked. Surgical options were not available and Malcolm was offered medication management in a discussion he perceived was “all about getting on top of this thing and getting on with life.”

Following discharge Malcolm received care as an outpatient. Due to his continuing breathlessness and fatigue he was unable to return to work and Anna became concerned about their financial situation. The social worker they had seen at the time of Malcolm’s hospital admission only worked in the hospital. No other practical or emotional support had been arranged outside of the hospital and neither Malcolm nor Anna knew who to call when their General Practitioner was unavailable.

As his disease progressed Malcolm was readmitted to hospital. He experienced more breathlessness, pain and weakness. Further treatment options were discussed but considered “limited in scope”. Malcolm had previously not expressed any wishes for care options at the end of life. There was a disagreement between Anna and Malcolm’s children (from a previous marriage) about his care. Anna felt she was not allowed to discuss the possibility that Malcolm might die. A family conference was arranged to talk about care options because Malcolm had become less able care for himself. It was agreed that this admission would continue while further discussions took place.

Before a decision could be made about Malcolm’s care options, Malcolm had a cerebrovascular event (stroke). His condition deteriorated and his doctors anticipated that he would not recover and indeed die soon. When Anna asked about taking Malcolm home to die she felt that the staff tried to protect her by suggesting he would be best cared for in hospital. Unfortunately Malcolm developed an agitation and the treating team commenced regular morphine and midazolam injections. The increased doses did not seem to help. Malcolm died in a way that was felt to be a release by some and a disappointment by others. There was no automatic bereavement support or follow up available from the hospital for Anna.

Malcolm’s story highlights the importance of having early and ongoing end of life discussions, and coordinated and timely care based on the needs of patients, their families and carers. Further, it points to the need for an improved understanding of safe best practice clinical care at the end of life. Currently the integrated network of services required to provide quality care based on assessed need is not available to all people in NSW approaching and reaching the end of life, their families and carers. The inability to access this range of services can be physically, emotionally and spiritually distressing for all involved.
3. WHAT DID WE DISCOVER?

ACI has identified and analysed diagnostic information about the current status of PEoLC in NSW: service needs, service delivery and capacity. A range of expert sources and stakeholders have been tapped, including carers and consumers, service providers from clinical and non-clinical settings, managers and researchers.

The findings of 4 recent projects are summarised in this section:

1. ‘Fact of death’ analysis: palliative and end of life care, analysis of admitted patients in the NSW public hospital system
2. Primary care and residential aged care: issues and opportunities
3. Survey of rural chronic and palliative care clinicians
4. ACI Statewide consultation

3.1. ‘Fact of death’ analysis: findings from acute care

Health Economics and Analysis Team (HEAT) at the ACI supports Networks and clinicians by analysing health service utilisation, economics and resourcing and program evaluation. HEAT collaborated with the Palliative Care Network and the Centre for Epidemiology and Evidence at the Ministry of Health to conduct a ‘Fact of Death’ analysis which focussed on the use of inpatient services by people who died in 2011-12 and were hospitalised in their last year of life.

Headline Findings

• Relatively intense use of admitted hospital services in the last year of life.
• Relatively low use of admitted “coded” palliative care services.
• High proportion of emergency/unplanned hospitalisations.
• High level of multiple hospitalisations.
• High number of deaths in hospital.

The analysis provides valuable information about the demand for PEoLC. The study linked hospital and death data. It identified:

• Patients who received coded PEoLC.
• Patients who were likely to require or would benefit from PEoLC.
• Sub-groups of admissions within that cohort.
• Costs and trends of service use.

There are limitations to the information at this stage:

• Cause of death data were not available (it is anticipated in 2014).
• Data about non-admitted palliative care (community based) service provision is not robust.
• Hospital and community based data systems are not linked, so it is not clear what PEoLC is provided to people who are discharged from hospital during their last year of life, and then die outside of acute care.
Patients included in the analysis: the PEoLC cohort

Of the 48,000 people who died in NSW in 2011/12, there were 37,000 people who were relevant to this analysis. Groups of patients that were most likely to benefit from or require PEoLC were selected, including hospitalisations listed as:

1. **Conditions/diseases identified by AIHW** as the major groups of conditions or diseases where patients are ‘more likely to benefit from PEoLC’.

   (‘AIHW conditions’ includes chronic obstructive pulmonary disease, dementia and Alzheimer disease, heart failure, HIV/AIDS, Huntington disease, liver failure, motor neurone disease, multiple sclerosis, muscular dystrophy, Parkinson’s disease and renal failure.)

2. **Palliative care service** type.

3. **Cancer diagnosis** codes.

4. **Grey area of interest**. This includes other conditions/diseases where patients are likely to require or benefit from PEoLC. It excludes patients already included in palliative care services, cancer and/or had AIHW specific disease/conditions.

   The top 3 principal diagnosis codes in the Grey area of interest were Pneumonia, Anaemia and Urinary tract infection. The top 3 AR-DRGs were OR Procedures Unrelated to Principal Diagnosis W Catastrophic CC, Red Blood Cell Disorders W/O Catastrophic or Severe CC and Other Digestive System Diagnoses W/O Catastrophic of Severe CC.

Further details are shown in Appendix 2: *Codes and classifications used in the Fact of Death Analysis.*
Hospitalisation in the last year of life

Figure 7:
Hospitalisations in last year of life, of 36,772 people who died in 2011/12
(a total 158,109 hospitalisations)

There was an intense use of admitted acute hospital services in the year leading up to death:

- On average, people each had 4 hospitalisations (24% had more than 10 admissions).
- When day-only admissions are excluded, the average length of stay (ALOS) was 10 days, compared to the ALOS for typical NSW admissions of 4 days.
- 70% of hospitalisations were for people aged 70 and over.
- A significant number of people in this cohort die in hospital – around 62%.
- These 150,000 hospitalisations involved nearly 1 million bed days.

Figure 8:
Hospitalisations in last year of life, per person, NSW 2011/12
## Day only admissions
A third of all hospitalisations were day-only. Extracorporeal dialysis was the most common reason for same day admissions representing 63% of all day-only hospitalisations, followed by anaemia unspecified and cataract unspecified.

## Overnight hospitalisations
The most common reason for admission for overnight hospitalisations were Congestive heart failure, Care involving use of rehabilitation procedure unspecified and pneumonia unspecified which represents 11% of all overnight hospitalisations.

## Emergency hospitalisations
60% of all admissions were through emergency. The top 5 reasons for an emergency admission were:

- congestive heart failure;
- pneumonia unspecified;
- chronic obstructive pulmonary disease with acute lower respiratory infection;
- urinary tract infection (site not specified); and
- pneumonitis due to food and vomit.

These top 5 represented 15% of all emergency admissions.
People who received in-patient palliative care

Figure 9: Bed days – People likely to require/benefit from PEoLC, NSW 2011/12
(a total 854,660 bed days)

- There were 10,773 admissions to palliative care which were linked to 8,058 deaths.
- 7% of all hospitalisations in the last year of life were ‘coded’ palliative care.
- 11% of hospitalisations for the conditions/diseases likely to require/benefit from PEoLC were coded palliative care.
- Half the hospitalisations for palliative care were unplanned emergency admissions.
- Average length of stay was 11 days (or 12 days when day-only admissions are excluded).
- The vast majority of palliative care admissions were cancer related.
- The most common non-cancer related reason for admission was congestive heart failure, pneumonitis due to food and vomit, pneumonia and stroke.

Figure 10: Palliative care admissions, NSW 2011/12
Percentage of hospitalisations in the last year of life, 10,773 admissions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIHW conditions</td>
<td>6</td>
</tr>
<tr>
<td>Cancer</td>
<td>33</td>
</tr>
<tr>
<td>PEoLC cohort (excluding trauma, etc)</td>
<td>11</td>
</tr>
<tr>
<td>Total hospitalisations</td>
<td>7</td>
</tr>
</tbody>
</table>
Figure 11:
Hospitalisations likely to require or benefit from PEOlC, NSW 2011/12
(102,344 hospitalisations)

- Cancer: 15%
- AIHW conditions: 42%
- Grey area: 33%
- Coded palliative care: 10%

Figure 12:
Diagnoses of patients receiving palliative care, NSW 2011/12
(10,773 hospitalisations in the last year of life, 8,058 deaths)

- Cancer: 73%
- AIHW conditions: 27%
Differences between groups of people hospitalised in their last year of life

There are some major differences between the sub groups of patients who are likely to require or would benefit from PEOlC:

- Patients with a cancer diagnosis are 5 times more likely to receive coded palliative care than people with AIHW diagnoses/conditions.
- People with AIHW diagnoses/conditions are twice as likely to die in hospital than people with cancer.
- People with cancer diagnoses die at an earlier age than people with AIHW diagnoses/conditions.
- Emergency admissions are more likely for AIHW diagnoses/conditions.

Table 1: Differences between groups of patients hospitalised during their last year of life

<table>
<thead>
<tr>
<th></th>
<th>‘AIHW’ diagnoses(^{17})</th>
<th>Cancer(^{18})</th>
<th>Palliative care(^{19})</th>
<th>Total PEOlC cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of deaths</td>
<td>19,528</td>
<td>7,868</td>
<td>8,058</td>
<td>36,772</td>
</tr>
<tr>
<td>Average age at death</td>
<td>82</td>
<td>70</td>
<td>75</td>
<td>78</td>
</tr>
<tr>
<td>% Died in hospital</td>
<td>44%</td>
<td>19%</td>
<td>93%</td>
<td>62%</td>
</tr>
<tr>
<td>% Emergency admission</td>
<td>83%</td>
<td>56%</td>
<td>48%</td>
<td>60%</td>
</tr>
<tr>
<td>% Received palliative care</td>
<td>6%</td>
<td>33%</td>
<td>100%</td>
<td>7%</td>
</tr>
<tr>
<td>% Day-only admissions</td>
<td>10%</td>
<td>24%</td>
<td>10%</td>
<td>34%</td>
</tr>
<tr>
<td>ALOS</td>
<td>10 days</td>
<td>7 days</td>
<td>11 days</td>
<td>7 days</td>
</tr>
</tbody>
</table>
Unplanned emergency admissions

There is a high level of Emergency admissions for patients in the last year of life, especially for older people with AIHW diagnoses/conditions:

- 60% of all hospitalisations are emergency, rising to 76% for people aged 85 and over.
- 83% of admissions with AIHW diagnoses/conditions, compared with 56% with cancer diagnoses and 48% for palliative care.

Figure 13:
Emergency and day-only admissions, NSW 2011/12
Percentage of hospitalisations of people likely to require/benefit from PEOlC
Age and setting of death for people hospitalised in their last year of life

- The median age of death was 78. The median age of death for people hospitalised with cancer diagnoses was 70; with AIHW diagnoses/conditions it was 82 and for those ‘coded’ as palliative care it was 75.

- Nearly two thirds (62%) of people in the PEoLC cohort died in hospital. This included 93% of people admitted for palliative care, 19% of people admitted with cancer diagnoses, 44% of people with AIHW diagnoses/conditions.

- People aged 85 and over were least likely to die in hospital (52%) while children aged 0-4 were the most likely to die in hospital (88%).

- People who did not die in hospital survived on average for 82 days after their last hospitalisation.

Figure 14:
Age and setting of death, NSW 2011/12
People likely to require/benefit from PEoLC

70 19 82 44 75 93 78 62
Cancer 7,868 deaths AIHW conditions 19,528 deaths Palliative care 8,058 deaths Total PEoLC cohort 36,772 deaths

Percentage who died in hospital
Median age of death
### People hospitalised in their last year of life: summary points

| Hospitalisations in the last year of life | Three quarters of the 48,000 people who died in NSW in 2011/12 had been hospitalised at least once in their last year of life. This group of 37,000 people had 150,000 hospitalisations, with nearly 1 million bed days at an estimated cost of over $900 million.  
On average, people had 4 hospitalisations each (24% had more than 10 admissions).  
Their average length of stay was 7 days (or 10 days when day-only admissions were excluded). This is considerably higher than the NSW ALOS of around 4 days. |
|---|---|
| Access to palliative care | Only 7% of all hospitalisations in the last year of life were ‘coded’ palliative care.  
The vast majority of palliative care admissions were cancer related. Patients with a cancer diagnosis are 5 times more likely to receive coded palliative care than people with conditions recognised by AIHW as ‘likely to benefit from PEoLC’. |
| People who were likely to require palliative care | Only 11% of the 100,000 hospitalisations of people with conditions/diseases that were likely to require/benefit from PEoLC were ‘coded’ as receiving palliative care. |
| Emergency | 60% of all hospitalisations in the last year of life are emergency admissions, rising to 76% for people aged 85 and over. Emergency admissions are more likely for people with AIHW diagnoses/conditions (83%) compared with cancer diagnoses (56%) and palliative care (48%). |
| Deaths in hospital | Nearly two thirds of this group died in hospital: 93% of people admitted for palliative care, 19% of people admitted with cancer diagnoses, 44% of people with AIHW diagnoses/conditions. |
| Deaths out of hospital | People who had a hospitalisation in their last year of life, but then died out of the hospital, the average survival time from last hospitalisation was 82 days. |

### Next Steps:

The Fact of Death Analysis is an exploratory analysis of linked ‘fact of death’ data for people who died in 2011/12 and were hospitalised a year prior to their death. The analysis highlighted a:

- Relatively intense use of admitted hospital services in the last year of life;
- Relatively low use of admitted “coded” palliative care services;
- High proportion of emergency/unplanned admissions;
- High level of multiple admissions; and
- High number of deaths in hospital.

To assist in the further development of the Model of Care, the next steps for this analysis include:

- A Cause of Death analysis;
- Projections of demand and cost over the next 10 to 20 years; and
- A more detailed analysis of particular clinical cohorts.
3.2. Primary care and residential aged care

In 2013 the ACI commissioned a project to analyse the strengths, weaknesses and limitations of PEoLC in the Primary Care and Residential Aged Care sectors in NSW. It also sought to better understand what types of things enabled better care. A wide range of community members and people working in primary care and RACFs were consulted in metropolitan, regional and rural areas. Interviews were tailored for specialist services, RACFs, Medicare Locals, LHD stakeholders, peak bodies, GPs, Department of Health and Aging, nursing services, carers, patients, RACF residents, and the NSW Ambulance service.

For this part of the consultations, 154 people completed an electronic survey and 335 people attended 75 interviews or consultation forums. Details of those who participated in consultations are provided at Appendix 4.

These diagnostic questions were considered:

| What are service providers’ perspectives on PEoLC? | • Definitions of PEoLC.  
• Roles of primary care, RACFs and specialist services. |
| What is good practice? | • Models available, evidence on outcomes.  
• Guidelines to support good practice. |
| What is the current status of non-specialist PEoLC in RACFs and primary care? | • Services provided: what models, where, by whom, for whom.  
• Service demand.  
• Integration with other services.  
• Capacity of non-specialist PEoLC workforce.  
• Funding of PEoLC in RACFs.  
• Monitoring and governance of PEoLC in RACFs. |
| What links specialist and non-specialist PEoLC? | • Primary care and RACF access to specialist supports.  
• Additional supports available/required. |
| What are the enablers? | • Current supports.  
• Opportunities to build enablers. |
| What are the barriers? | • Barriers to people and families receiving what they need.  
• Opportunities to remove barriers. |

Residential aged care settings

People entering RACFs have increasingly complex and acute care needs. About 10% of deaths, or 5,000 people, die each year in residential aged care facilities (RACFs) in NSW.

The proportion of people dying who are aged care residents is increasing. Residential aged care services face unique difficulties in administering palliative care, with residents often having dementia and/or communication difficulties and multiple diagnoses (NHMRC 2006). When compared with hospices, where patients are more likely to have a cancer diagnosis, residents in aged care services are more likely to have a diagnosis of a chronic degenerative disease(s). (Grbich et al. 2005)
Over the course of consultations, interviewees identified the following challenges and barriers:

## Barriers and challenges for PEOlC in RACFs

<table>
<thead>
<tr>
<th>Category</th>
<th>Challenge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nursing capacity</strong></td>
<td>There are no mandated staff/resident ratios to ensure safe care. The shortage of RNs is most serious after hours and at weekends. RNs frequently work in isolation from professional peer networks.</td>
</tr>
<tr>
<td></td>
<td>‘There is currently only one overnight nurse overseeing the 180 bed facility, and in another low care facility, there are two registered nurses overseeing 230 residents.’ —RACF staff member</td>
</tr>
<tr>
<td><strong>Specialist services capacity</strong></td>
<td>RACFs have limited access to palliative care specialists.</td>
</tr>
<tr>
<td><strong>GP capacity</strong></td>
<td>RACFs lack access to GPs due to generally reduced levels of home visiting and also due to limited financial remuneration. Many GPs are also reluctant to deliver active pain management and are unavailable to complete pain assessments required to obtain additional Medicare funding for patients requiring palliative care.</td>
</tr>
<tr>
<td><strong>Unrealistic care plans</strong></td>
<td>Acute services and specialist palliative care services have unrealistic expectations of RACF capacity to administer medications and review patients. They are unaware of nursing benchmarks in RACFs. The RACF sector is reliant on low paid carers who often have only basic level knowledge, skills and experience in PEOlC.</td>
</tr>
<tr>
<td><strong>Pain management</strong></td>
<td>Problems with pain medication include:</td>
</tr>
<tr>
<td></td>
<td>1. Residents can miss out on pain relief partly due to the reluctance of GPs to prescribe Schedule 8 medications.</td>
</tr>
<tr>
<td></td>
<td>2. Low Care RACFs cannot store imprest Schedule 8 drugs, despite having residents who may need them.</td>
</tr>
<tr>
<td></td>
<td>3. Access to medications that need to be titrated is limited partly due to regulations that prevent Enrolled Nurses (Cert IV) from providing these to residents who are in pain.</td>
</tr>
<tr>
<td></td>
<td>4. Shortages of access to syringe drivers for medications.</td>
</tr>
<tr>
<td></td>
<td>‘Particularly among some RNs, there is a refusal to give morphine because they believe they are killing the resident. They don’t see pain in the same way. This is hard because they are often the only RN on shift at the time.’ —RACF staff member</td>
</tr>
<tr>
<td><strong>Rural and remote</strong></td>
<td>Escalating care needs are difficult to address in remote areas where most types of services are limited and over-stretched.</td>
</tr>
<tr>
<td><strong>Allied health services</strong></td>
<td>There is limited access to allied health services including speech therapy, nutritionists, occupational therapy.</td>
</tr>
<tr>
<td><strong>Staff shortages</strong></td>
<td>Inadequate staffing levels, high workloads and inadequate debriefing systems lead to staff turnover which in turn reduces quality of care.</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Workforce development</strong></td>
<td>Staff have limited training in end of life care, and less access to continuing education. Barriers to workforce development include cost, inability to replace staff to attend training and staff turnover. Implementation of Advanced Care Plans is a priority.</td>
</tr>
<tr>
<td><code>'Many RACFs will rely on ambulance services to provide education. When they arrive, ambulance services will ask simple questions that the facility staff should know, such as 'Have you done X? Have you contacted the doctor? Have you spoken to their oncologist? When was the last time the patient was managed?' However the staff don’t know the answers.’ —Ambulance staff member</code></td>
<td></td>
</tr>
<tr>
<td><strong>Language and cultural issues</strong></td>
<td>Culture-specific services tend to be isolated from other services. Significant rates of language barriers amongst care staff. Pain management is influenced by both staff and patients’ cultural attitudes towards pain, death and dying.</td>
</tr>
<tr>
<td><strong>Funding anomalies</strong></td>
<td>Stakeholders identified problems with the restricted funding available for PEoLC through the Aged Care Funding Instrument (ACFI) which hampers RACF’s capacity to provide adequate end of life care for many residents. Issues include:</td>
</tr>
<tr>
<td>1. Funding is not available until death is imminent.</td>
<td></td>
</tr>
<tr>
<td>2. Funding is restricted to those with pain and not available for patients with non-pain distress common in non-malignant diseases (such as end stage respiratory disease).</td>
<td></td>
</tr>
<tr>
<td>3. Funding does not cover equipment costs.</td>
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<tr>
<td>ACFI funding to care for people as they approach and reach the end of life in RACFs is around a third of the amount that specialist palliative care services receive per individual.²⁴</td>
<td></td>
</tr>
<tr>
<td><strong>Building layout and design</strong></td>
<td>The design of many RACFs is not suited for PEoLC. Residents share rooms and there is limited private space for families.</td>
</tr>
</tbody>
</table>

**Enablers in residential aged care**  
Stakeholders highlighted factors that would enable effective PEoLC:

2. Access to competent GPs.
3. Access to PEoLC specialists.
4. Formalised professional and service networks that facilitate case conferences.
5. Advance care planning.
6. Improving community knowledge and attitudes towards death.
7. Workforce development systems.
8. Standard tools, templates, policies to guide practice.
9. Authorised Care plans for use with ambulance services.
10. Medication review systems to manage polypharmacy.
### Primary care settings

Interviewees identified the following barriers and challenges in a range of primary care settings:

#### Barriers and challenges for PEoLC in Primary Care

<table>
<thead>
<tr>
<th>Barriers and challenges</th>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td><strong>Access to GPs</strong></td>
<td>GPs face escalating demand to provide increasingly complex care. The proportion of GPs providing home visits is declining. Financial barriers reduce GPs’ willingness and capacity to provide PEoLC. There is no specific Medicare Benefits Schedule (MBS) item for palliative care provided by GPs. This also means that there is no accurate data about PEoLC provided by GPs. GPs knowledge of best practice PEoLC is variable, due to competing priorities for professional development.</td>
</tr>
<tr>
<td><strong>Support after hours</strong></td>
<td>Limited access to RNs, GPs and pharmacies after hours create serious problems at end of life and with pain management.</td>
</tr>
</tbody>
</table>
| **Links between primary and specialist services**                                      | Lack of formal links between primary and specialist PEoLC  
  - reduces equitable access.  
  - Reduces capacity to coordinate care between community nursing, GPs, specialist and non-clinical services.                                                                                   |
<p>| <strong>Workforce shortages</strong>                                                                | Pronounced shortages of primary PEoLC in rural areas. Access to palliative care is described as a ‘postcode lottery’ where geographic location plays the key role in deciding the quality of care an individual will receive. Low pay rates for case workers. |
| <strong>Telehealth</strong>                                                                         | A perceived lack of financial incentives for specialists or GPs to provide PEoLC via telehealth. Scope to improve equitable access in rural, remote and Aboriginal communities. |
|                                                                                        | ‘If there was a larger uptake of telehealth, with associated telehealth specific item numbers that would be a huge step in providing care over large areas.’ —Medicare Local |
| <strong>Workforce development</strong>                                                              | Limited skills and knowledge of PEoLC amongst community nurses and GPs: staff turnover, cost of replacement during training.                                                                               |
| <strong>Equipment</strong>                                                                          | Delays and costs accessing equipment, especially for extended end of life care.                                                                                                                          |
| <strong>Carers needs</strong>                                                                       | Carers seek recognition as advocates, access to respite, counselling support, training in palliative care, help with their own medical needs, bereavement support. There is a lot expected of carers, and many feel their own emotional and practical needs are not being met. |
| <strong>Bereavement</strong>                                                                        | Limited supports and recognition of the bereavement process.                                                                                                                                             |</p>
<table>
<thead>
<tr>
<th>Tailoring services</th>
<th>Limited capacity to tailor services to address for the particular needs of Aboriginal, CALD, different faith groups.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care packages</td>
<td>Delays and limits to eligibility for home care packages through ComPacks lead to preventable admissions to hospital.</td>
</tr>
</tbody>
</table>

‘Our Home Care packages currently have a waiting list of 65 people’
—ComPacks provider

<table>
<thead>
<tr>
<th>Community attitudes and expectations</th>
<th>Incongruence between community expectations and what is available or possible.</th>
</tr>
</thead>
</table>

### Consumers’ perspectives on PEoLC provided in RACFs and Primary care

People who receive PEoLC services were consulted to obtain their perspective on care. This included patients, residents of RACFs and family members. There was a broad consensus amongst consumers that care needs to be patient centred care that provides dignity, pain management and connection to significant others in familiar surroundings.

Stakeholders described areas of good service but also raised concerns related to problems in current practice:

<table>
<thead>
<tr>
<th>Access to services</th>
<th>There is inequitable access to services related to disease group and geographical location.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service integration</td>
<td>Information, care plans and treatment regimes are not transferred between service providers.</td>
</tr>
<tr>
<td></td>
<td>GPs are not sufficiently connected to care management.</td>
</tr>
<tr>
<td>Care in the preferred setting</td>
<td>Most consumers want choice. People in rural settings need more help to stay out of emergency acute services.</td>
</tr>
<tr>
<td>Relationships, dignity and respect</td>
<td>Loneliness and lack of dignity are key concerns.</td>
</tr>
<tr>
<td></td>
<td>Carers don’t know where to take their complaints and fear the repercussions of making a complaint.</td>
</tr>
<tr>
<td>Information and communication</td>
<td>Consumers want GPs to proactively start end-of-life discussions and provide information. Carer mentoring and links to information channels is appreciated</td>
</tr>
<tr>
<td>Carers and volunteers</td>
<td>Carers seek recognition, support, needs assessment and support after caring.</td>
</tr>
<tr>
<td></td>
<td>Volunteers are valued as they provide a community of support, education and enable a discourse about death.</td>
</tr>
</tbody>
</table>
Themes shared by both primary care & residential aged care

1. Structural problems
   Structural problems reduce the capacity of primary care and RACFs to respond to demands:
   - Staffing mix (ratios of residents: RNs) and funding barriers in RACFs (ACFI).
   - Shortfall in GPs’ capacity to respond to increasing demand.
   - Workforce shortages: recruitment, retention.
   - Limited access to evidence-based training and systems that build workforce capacity.
   Scope to extend service delivery through Nurse Practitioners, Extended Care Paramedics, 24 hour phone support systems, Telehealth, formalising partnerships. A need to enhance the specialist palliative care workforce was also raised.

2. Coordination
   Links to specialist advice is often based on local arrangements rather than on systematic, population-based, formal agreements.
   Information is often siloed within medical specialties. Local pathways/collaborations between all services are needed to smooth the journey to:
   - Provide patient centred care and holistic approaches.
   - Clarify roles of local service providers: clinical, non-clinical, carers and volunteers.
   - Access services to address identified problems.
   - Develop the capacity of non-specialist service providers.

3. Unmet needs
   - After hours services.
   - Pain management and access to medication.
   - Particular communities and groups: CALD, Aboriginal, younger people, chronic conditions.
   - Bereavement services.
   - Equipment.
   - Rural / remote services.

4. Effects of aged care reform
   Home care packages and home support programs enable more people remain at home for longer. People enter RACFs with increasingly complex medical and psychogeriatric disorders that would have previously been cared for in acute medical or psychiatric hospital environments.

5. Expectations
   Expectations for care are increasingly unsustainable: from community members, specialists, primary care and RACFs.
3.3. ACI state-wide consultation

ACI met with people across NSW to understand what currently enables and creates barriers to quality care for people approaching and reaching the end of their lives. Information was gathered about the features of services that are currently provided, their strengths and the challenges that are being faced. Attention was focussed on the groups of people and clinical cohorts that lack equitable access to services. Ideas were canvassed about ways forward. The questionnaires and interview guides are shown at Appendix 3.

Who we spoke to

Consultations occurred across all NSW Local Health Districts and included 720 clinicians and managers from a range of disciplines in specialist palliative care, acute care, critical care, primary care and community health services. Input was provided by 12 consumers including patients, family members and carers. An additional 231 key stakeholders from government statutory authorities, ACI clinical networks, NSW Health pillars, professional groups, non-government and community agencies were consulted. Details of those who participated in consultations are provided at Appendix 5.

What people said

Specialist palliative care providers

Specialist palliative care service providers from a range of agencies and clinical settings provided their perspectives on the current strengths and challenges in providing care to people as they approach and reach the end of their lives.

Strengths

- High level of commitment, flexibility and teamwork by staff.
- Leadership and new, more representative governance arrangements.
- Close working relationships with other primary care providers.
- A multidisciplinary, and at times, inter-professional approach.
- The use of Palliative Care Outcomes Collaboration (PCOC) assessment tools assist in standardising communication among health providers.
- Paediatric Specialist Palliative Care services deliver care with an interdisciplinary approach and can provide a strong advocacy and care coordination role.
- Paediatric Specialist Palliative Care services provide expert “pop-up” support to primary care services across NSW.
- Volunteer services can play an integral role but need sustained leadership.

These and other strengths are illustrated below:

Early referral/involvement

‘Seeing people earlier on helps prevent crisis calls later on – ensuring home is suitable for them to manage.’ —Metro Specialist Palliative Care Service

‘[I] don’t know if referrals have changed, but the patients are sicker, referred later and more complex.’ —Rural Specialist Palliative Care Service

Commitment

‘We’re a “Community of care.” We have a holistic approach and an interdisciplinary model. There is crossover with inpatient and ongoing follow-up in community. Then we can admit from the community if necessary.’ —Metro Specialist Palliative Care Service

‘The key strengths of the service are firstly, the ingenuity, creativity, and resilience of the staff. A second strength is excellent symptom control because of a consistency in approach to therapeutics and care.’ —Rural Specialist Palliative Care Service

‘The level of commitment from our staff is phenomenal. I’m just so proud of the level of care our team here provide.’ —Rural/Remote Specialist Palliative Care Service
Flexibility

‘We’re very good at thinking outside the square. We cobble together a service that is appropriate for that patient – try to help rather than explain to people why we can’t help. This requires people to go above and beyond. We try to achieve the best outcome for every patient, and that means going above and beyond. A seven day a week service is very important – have to look beyond to work as a seven day service – from the perspective of the patient there is no such thing as a weekend.’
—Rural Specialist Palliative Care Service

Building capacity of primary care

‘We need to be palliative care specialists but be alongside people. Not coming in and consulting and going away – but doing things with them – do clinics with them, show them what it means to have difficult conversations – demonstrate that it’s everyone’s business – increasing the standard across the system’
—Metro Specialist Palliative Care Service

Paediatric Palliative Care

‘The whole team meets with the family with much less of a medical focus. Often longer term patients with long deterioration. They have a number of links outside of the hospital. Then they can tap into particular services they’ve learned about through our multidisciplinary team meeting. For example, financial issues, support for siblings.’
—Paediatric Specialist Palliative Care Service

‘A strength is how we work with everyone else in the hospital. It’s not nuclear; we work with everyone else. Palliative Care is the access point to all the other services.’
—Paediatric Specialist Palliative Care Service

‘A child may have very normal cancer symptoms, but if you haven’t seen a child with those needs before it would look unusual and wouldn’t know how to deal with them. Pop up health training is provided to regional staff at the time when there is a child with particular needs.’
—Paediatric Specialist Palliative Care Service

Volunteers

‘A Volunteer service depends on having a supportive coordinator; a strong volunteer base with a leader.’
—Rural Specialist Palliative Care Service

Challenges

Challenges and barriers highlighted by Specialist Palliative Care providers are summarised and exemplified in the following section.

Overload

• Strong sense that ‘the system’ is overloaded.
• Staff often work beyond their scope of practice and after-hours to meet patient need.
• Increasing demand for care and patients with increasingly complex care needs challenge specialist palliative care and community-based services.

‘Our outreach service is overwhelmed. We focus on unstable patients and discharge stable ones. This transition has been difficult for some GPs. The issue is also not all of these patients need Specialist Palliative Care.’
—Metro Specialist Palliative Care Service

‘There has been a gross dilution of the ability to service the community. Patient numbers have ballooned, balanced against a static workforce encumbered with lots of new things that take up their time away from clinical provision of care. This gives rise to a mismatch of expectation from policy drivers and community.’
—Rural Specialist Palliative Care Service

‘We’re back 25 years ago now in the way we provide support – as the whole health system is overloaded – people are going to the RACF with far more acute problems – higher acuity of problems without providing extra support.’
—Metro Specialist Palliative Care Service
Access to General Practitioners

- Access to skilled and willing General Practitioners is variable.
- Lack of ability for GPs to do home visits impacts on care.
- Limited availability of GPs to provide support to RACFs.

‘Some patients miss out on care because of the reluctance of GPs or Specialists to refer with appropriateness.’
—Rural Specialist Palliative Care Service

‘There’s no GP support to RACFs at the weekend. A Palliative Care patient came in in pain from an RACF because they couldn’t find a GP to visit. Very few GPs undertake home visits.’
—Rural Specialist Palliative Care Service

Workforce capacity

- Recruitment of specialist staff, including allied health is a challenge.
- Building capacity in other sectors is an ongoing challenge.
- Lack of a Palliative Care Medical Specialist in some areas inhibits services’ ability to meet the needs of their communities.

‘We don’t have a specialist – so that’s a problem.’
—Rural Primary Care Service

‘We have troubles attracting specialist staff to come to these roles – we get primary care practitioners and we have to train them up.’
—Metro Specialist Palliative Care Service

‘A big gap is the lack of allied health across the board’
—Rural Specialist Palliative Care Service

‘The big challenge for us in the next decade; our senior palliative care nursing staff are aging – we’ll be retiring. We have one CNC who is ‘youngish’.’
—Metro Specialist Palliative Care Service

‘There’s no way our staffing levels have kept pace for the need to provide population-based approaches to end of life care.’
—Metro Specialist Palliative Care Service

Resourcing

- Insufficient resources to address increasing complexity and demands.

‘There’s never any permanent funding so we have to apply through opportunistic grants processes to fund basic components of our ongoing service. The demand is growing and becoming more complex and we’re not resourced for this.’
—Metro Specialist Palliative Care Service

Extended hours

- Working flexibly often leads to vulnerable staff and services.

‘We provide a good, flexible service for our community, often reaching after hours, but as long as we do this, there will be a feeling that all is fine with the way we’re resourced and supported – and it’s not okay. Some staff work 7 days a week or well into the evening’
—Rural Specialist Palliative Care Service

‘The after-hours stuff is not a formalised proper thing – our manager allows us to do it. But when we get another manager who’s not into it then we may get into a bit of trouble.’
—Rural/Remote Specialist Palliative Care Service
Informal arrangements

- Lack of formal links leads to gaps in services.

‘We’ve always had an informal link with specialists… it’s never been formalised really. And they don’t come out as often… We need formalised links.’
—Rural Primary Care Service – Hospital

‘The problems with the model are the vagaries that exist at the intersections between the levels and the fluidity of the patient cohort between the levels. Additionally, there are gaps in care provision at all levels.’
—Rural Specialist Palliative Care Service

Defining palliative care

- Varied understandings of palliative care is a challenge among both health providers and in the community.

‘A lot of our work is invisible – the way we communicate, the organising…’
—Metro Specialist Palliative Care Service

‘Huge issues with terminology. There’s confusion about what is palliative care and a palliative approach.’
—Rural Specialist Palliative Care Service

‘Sometimes we don’t define what we do clinically very well.’
—Metro Specialist Palliative Care Service

Discharge planning

- Delays in referrals from other medical specialists hampers care.

‘Poor discharge planning from wards is a big issue. Our CNC gets a phone call at 2pm from the renal ward who tells us they’re sending Jo home this afternoon – we have to do a lot of mobilising then.
—Metro Specialist Palliative Care Service

‘The other big element is how to move people in a timely way, to get them back home and into their communities.’
—Rural Specialist Palliative Care Service

‘Transition – there’s usually not anywhere to transition to, so we tend to hold onto patients a bit longer.’
—Paediatric Specialist Palliative Care Service

Community expectations

- Choice of how to die, rather than where to die.

‘Community and policy-maker expectations; the political drive is around place of death. Too much importance is placed on this. It should be about providing the appropriate care when needed and the geography shouldn’t matter. We may not have a choice where we die, but it’s important people have a choice how they die.’
—Rural Specialist Palliative Care Service

‘The patient/family/societal barrier of looking at death and dying – people don’t want to admit that they’re in the last year of life and want to prolong life on the off chance they’ll survive. They think ‘surely modern medicine can provide’ a miracle cure.’
—Rural Primary Care Service
Data

- Data and access to patient information is fragmented (particularly between acute and community).

‘Databases don’t speak to each other – we have five different health service records if you include digital and paper-based. This can take a long time to put together a complete record.’
—Rural Specialist Palliative Care Service

‘The issue of clarity around funding model and data collection; it’s difficult to show outcomes, and to collect data in multiple sites to meet different LHD requirements. We’re working with PCOC to develop outcomes and have piloted the problem severity score that was implementable… phases don’t work for chronic and complex patients.’
—Paediatric Specialist Palliative Care Service

Bereavement

- Service gaps.

‘We don’t have funding to provide that.’
—Metro Specialist Palliative Care Service

‘Big gap in bereavement – we could use telehealth infrastructure if there was a bereavement worker and there’s no way to capture occasions of service in ABF.’
—Rural Specialist Palliative Care Service

‘How do we assess individual complexity in terms of levels? All bereaved people for example, subjectively have complex bereavement issues’
—Rural Specialist Palliative Care Service

‘There’s never been any proper follow-up on families who have lost a child – no studies on families. There is a great evidence gap here.’
—Paediatric Specialist Palliative Care Service

Primary care providers

Across the breadth of responses from primary care providers, a range of themes were identified. These are listed below. Quotations from respondents follow at the end of this list of themes.

Role definition

- Diverse views of the role of specialist palliative care and the range of services available.
- Primary care providers can have multiple roles: facilitator, care coordinator.
- Capacity of primary care providers to provide care to people as they approach and reach the end of life is varied.

Care coordination

- Coordinating care remains a challenge: services can be siloed across sectors.
- Primary carers’ good networks with other services are a key strength.

Access to essential services

- Access to home care support is limited and perceived as inflexible.
- Lack of allied health staff was widely reported in both metropolitan and rural regions.
- Access to skilled, willing and available General Practitioners is variable.

Recognising end of life stages

- Lack of timely or early referrals hampers quality care to people approaching end of life.
- Need to better recognise patients’ approaching the end of life in acute settings.
- ICUs are developing more collaborative and consultative structures to plan for and implement end of life care.

Expectations

- Family’s end of life expectations are challenging for clinicians in acute care.
Advance care planning

- Difficult discussions with families and carers in acute settings are a challenge for health workers and can be time consuming.
- Uptake of Authorised Care Plans and standardised Advance Care Plans need to be supported through policy, guidelines and through education for NSW Ambulance staff.
- There are cultural, ethical and legal aspects to Advance Care Planning that can limit understanding and uptake.

Emergency care

- Emergency staff report a great deal of end of life decision-making and report ongoing frustration at the lack of discussions or decisions made prior to the patient’s admission.
- Changes to ambulance protocols are likely to have enormous benefits to home based patients and carers approaching and reaching the end of life.

Acute care

Emergency Departments

‘We see a lot of patients at the end of life – we make quite a lot of decisions around a patient’s care at the end of life. We sometimes are frustrated at the lack of decisions prior to them coming to our department. Often we’ll make end of life decisions in consultation with ICU and try to manage patients.’
—Rural Primary Care – Emergency

‘Emergency Department – it’s the environment, noise and other things that go with it. There is a need for nurse education to recognise end of life patients so they’re more aware of the deteriorating patient. Syringe drivers in ED have to be done by palliative care nurses because they don’t know how to do it’
—Rural Primary Care – Emergency

ICU

‘A big issue with clinicians is not knowing how to communicate with families. One of the biggest issues for the clinicians is the family’s expectations. They don’t expect to have an end of life conversation about comfort, pain reduction, etc.’
—Intensive Care Nurse

‘Staff need time to manage end of life issues. Less experienced staff can be traumatised.’
—Rural Intensivist

‘I try to work with families on the wards. It takes a lot of time talking to families and defining the limitations of care. If we write Not for Resuscitation orders we sometimes have senior staff feel like they’re giving up on their patients. There’s a great reluctance out there. A lot of that is cultural as well.’
—Rural Intensive Care Liaison Nurse

Hospital

‘The facilities need to be honest with the families about what is happening – there are issues about withdrawing treatment and communicating with the family – often the health worker doesn’t have the knowledge that death is a natural part of life and it’s not a deficit of skill. Death is not a failure. It’s a fact of life – we need to promote that.’
—Metro Hospital

‘There’s a struggle to get a palliative care bed in another hospital because of the waiting list. It’s also difficult to get equipment in the community such as bed in the home – particularly when it is needed quickly. We’re not able to provide a sense of calm and smooth transition.’
—Rural Hospital
Ambulance Service

‘I think paramedics are only used to seeing authorised care plans and need more training on advance care plans.’ —Ambulance Service of NSW

‘In the absence of support we fall back to these protocols or pathways. …Protocols are what we need, explicit guidelines. Our palliative care protocol – it’s very generic. There’s lots of room for interpretation here.’ —Ambulance Service of NSW

Community nursing

‘It’s easier to get someone into ED – and I say ‘while you’re there see a social worker’, then you get personal care, COMPACKS, etc.’ —Metro Primary Care Nurse

‘Prognosis uncertainty and hence, crossover into the Palliative Approach is a challenge.’ —Metro Primary Care – Aged Care/Dementia Nurse

General Practitioners

‘In General Practice it’s the time that limits you.’ —Rural GP

‘It’s about recognising when a patient is reaching the last stage of their life.’ —Rural GP

‘A palliative care specialist can drive all of these issues – supporting clinical networks and GPs in the process.’ —Rural GP

[Regarding Advance Care Planning/Directives] ‘GPs must understand and have access to Practice Nurse to initiate. GPs need clarity and tools.’ —Metro GP

‘Support for GPs is needed because they don’t do [EOL Care] on a regular basis. Skills transfer from Specialist to GP.’ —Metro GP

Other medical specialists

‘Many of our diseases are curative – when do we say enough is enough?’ —Haematologist

‘A practical difficulty is being able to provide palliative care medications in some of the [RACF] facility settings depending on the skill set of the nursing staff and if there’s nursing staff.’ —Geriatrician

‘The problem we have is getting patients home if we can’t get equipment and support.’ —Renal Physician

‘A challenge is determining when to move from one phase to another. There is huge difficulty in being certain about prognosis.’ —Metro Intensivist

Priority populations/clinical cohorts

Interviewees

Aboriginal people

The NSW Aboriginal Health Plan 2013–202335 acknowledges the significant health disparities between Aboriginal and non-Aboriginal people in NSW. The vision for the plan is “Health equity for Aboriginal people, with strong, respected Aboriginal communities in NSW, whose families and individuals enjoy good health and wellbeing.” The plan sets out a partnership approach, key principles, strategic directions and actions and an implementation and evaluation approach to meet this vision.

The Plan also provides a useful definition of Aboriginal Health for the Model of Care to draw from:

Aboriginal health means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-being of their community.

The findings in this section draw primarily from the AIHW data, the ACI’s Fact of Death Analysis, the Australian Government’s 2004 resource “Providing Culturally appropriate palliative care to Aboriginal and...
Torres Strait Islander Peoples’ Practice and Principles and interviews conducted with a sample of Aboriginal Health Workers in NSW.

Access to care and support

AIHW points out how Aboriginal people’s disadvantage across a range of health-related and socioeconomic indicators may affect their use of, and access to admitted patient palliative care.²⁶ ACI’s 2013 Fact of Death Analysis found that less than 2% of people hospitalised in their last year of life in NSW in 2011-12 were from Aboriginal backgrounds. This figure may be an under-estimation since Aboriginal people are 2.5 times more likely to be hospitalised than people who are not Aboriginal.²⁷ Further information is required.

The Department of Health and Ageing also highlights how Aboriginal people are not accessing the PEOlC that they need:

‘Statistics from palliative care services and research within Aboriginal and Torres Strait Islander communities and health services indicate that very few Aboriginal and Torres Strait Islander people are accessing palliative care support… Terminally ill Aboriginal and Torres Strait Islander people are being supported by family, their community and/or Aboriginal and Torres Strait Islander primary health or community services. These services may not be funded to provide palliative care and staff providing the care may not necessarily be trained in this specialised area.’²⁸

Recognition of cultural values and traditions

The need to improve the way that health services interact and provide care for Aboriginal people as they approach and reach the end of life was reinforced in a number of consultations with health professionals, including Aboriginal Health Workers:

‘Grief, loss and dying are viewed in a different way. It’s a big process involving the whole community.’
—Rural Primary Care Service

‘The whole mob come, including to the hospital. This is sorry business and ongoing education for staff is needed. There’s a language barrier with the type of words you use. Conferences need to have more Aboriginal input. We die 20-30 years before everyone else.’
—Rural Aboriginal Health Worker

‘If a person wants to use traditional medicine we need to be able to accommodate that. I would like it in writing in relation to if people want traditional medicine we have the processes that support that.’
—Rural Aboriginal Health Worker

Respectful partnerships

Aboriginal Health Workers underlined the need for respectful connections to be made between Aboriginal people and service providers:

‘It comes down to trust. It comes down to respect.’
—Rural Aboriginal Health Worker

‘It’s about consultation with families, Aboriginal communities and elders.’
—Rural Aboriginal Health Worker

‘My challenges are that the people I look after and care for are people in my community and I can’t separate my identity as a member of the local community from my role as a healthcare provider. The community members I lose are my relatives.’
—Rural Aboriginal Health Worker

Enhancing and strengthening partnerships with Aboriginal people is a key element of the NSW Aboriginal Health Plan 2013-2023 which aims to provide better primary and community health services and promote better use of these services by Aboriginal people. The New South Wales Government recognises Aboriginal people’s rights to self-determination and their role in determining where and how government responds to their needs and aspirations.²⁹

An Aboriginal Health Impact Statement will be developed as part of the Model for Palliative and End of Life Care Service Provision to ensure the health needs and interests of Aboriginal people are reflected.
Culturally and linguistically diverse backgrounds

One of the thirteen National Standards for Palliative Care states that PEoLC needs to be accessible to everyone, regardless of their cultural background. “Respecting and being sensitive to people from diverse cultural and linguistic backgrounds and their community ties is integral to the delivery of quality care at the end of life.”

Service providers interviewed in the statewide consultation expressed concern that people from culturally and linguistically diverse backgrounds tended to under utilise PEoLC or are referred late to specialist palliative care service. A range of reasons were cited, including:

- lack of awareness of such services;
- a perception that people from some cultural groups are reluctant to seek support or to discuss death and dying; and
- some services may not be culturally sensitive or inclusive.

People who are geographically isolated

Across Australia, the more remote the patients’ usual residence, the lower the proportion of palliative-care related hospital separations. The lack of locally available specialist palliative care services to people living in rural, regional and remote areas of NSW is a key reason for people not receiving specialist palliative care. Other problems include:

- limited outreach services that rely on staff working 7 days a week;
- limited availability of community services and in particular, allied health;
- problems having timely access to medication;
- lack of access to equipment that enables people to function at home;
- variable access to skilled and knowledgeable general practitioners.

People under the age of 65

In 2012 more than 1 in 4 of inpatient and ambulatory/community care palliative care separations reported to PCOC were for people under the age of 65. Both primary care providers and specialist palliative care providers reported to ACI’s statewide consultations that that people under the age of 65 do not receive timely access to specialist palliative care. This was due to:

- their perceived ineligibility for services that may be linked to aged care;
- the emphasis on a curative intent and failure to recognize the value of concurrent supportive care;
- the difficulties that service providers found in having end of life discussions with younger people.
People with non-cancer diagnoses
For many health workers and some carers, specialist palliative care was viewed as a service primarily oriented for people living with cancer. For this reason, specialist palliative care was not viewed as a viable care option. Some health workers expressed concern that if specialist palliative care was available to all people living with a life limiting illness, demand would quickly deplete already limited resources.

‘Sometimes people aren’t getting recognized soon enough for palliative care. Particularly with chronic illnesses. There’s huge gaps identifying who is in the last 12 months of their life.’ —Rural/Remote Primary Care Service

People who live alone
With an increased state policy focus on the provision of care to people as close to home as possible, concern was expressed by many that the burden of care may fall disproportionately onto family members or loved ones. For those who live alone, the ability to provide safe and timely care was viewed as extremely limited.

People living with Dementia
The NSW Dementia Services Framework 2010–2015 identifies dementia as one of the fastest growing sources of major disease burden, now being the third leading cause of death, after heart disease and stroke. The number of people with dementia is projected to increase significantly. Dementia is a chronic condition, often with complex physical co-morbidities as well as psychological and behavioural symptoms that require expert clinical assessment and management. A palliative care approach is required for people with advanced dementia and access to specialist palliative care when required.

Many respondents reported poor experiences for people with dementia in residential care facilities, including delays in diagnosis and the lack of adequate advance care planning.

Patients, families and carers
In partnership with the Patient and Staff Experience Team at the ACI, an open-ended survey was developed to enable patients, families and carers to describe their experiences with the health system over time. Although the range of experiences and situations varied, the following key themes and examples were described:

Emotional load
- Lack of conversations about end of life care can hamper people’s readiness and ability to cope when the time comes.
- Witnessing someone dying can be distressing for carers and family members

‘I think carers need to know that anything they say and anything they do isn’t wrong. There’s so much guilt for carers.’ —Carer

Patient centred care
- Palliative and end of life care can provide flexible, patient-centred care.

‘The Palliative Care nurses told us that if you call an ambulance when she dies the police will come. They said if you feel ok with it, wait until the morning then call me and I’ll come and soon as you ring. I did that and in the morning we washed her together. It was lovely.’—Rural carer

Holistic care
- Palliative and end of life care can provide flexible, patient-centred care

‘We need a case manager who is the one contact to manage the whole body and all the organs and to tap us into resources. [Specialist Acute team] have done this for us but not everyone is so lucky. We had to figure out the resources on our own. We want the teams to talk to us and involve us. The new handover in the rooms is great but it doesn’t always happen. We want to hear the handover.’ —Carer
Shared expertise

• Some care providers do not view family or other unpaid carers as experts in providing care

‘We are so used to caring for him that it is hard to hand the care over. We see them doing something wrong and we try to gently tell them but often they ignore us. [Name’s] feeding tube gets blocked every time we’re admitted, and then he has a crisis because he’s not getting his sugars. Some nurses won’t listen to you and accept you as the expert carer. They are very protocol driven – we know the exceptions for [Name’s] condition but they don’t and have to do things by the book. I don’t want to create a scene and be ‘that’ mother. We have to accept human error and get on with it. We’ve only complained once. We can’t afford to upset them because we need them.’ —Carer

Practical problem solving

‘They got me the bed, walker, shower stool, oxygen, things I wouldn’t be able to arrange myself. Without the Palliative Care Service I don’t know how you’d get all this.’ —Rural patient

3.4. Chronic disease and palliative care

More than half of all Australian deaths are due to chronic disease and treatment of chronic disease accounts for almost 70% of total health expenditure.

‘Referral to palliative care can, and will, provide the most appropriate care for people dying with a chronic disease. However often this process is poorly handled, and general practitioners and primary care clinicians are left to manage an uncoordinated and challenging situation.’

Contrary to popular opinion, there is no clear transition from interventional disease management to specialist palliative care. People with chronic disease often have multiple co-morbidities and need systematic disease management in addition to palliative care to manage their symptoms. They often receive a complex array of health services from a range of providers. Care coordination is increasingly important for people with chronic disease but roles and communication systems are frequently unclear. The implications are especially pronounced for people in community settings and in residential aged care.

The Dying to Know: Integrating Palliative Approaches to Chronic and Life Limiting Illness conference in Dubbo, September 2013 aimed to increase knowledge of essential elements of evidence-based practice relating to the palliative management of people with chronic and life limiting illness. The conference primarily targeted rural clinicians. ACI asked 130 clinicians from a range of disciplines to respond to multiple choice questions about caring for people with chronic diseases as they approach and reach the end of life.

People consulted

• 42% of conference participants were working in remote NSW.

• 31% were from specialist palliative care, 23% primary care, 15% aged care, 12% acute care, 9% specialist chronic disease, 2% critical care and 9% other.

• 79% nursing, 9% allied health, 4% health service manager, 2% educator/researcher and 4% other.

• 27% of participants have worked in their primary area of work for over 20 years.

• 13% spend 1 day a week on work-related travel, 8% about 1.5 days and 8% more than 2 days a week.
### Findings

| Responsibility | 71% agreed or strongly agreed.  
| 20% said it depends.  
| 8% disagreed or strongly disagreed. |
| **Equitable access to care** | 67% either disagreed or strongly disagreed. |
| **Main challenges** | Lack of resources including workforce (31%).  
| Increased complexity and coordination required to provide care (27%). |
| **Best ways to improve care** | Ongoing professional education and training (23%).  
| Formalising networking and shared care arrangements (20%). |
| **Challenge to our current ways of working** | 90% either agreed or strongly agreed. |
| **How big are the challenges** | 93% rated the challenges as major or enormous. |

### Headline findings

This snapshot consultation with rural chronic and specialist palliative care clinicians revealed some important clinical perceptions. These are:

- That equitable access to quality care based on assessed need for people approaching and reaching the end of life in rural NSW with chronic disease is variable.
- That key challenges to providing such care include a lack of resources including workforce; the growing demand for care among people with chronic disease; the perceived increased complexity of care required; and the coordination of care.
- Professional education and formalised networking and shared care arrangements were viewed as key ways to improve care into the future.
### 3.5. Mapping feedback to common themes

Table X summarises feedback from all those consulted for this Diagnostic Report. It lists common issues that arose and identifies the groups of clinicians and key stakeholders, patients, families and carers who most frequently identified those issues as being a priority for our work in developing the model of care. The table also illustrates differing perspectives on the nature of the underlying issues and problems – a key feature of a ‘wicked problem’.

**Table 2: Feedback received for this report**

<table>
<thead>
<tr>
<th>Issue</th>
<th>Consultation Source</th>
<th>Commissioned</th>
<th>ACI</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Primary Care</td>
<td>RACF</td>
</tr>
<tr>
<td>Pain management</td>
<td></td>
<td>ü</td>
<td>ü</td>
</tr>
<tr>
<td>Support for carers</td>
<td></td>
<td>ü</td>
<td>ü</td>
</tr>
<tr>
<td>Bereavement support</td>
<td></td>
<td>ü</td>
<td>ü</td>
</tr>
<tr>
<td>Special needs populations</td>
<td></td>
<td>ü</td>
<td>ü</td>
</tr>
<tr>
<td>Dignity/social support</td>
<td></td>
<td>ü</td>
<td>ü</td>
</tr>
<tr>
<td>Language/cultural issues</td>
<td></td>
<td>ü</td>
<td>ü</td>
</tr>
<tr>
<td>Access to specialist palliative care</td>
<td></td>
<td>ü</td>
<td>ü</td>
</tr>
<tr>
<td>Rural and remote access</td>
<td></td>
<td>ü</td>
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</tr>
<tr>
<td>Access to GPs</td>
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<td>Access to Allied Health</td>
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<tr>
<td>After-hours support</td>
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<tr>
<td>Access to community packages</td>
<td></td>
<td>ü</td>
<td>ü</td>
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<tr>
<td>Equipment</td>
<td></td>
<td>ü</td>
<td>ü</td>
</tr>
<tr>
<td>Language/definitions</td>
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<td>ü</td>
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<tr>
<td>Awareness and choice of care options</td>
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<tr>
<td>Issue</td>
<td>Commissioned</td>
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<tr>
<td></td>
<td>Primary Care</td>
<td>RACF</td>
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<td>Advance Care Planning</td>
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<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Earlier end-of-life discussions</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Involvement of families and carers</td>
<td></td>
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<tr>
<td>Specialist palliative care staffing levels</td>
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</tr>
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<td>Primary care workforce capability</td>
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<tr>
<td>Capacity and expectations of primary care</td>
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<tr>
<td>Community expectations and attitudes</td>
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<tr>
<td>Links between services/integration</td>
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<td>✓</td>
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<tr>
<td>Information and advice for patients, families and carers</td>
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<td>✓</td>
</tr>
<tr>
<td>Communication (among providers)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Communication (with consumers)</td>
<td></td>
<td>✓</td>
<td></td>
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<tr>
<td>Increasing demand for care</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Increasing complexity of care (ie chronic disease)</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Need for better data</td>
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<td>✓</td>
<td></td>
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<tr>
<td>Resourcing/Funding</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Earlier recognition of need</td>
<td>✓</td>
<td>✓</td>
<td></td>
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</tbody>
</table>
4. WHAT DID WE LEARN?

Drawing on the experience of patients, carers and family members as well as the views and experiences of specialist palliative care providers, primary care providers, other stakeholders and the growing field of evidence (including the Fact of Death Analysis), the following list of ten key findings has been generated. This list is a prioritised and condensed version of the more extensive inventory of ‘central drivers’ that our improvement journey has uncovered. The ‘central drivers’ follow the list of ten key findings and provide a more comprehensive, contextual backdrop for our future work in developing a model of care. These ‘drivers’ include a range of enablers for us to consider when developing the model of care.

4.1. Twelve key findings

1. People’s needs change
The needs of the patient, family and carer during their end of life journey vary over time and care setting. Services need to be responsive, coordinated and flexible in meeting these changing needs.

2. Geography matters
People living in rural and remote areas experience additional barriers to receiving quality care at the end of life and rely on local, innovative strategies to help overcome these.

3. There are gaps in the reach of specialist palliative care services
Gaps in specialist palliative care services inhibit the reach of care to people with complex needs and limit the support available to primary care providers.

4. Many people fall through the gaps
Care to people approaching and reaching the end of life is often fragmented and under-utilised by identified population groups or clinical cohorts. These include but are not limited to:
- Aboriginal people
- People of culturally and linguistically diverse backgrounds
- People under the age of 65
- People with non-cancer diagnosis such as Motor Neurone Disease
- People who live alone
- People living with Dementia.

5. Not every patient journey is the same
Current patient journeys are often poorly coordinated. This is particularly true for people with advanced chronic disease who have multiple comorbidities and a much slower and more unpredictable trajectory of functional decline.

6. Hospitals are the ‘default’ carers for many people
People in their last year of life make intense use of admitted acute hospital services including unplanned emergency admissions. Lack of advance care planning for admitted patients inhibits timely and coordinated care for people approaching and reaching the end of life.

7. There is unwarranted variation in clinical care
There are numerous factors that impact on reported unwarranted variation in clinical care. These include a lack of agreed and standardised clinical assessment tools and referral practices; insufficient resourcing, capability and workforce.

8. People want care to be provided as close to home as possible
Although most patients prefer to be cared for as close to home as possible, services required to provide such care are limited and often inflexible.

9. General practitioners and residential aged care providers experience a unique range of structural barriers that limit their capacity to provide palliative and end of life care
A range of structural barriers were identified that reduce the capacity of primary care providers (including GPs) and residential aged care facilities to provide optimal care to people approaching and reaching the end of life. For GPs these include an escalating demand to provide.
increasingly complex and at times, time consuming care. For residential aged care facilities these include inadequate staffing ratios, limited access to specialist palliative care expertise, limited access to GPs with skills and knowledge in providing PEoLC, limited access to a range of allied health services and inadequate training and other workforce development opportunities.

10. Community denial and discomfort of death and dying can block access to appropriate care at the end of life

Patients, families and some health providers are often reluctant to agree to referral to specialist palliative care services or to initiate end of life discussions. The stigma associated with death and dying along with often unrealistic expectations of modern medicine can make preparing for death less likely and this mitigates against a healthy approach to death and a peaceful death in many cases.

11. Language can be confusing

Palliative care means different things to different people. This range of definitions and conceptual understandings inhibit the ability develop an integrated approach to care – one that crosses jurisdictions.

12. Leadership and collaboration is needed

For significant improvements to be made, strong leadership and collaborative action across jurisdictions including public, private, community sectors and individuals needs to occur.

4.2. Central drivers: a more detailed list of findings

This is an expanded list of issues that serve to tease out the ten key findings. When people are approaching and reaching the end of life they need access to the right care at the right time, by the right team and in the right place. The diagnostic review process identified a broad range of issues that impact on care grouped under four major drivers:

Needs of the patient, family and carer during their end of life journey

Roles and relationships with health services

- Patients, families & carers play an integral role in the provision of holistic, patient-centred care to people approaching and reaching the end of life.
- Carers report that specialist palliative care providers help them coordinate care, provide psycho-social support and at times, act as advocates to other services on their behalf.
- Carers seek increased recognition of their expertise and require explicit opportunities for joint care planning.

People living in rural and remote areas

- People living in rural and remote areas experience a range of additional barriers to receiving quality care at the end of life.
- People living in rural and remote areas often describe a strong sense of community that enables and supports patient-centred care.

Support needs of patients, families and carers

- Patients, families and carers need timely support, information and advice to help navigate care and make informed decisions when required.
• Patients, families and carers have expressed a need for earlier end-of-life discussions to help prepare and plan for care. Ideally, these discussions could be initiated by their GP.
• Carers need a range of supports before, during and after the care they provide.

Volunteer services
• Volunteers can provide an invaluable service to support the care provided to people as they approach and reach the end of life.
• Volunteers provide a range of services and support, often supplementing health services.
• Volunteer services can be leveraged to support increased community dialogue about death and dying.

Need for an integrated approach to care

Defining our terms
• Palliative care means different things to different people. It is both described and used to provide care in various ways. The range of interpretations can prevent a coordinated, population-based approach to planning and ensuring quality care to people as they approach and reach the end of life.

Access
• Gaps in specialist palliative care services inhibits the reach of care to people with complex needs as they approach and reach the end of life.
• Gaps in the number and reach of specialist palliative care services inhibit the ability to build capacity in the primary care sector.
• The growing demand associated with end stage of chronic disease poses a major challenge to current ways of providing care to people approaching and reaching the end of life.
• The nature of the chronic illness journey creates challenges to delivery of care to people approaching and reaching the end of life.
• Care to people approaching and reaching the end of life is often fragmented and under-utilised by identified population and community groups. These include Aboriginal people, people with chronic disease, people of culturally and linguistically diverse backgrounds, people under the age of 65, people who are geographically isolated, people with non-cancer diagnosis such as motor neurone disease, people who live alone and people living with dementia.
• Although the number of people with conditions other than cancer receiving specialist palliative care is growing they are currently much less likely to receive specialist (coded) inpatient palliative care.
• Intensive Care Units play a key role in the provision of care to people approaching and reaching the end of life, their families and carers.

Care planning and coordination
• People in their last year of life make intense use of admitted acute hospital services.
• Emergency department resources are heavily consumed by people in their last year of life.
• The lack of advance care planning for people who are admitted to emergency departments, and other departments in acute hospitals, inhibits timely and coordinated care.
• The need for earlier recognition of the dying process in acute care hospitals in particular was broadly identified as a priority.
• Advance Care Planning was viewed by patients, families, carers and health providers as a promising strategy to improve end of life care by honouring and integrating patients’ wishes into care plans.
• Medicare Locals may be well placed to support improved local information sharing among stakeholders (for example, LHDs, RACFs, ambulance services, GPs and other community service providers) to improve care coordination and patient flows between services.

Workforce
• An aging workforce, workforce gaps and ongoing challenges to timely recruitment of specialist palliative care providers contributes to staff working unpaid hours, beyond their scope of practice and to informal and vulnerable service arrangements.
• Specialist palliative care services require new forms of support and educational approaches to primary care providers including other medical specialists –ones that provide ongoing clinical support to empower, build confidence and clarify roles.
• The ability of GPs to provide care to people as they approach and reach the end of life is varied.
• Residential aged care facilities experience a unique set of challenges in providing end of life care to
residents. These include limitations in terms of RACF staff knowledge and experience in end of life care, staffing mixes which favour a low ratio of RNs to other nursing staff (particularly at night) and high levels of staff turnover at some facilities.

Clinical assessment and decision-making
- The lack of standardised clinical assessment tools and referral criteria inhibits the capacity to provide quality care to people approaching and reaching the end of life based on assessed need.

Leadership and governance
- Local Health District End of Life Committees have the potential to provide leadership and the necessary governance arrangements to improve the level and coordination of care to people approaching and reaching the end of life.
- Leadership in the development of a state-wide approach to improving care to people as they approach and reach the end of life needs significant leadership, coordination, inter-sectoral communication and at times, collaboration.

Need to provide care as close to home as possible
- The opportunity to provide care to a loved one in their own home was described by some carers as a comforting and supported experience.
- Good experiences of home care were often associated with good communication with a specialist palliative care nursing team and adequate after-hours support.

Barriers preventing care as close to home as possible
- There are multiple and significant barriers that prevent GPs and RACFs from providing quality end of life care which often pushes patients back to larger acute centres.
- Primary care providers have varied perceptions of the roles of specialist palliative care providers. This can impact negatively on how referrals occur and in how need is assessed more broadly. For example, late referrals or by limiting referrals to people with cancer only.
- Some people living in rural and remote areas want to be cared for in local facilities but not in their home.
- Inadequate discharge planning processes can pose a number of barriers to receiving care as close to home as possible.
- A lack of community services that support people to receive care as close to home as possible prevents such care from occurring.
- People living in RACFs have increasingly complex and acute care needs.
- A lack of adequately trained clinical staff in RACFs prevents their ability to provide quality care to residents as they approach and reach the end of life and increases preventable admissions to emergency departments and use of ambulance services.
- The lack of availability of drugs to support people to receive care at home and in residential aged care facilities limits their ability to manage pain and symptoms.
- Lack of a range of support for people to receive care at home leads to preventable admissions to emergency departments and use of ambulance services.
- Some carers did not know of the resources and supports available that could enable care as close to home as possible to occur.

Community expectations and perceptions
- Health providers often reported that patients and families believe that modern medicine can cure everything and are therefore unwilling to consider having end of life discussions.
- Lack of understanding of what death ‘looks like’ and what to expect as they or their loved one approaches and reaches the end of life can make preparing for death less likely and more traumatic.
- Patients, families and some health providers are often reluctant to become involved with specialist palliative care services because of the stigma associated with death and dying.
- Patients, families and some health providers spoke of the dying process as becoming overly medicalised rather than being seen as a natural and inevitable process.
- End-of-life discussions are often difficult to initiate – particularly with loved ones.
4.3. Charting our findings to patient journeys as they approach and reach the end of life

This section aims to put into context the various perspectives and experiences of those interviewed along three, well recognised trajectories of functional decline put forward by Lynn. These trajectories broadly map the patient’s journey towards the end of life and illustrate typical patterns of need and interactions with health and social services over time.

The three illness trajectories are presented in Figure 15 and described below.

**Figure 15: End of Life Trajectories**

1. **Cancer**: The first trajectory is a period of wellness until a short period of relatively predictable rapid decline as the patient approaches and reaches the end of life. This is commonly associated with cancer, although other diagnoses can have a similar course, and not all cancers follow this course.

2. **Organ failure**: The second trajectory is organ failure due primarily to chronic illness, with slow decline punctuated by acute episodes that often end in sudden death. Chronic heart, lung and kidney disease may fall into this group.

3. **Physical and cognitive frailty**: The third trajectory is characterised by poor long term function with slow decline. Very old patients with dementia, frailty, or multiple comorbidities fall into this category. Younger patients with, for example, motor neurone disease, neurological complications of AIDS, and strokes can also follow this path.

Health systems tend to be organised around patients who are categorised according to primary diagnoses. Dy points out that care should be customised and reorganised “to match the needs, rhythms, and situations of these three trajectories” rather than constructed around a diagnosis or care setting.

Some aspects of care are required across all trajectories such as integrated care plans, seamless coordination,
crisis prevention, symptoms management and support for families and carers. Other elements are mainly relevant to the needs of patients in a particular trajectory. These are summarised below.

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Care</th>
<th>Model of care</th>
<th>Specific care needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Rapid decline over a short period</td>
<td>Well-coordinated care; integration with hospice or palliative care when needed.</td>
<td>Maximise continuity; plan for rapid decline, changing needs, and death; at-home management of patient’s symptoms, acute needs of the care giver, and the dying process.</td>
</tr>
<tr>
<td>2.</td>
<td>Organ Failure</td>
<td>Disease management with education and rapid intervention when needed.</td>
<td>Education on self-care; prevention, early recognition, and management of exacerbations to avoid hospital admission when possible; maintenance of function; assistance with decision making about potentially low yield interventions; plan for potential sudden death.</td>
</tr>
<tr>
<td>3.</td>
<td>Poor function with long-term slow decline</td>
<td>Long term supportive care.</td>
<td>Plan for long term care and future problems; avoid non-beneficial and harmful interventions; support and assistance for long term care givers; reliable institutional care when necessary.</td>
</tr>
</tbody>
</table>

Figures 16–18 illustrate the varied quotes drawn from our consultations, plotted along these three trajectories. Plotting statements made by interviewees along these trajectories provides us with a visual representation of the diverse care needs for patients, families and carers. The figures also help to demonstrate the need for different forms of care coordination required at different points in time.
Figure 16: Trajectory 1
Rapid decline over a few weeks or months before death; mostly cancer

"Dad was diagnosed in April. For 12 months he was okay but then he deteriorated. The pain got to Dad in the end."

"Seeing someone earlier on helps prevent crisis cells later on - ensuring home is suitable to manage."
   Palliative Care Specialist

"Very few GPs would do any home visits and that has a huge impact on what we can achieve."
   (Rural Specialist Palliative Care Nurse)

"The community nurses came. We had a lot of medication for each possible thing ... The home care during this time was very good."
   (Family Member)

"There’s a lack of 24-hour care in the community to allow people to die at home. Services tend to operate 8am-5pm Monday to Friday."
   (Rural Community Nurse)

"In the last week they put the catheter in so I could administer his medications. They wrote down all the details and I added notes to help me. It was very important they could say that out for me – because when you’re in shock you’re going on raw feelings."
   (Carer)
Trajectory 2: Organ failure due primarily to chronic illness

"We're not always in the loop when shared care is with other medical specialists and GPs, so communication is a big problem."
(Rural Palliative Care Specialist)

"Patients with chronic heart failure and respiratory disease miss out. It's hard to know when to change to a palliative approach. They fall through the cracks because we don't know whether they're going to live for 3 days or 3 years."
(Rural Discharge Planner)

"Discharge planning is so important. It should start when people walk through the door of the hospital."
(Metro Palliative Care Specialist)

"Don't know if referrals have changed, but patients are sicker, referred later and more complex."
(Metro Palliative Care Specialist)

"Our acute hospitals need to become more dying friendly. Many hospital clinicians do not know what they do not know about safe, high quality end of life care."
(Metro Specialist Palliative Care Nurse)

"Bereavement counselling closes the loop for family members."
(Intensivist)

“When asked, 93% of rural chronic care and palliative care clinicians believed that the nature of the chronic illness journey creates major challenges to delivering care.”
(Survey of Rural Clinicians – Dubbo 2013)
Trajectory 3: Poor function with long-term slow decline; mostly dementia and frailty

“People with Motor Neurone Disease don’t spend a lot of time in hospital. The need is in the community. That’s where the emphasis of need is.”
(MND Stakeholder)

“There are delays because services are often siloed in the community – they work well within their teams but not often across their silos.”
(Rural Community Nurse)

“A practical difficulty is being able to provide palliative care medications in some of the facility settings.”
(Geriatrician)

“They got me the bed, walker, shower stool and oxygen – things I wouldn’t have been able to arrange myself. Without the specialist palliative care service I don’t know how you’d get all this.”
(Patient at home)

“We couldn’t leave Mum in the room. She had to be moved right away – before the other residents awoke. I would have liked to have some time with her right after she died.”
(Family member of an RACF resident)

It starts the day they come in. Firstly, opening up the conversation even though it’s a difficult time… the conversation has to start straight away. We talk about their life, their stories, their history… which are then coordinated into our care plans.”
(Rural RACF)

People entering Residential Aged Care Facilities have increasingly complex and acute care needs.
5. NEXT STAGES

This diagnostic phase has identified important ways in which the patient’s end of life journey can be improved. The findings of this Diagnostic Report provide ACI with the basis on which to develop solutions and a Model of Care that directly address the core problems that have been identified.

Solutions will:

- be patient-centred;
- be based on strong leadership and inter-sectoral partnerships; and
- involve cycles of improvement, evaluation and adaptation.
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Figure 2. Trajectory 1: Rapid decline over a few weeks or months before death; mostly cancer
Figure 3. Trajectory 2: Organ failure due primarily to chronic illness
Figure 4. Trajectory 3: Poor function with long-term slow decline; mostly dementia and frailty
Figure 5. ACI process for developing the Model of Care: the diagnostic stage
Figure 6. A networked approach for the care of people approaching and reaching the end of life in NSW
Figure 7. Hospitalisations in last year of life, of 36,772 people who died in 2011/12
Figure 8. Hospitalisations in last year of life, per person, NSW 2011/12
Figure 9. Bed days – People likely to require/benefit from PEoLC, NSW 2011/12
Figure 10. Palliative care admissions, NSW 2011/12
Figure 11. Hospitalisations likely to require or benefit from PEoLC, NSW 2011/12
Figure 12. Diagnoses of patients receiving palliative care, NSW 2011/12
Figure 13. Emergency and day-only admissions, NSW 2011/12
Figure 14. Age and setting of death, NSW 2011/12
Figure 15. End of Life trajectories
Figure 16. Trajectory 1: Rapid decline over a few weeks or months before death, mostly cancer
Figure 17. Trajectory 2: Organ failure due primarily to chronic illness
Figure 18. Trajectory 3: Poor function with long-term slow decline; mostly dementia and frailty

Table 1. Differences between groups of patients hospitalised during their last year of life.
Table 2. Feedback received for this report
FOOTNOTES


5. Bate, Mendel and Robert 2008. Organizing for Quality; the improvement journeys of leading hospitals in Europe and the United States, Radcliffe Publishing Ltd.

6. A report prepared by the ACI’s Health Economics and Analysis Team for the Palliative Care Network

7. NSW Agency for Clinical Innovation 2012. Framework for the Statewide Model for Palliative and End of Life Care Service Provision

8. NSW Ministry of Health 2012. NSW Government Plan to Increase Access to Palliative Care 2012-2016, Department of Health


10. Australian Commission on Safety and Quality in Health Care 2013. Safety and Quality of End-of-life Care in Acute Hospitals, Commonwealth of Australia


12. Ibid

13. AIHW 2013. Palliative care services in Australia 2013. Cat. no. HWI 123. Canberra: AIHW.

14. 66 Palliative Medicine Fellows were listed in the NSW branch of the Australasian Chapter of Palliative Medicine in March 2012

15. Palliative care is recognised as a speciality in nursing, but it is not mandatory for nurses working in the area to have specialist palliative care qualifications


17. Diseases/conditions more likely to benefit from PEOlC identified by AIHW: ICD-10-AM diagnosis codes. Excluding palliative care services

18. Excluding palliative care services

19. To avoid double counting, patients with AIHW conditions and cancer admitted for palliative care are counted in the palliative care numbers

20. NSW Agency for Clinical Innovation 2013. Palliative and End of Life Care Diagnostic Report: Issues and Opportunities in Primary Care and Residential Aged Care


22. NSW Ministry of Health 2012. The NSW Government plan to increase access to palliative care 2012-2016. Sydney: NSW Ministry of Health

23. AIHW 2013. Palliative care services in Australia 2013. Cat. no. HWI 123. Canberra: AIHW p 44


26. AIHW 2013. Palliative care services in Australia 2013. Cat. no. HWI 123. Canberra: AIHW


29. NSW Health 2013. Aboriginal Health Impact Statement Policy and Guidelines

30. National Standards Assessment Program 2013. Standards for Palliative Care


32. AIHW 2013. Palliative care services in Australia 2013. Cat. no. HWI 123. Canberra: AIHW p67

33. AIHW 2013. Palliative care services in Australia 2013. Cat. no. HWI 123. Canberra: AIHW p17

34. Burgess, TA, Braunack Mayer AJ, Crawford GB, Beilby JJ 2013. MJA 198(4) Meeting end-of-life care needs for people with chronic disease: palliative care is not enough


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14. Health Economics and Analysis Team ACI 2013. Fact of Death Analysis Palliative and End of Life Care: Analysis of Admitted Patients in the NSW Public Hospital System


18. National Standards Assessment Program 2013. Standards for Palliative Care, Palliative Care Australia

19. NSW Agency for Clinical Innovation 2012. Framework for the Statewide Model for Palliative and End of Life Care Service Provision

20. NSW Agency for Clinical Innovation 2013. Palliative and End of Life Care Diagnostic Report: Issues and Opportunities in Primary Care and Residential Aged Care


22. NSW Ministry of Health 2012. NSW Government Plan to Increase Access to Palliative Care 2012-2016, Department of Health


### ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACI</td>
<td>Agency for Clinical Innovation</td>
</tr>
<tr>
<td>ACFI</td>
<td>Aged Care Funding Instrument</td>
</tr>
<tr>
<td>APDC</td>
<td>Admitted Patient Data Collection</td>
</tr>
<tr>
<td>ALOS</td>
<td>Average length of stay</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>DoHA</td>
<td>Australian Department of Health and Ageing</td>
</tr>
<tr>
<td>EOL care</td>
<td>End-of-life care</td>
</tr>
<tr>
<td>FTE</td>
<td>Full-time equivalent</td>
</tr>
<tr>
<td>LHD</td>
<td>Local Health District</td>
</tr>
<tr>
<td>HEAT</td>
<td>Health Economics and Analysis Team, Agency for Clinical Innovation</td>
</tr>
<tr>
<td>MoC</td>
<td>Model of Care</td>
</tr>
<tr>
<td>PCA</td>
<td>Palliative Care Australia</td>
</tr>
<tr>
<td>PCOC</td>
<td>Palliative Care Outcomes Collaboration</td>
</tr>
<tr>
<td>PEOeLC</td>
<td>Palliative and End of Life Care</td>
</tr>
<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
</tr>
<tr>
<td>RDF</td>
<td>NSW Palliative Care Role Delineation Framework</td>
</tr>
<tr>
<td>SPCS</td>
<td>Specialist Palliative Care Service</td>
</tr>
</tbody>
</table>
## APPENDICES

### Appendix 1. ACI Palliative Care Network Executive

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ghauri Aggarwal (Co-Chair)</td>
<td>Head Palliative Care</td>
<td>Head Palliative Care Concord Repatriation General Hospital</td>
</tr>
<tr>
<td>Geoffrey Berry</td>
<td>ACI Consumer Council</td>
<td>Macarthur Health Service</td>
</tr>
<tr>
<td>Andrew Broadbent</td>
<td>Head Palliative Care</td>
<td>Head Palliative Care Hammondcare HHN Royal North Shore Hospital</td>
</tr>
<tr>
<td>Richard Chye</td>
<td>Director, Sacred Heart Supportive and Palliative Care</td>
<td>Director, Sacred Heart Supportive and Palliative Care St Vincent’s Hospital</td>
</tr>
<tr>
<td>Peter Cleasby</td>
<td>Service Director, Palliative Care</td>
<td>Service Director, Palliative Care Central Coast LHD</td>
</tr>
<tr>
<td>Joshua Cohen</td>
<td>Clinical Nurse Consultant, Palliative Care</td>
<td>Clinical Nurse Consultant, Palliative Care Concord Hospital</td>
</tr>
<tr>
<td>Sue Hanson (Co-Chair)</td>
<td>National Manager, Palliative Care</td>
<td>National Manager, Palliative Care Little Company of Mary</td>
</tr>
<tr>
<td>Janeane Harlum</td>
<td>Area Palliative Care Manager and Service Development</td>
<td>Area Palliative Care Manager and Service Development South West Sydney LHD</td>
</tr>
<tr>
<td>Nick Goryl</td>
<td>Palliative Care Network Project Officer</td>
<td>Palliative Care Network Project Officer Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Theresa Jacques</td>
<td>Director ICU</td>
<td>Director ICU St George Hospital</td>
</tr>
<tr>
<td>Craig Lewis</td>
<td>Senior Staff Specialist, Conjoint Associate Professor UNSW</td>
<td>Senior Staff Specialist, Conjoint Associate Professor UNSW Department of Medical Oncology, Prince of Wales Hospital</td>
</tr>
<tr>
<td>Liz Lobb</td>
<td>Professor, Calvary Health Care Sydney and Cunningham Centre for Palliative Care</td>
<td>Professor, Calvary Health Care Sydney and Cunningham Centre for Palliative Care</td>
</tr>
<tr>
<td>Coral Marks</td>
<td>Clinical Nurse Consultant</td>
<td>Clinical Nurse Consultant Mercy Hospital</td>
</tr>
<tr>
<td>Jenny McKenzie</td>
<td>Nurse Practitioner</td>
<td>Nurse Practitioner Wagga Wagga Community Health Centre</td>
</tr>
<tr>
<td>Yvonne McMaster</td>
<td>Palliative Care Advocate</td>
<td>Palliative Care Advocate</td>
</tr>
<tr>
<td>Sarah Ramsey</td>
<td>Head of Allied Health</td>
<td>Head of Allied Health Hammondcare</td>
</tr>
<tr>
<td>Rob Wilkins</td>
<td>Palliative Care Network Manager</td>
<td>Palliative Care Network Manager Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Stefanie Williams</td>
<td>A/Manager Dementia Care and Disability</td>
<td>A/Manager Dementia Care and Disability NSW Health</td>
</tr>
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</table>
Appendix 2. Codes and classifications used in the Fact of Death Analysis

‘AIHW conditions and diseases’ included in the analysis

AIHW uses the following diagnosis codes to identify patients with diseases other than cancer who are likely to require palliative care.

<table>
<thead>
<tr>
<th>Specific disease</th>
<th>Diagnosis codes (ICD-10-AM)</th>
<th>Source for code specification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic obstructive pulmonary disease (COPD)</td>
<td>J40–J44</td>
<td>WHO 2008</td>
</tr>
<tr>
<td>Dementia and Alzheimer disease</td>
<td>F00–F03, G30</td>
<td>AIHW 2010d</td>
</tr>
<tr>
<td>Heart failure</td>
<td>I50</td>
<td>AIHW 2010d</td>
</tr>
<tr>
<td>Huntington disease</td>
<td>G10, F02.2</td>
<td>Begg et al. 2007</td>
</tr>
<tr>
<td>Liver failure</td>
<td>K70.4, K71.1, K72</td>
<td>—</td>
</tr>
<tr>
<td>Motor neurone disease</td>
<td>G12.2</td>
<td>AIHW 2010d, Begg et al. 2007</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>G35</td>
<td>AIHW 2010d, Begg et al. 2007</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>G71.0</td>
<td>Begg et al. 2007</td>
</tr>
<tr>
<td>Parkinson disease</td>
<td>G20, G21, G22</td>
<td>AIHW 2010d</td>
</tr>
<tr>
<td>Renal failure</td>
<td>N17–N19</td>
<td>AIHW 2010d</td>
</tr>
</tbody>
</table>

Source: Palliative Care Services in Australia 2012, AIHW
### 'Grey Areas': Diagnoses included/excluded from the analysis

<table>
<thead>
<tr>
<th>Underlying diagnosis category</th>
<th>ICD-10-AM principal diagnosis code</th>
<th>Inclusion/Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Certain Infectious and parasitic diseases</td>
<td>A00-B99</td>
<td>Inclusion</td>
</tr>
<tr>
<td>2 Neoplasm (Cancer)</td>
<td>C00-D48</td>
<td>Inclusion</td>
</tr>
<tr>
<td>3 Blood and Immunity Disorders</td>
<td>D50-D89</td>
<td>Inclusion</td>
</tr>
<tr>
<td>4 Endocrine, nutritional and metabolic diseases</td>
<td>E00-E90</td>
<td>Inclusion</td>
</tr>
<tr>
<td>5 Mental and behaviour disorders</td>
<td>F00-F99</td>
<td>Exclusion</td>
</tr>
<tr>
<td>6 Diseases of the nervous system</td>
<td>G00-G99</td>
<td>Inclusion</td>
</tr>
<tr>
<td>7 Eye conditions</td>
<td>H00-H59</td>
<td>Exclusion</td>
</tr>
<tr>
<td>8 Ear Conditions</td>
<td>H60-H95</td>
<td>Exclusion</td>
</tr>
<tr>
<td>9 Diseases of the circulatory system (heart and blood vessels)</td>
<td>I00-I99</td>
<td>Inclusion</td>
</tr>
<tr>
<td>10 Diseases of the respiratory system</td>
<td>J00-J99</td>
<td>Inclusion</td>
</tr>
<tr>
<td>11 Diseases of the digestive system</td>
<td>K00-K93</td>
<td>Inclusion</td>
</tr>
<tr>
<td>12 Diseases of the skin and subcutaneous tissue</td>
<td>L00-L99</td>
<td>Exclusion</td>
</tr>
<tr>
<td>13 Diseases of the musculoskeletal system and connective tissue</td>
<td>M00-M99</td>
<td>Inclusion</td>
</tr>
<tr>
<td>14 Diseases of the genitourinary system (kidneys, urinary system and genitals)</td>
<td>N00-N99</td>
<td>Inclusion</td>
</tr>
<tr>
<td>15 Pregnancy and childbirth</td>
<td>O00-O59</td>
<td>Exclusion</td>
</tr>
<tr>
<td>16 Conditions originating in the parental period</td>
<td>P00-P96</td>
<td>Exclusion</td>
</tr>
<tr>
<td>17 Congenital and chromosomal abnormalities</td>
<td>Q00-Q99</td>
<td>Exclusion</td>
</tr>
<tr>
<td>18 Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified</td>
<td>R00-R99</td>
<td>Inclusion</td>
</tr>
<tr>
<td>19 Injuries and poisonings</td>
<td>S00-T98</td>
<td>Exclusion</td>
</tr>
<tr>
<td>20 External Causes</td>
<td>V01-Y98</td>
<td>Exclusion</td>
</tr>
<tr>
<td>21 Factors influencing health status</td>
<td>Z00-Z99 except when Z51.5 is an additional diagnosis</td>
<td>Exclusion</td>
</tr>
<tr>
<td>22 Special purposes (used for SARS outbreak)</td>
<td>U00-U49 and U80-U89</td>
<td>Exclusion</td>
</tr>
</tbody>
</table>

*Source: Centre for Epidemiology and Evidence, NSW Ministry of Health*
**Top 20 principal diagnosis codes in underlying diagnosis categories of inclusion**

<table>
<thead>
<tr>
<th>Underlying diagnosis category</th>
<th>Principal diagnosis</th>
<th>No of separations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease of the respiratory system</td>
<td>Pneumonia, unspecified</td>
<td>1,575</td>
</tr>
<tr>
<td>Blood and Immunity Disorders</td>
<td>Anaemia, unspecified</td>
<td>1,570</td>
</tr>
<tr>
<td>Diseases of the genitourinary system (kidneys, urinary system and genitals)</td>
<td>Urinary tract infection, site not specified</td>
<td>1,265</td>
</tr>
<tr>
<td>Disease of the respiratory system</td>
<td>Unspecified acute lower respiratory infection</td>
<td>705</td>
</tr>
<tr>
<td>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified</td>
<td>Chest pain, unspecified</td>
<td>630</td>
</tr>
<tr>
<td>Disease of the digestive system</td>
<td>Other and unspecified intestinal obstruction</td>
<td>619</td>
</tr>
<tr>
<td>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified</td>
<td>Ascites</td>
<td>584</td>
</tr>
<tr>
<td>Disease of the circulatory system (heart and blood vessels)</td>
<td>Atrial fibrillation and flutter</td>
<td>549</td>
</tr>
<tr>
<td>Disease of the circulatory system (heart and blood vessels)</td>
<td>Acute subendocardial myocardial infarction</td>
<td>543</td>
</tr>
<tr>
<td>Disease of the digestive system</td>
<td>Constipation</td>
<td>540</td>
</tr>
<tr>
<td>Certain Infectious and parasitic Diseases</td>
<td>Sepsis, unspecified</td>
<td>507</td>
</tr>
<tr>
<td>Disease of the circulatory system (heart and blood vessels)</td>
<td>Cerebral infarction, unspecified</td>
<td>481</td>
</tr>
<tr>
<td>Disease of the digestive system</td>
<td>Gastrointestinal haemorrhage, unspecified</td>
<td>478</td>
</tr>
<tr>
<td>Disease of the respiratory system</td>
<td>Pleural effusion, not elsewhere classified</td>
<td>473</td>
</tr>
<tr>
<td>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified</td>
<td>Syncope and collapse</td>
<td>457</td>
</tr>
<tr>
<td>Certain Infectious and parasitic Diseases</td>
<td>Gastroenteritis and colitis of unspecified origin</td>
<td>455</td>
</tr>
<tr>
<td>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified</td>
<td>Nausea and vomiting</td>
<td>430</td>
</tr>
<tr>
<td>Disease of the circulatory system (heart and blood vessels)</td>
<td>Pulmonary embolism without mention of acute cor pulmonale</td>
<td>393</td>
</tr>
<tr>
<td>Disease of the circulatory system (heart and blood vessels)</td>
<td>Stroke, not specified as haemorrhage or infarction</td>
<td>391</td>
</tr>
<tr>
<td>Disease of the respiratory system</td>
<td>Pneumonitis due to food and vomit</td>
<td>388</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td></td>
<td><strong>13,033</strong></td>
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*excluded were those who received palliative care service and/or had cancers and/or had an AIHW principal diagnosis*
### Top 25 AR-DRGs for those inclusions in the underlying diagnosis category

<table>
<thead>
<tr>
<th>AR-DRG</th>
<th>Number of separations</th>
<th>Bed days</th>
<th>NWAU13</th>
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<tbody>
<tr>
<td>OR Procedures Unrelated to Principal Diagnosis W Catastrophic CC</td>
<td>5,602</td>
<td>23,216</td>
<td>6,945</td>
</tr>
<tr>
<td>Red Blood Cell Disorders W/O Catastrophic or Severe CC</td>
<td>1,829</td>
<td>2,926</td>
<td>624</td>
</tr>
<tr>
<td>Other Digestive System Diagnoses W/O Catastrophic or Severe CC</td>
<td>1,015</td>
<td>2,556</td>
<td>395</td>
</tr>
<tr>
<td>Chest Pain</td>
<td>837</td>
<td>2,900</td>
<td>159</td>
</tr>
<tr>
<td>Kidney and Urinary Tract Infections W/O Catastrophic or Severe CC</td>
<td>822</td>
<td>3,312</td>
<td>461</td>
</tr>
<tr>
<td>Respiratory Infections/Inflammations W Severe or Moderate CC</td>
<td>819</td>
<td>4,772</td>
<td>872</td>
</tr>
<tr>
<td>Circulatory Disorders W AMI W/O Invasive Cardiac Inves Pr W/O Catastroph0ic CC</td>
<td>740</td>
<td>2,131</td>
<td>488</td>
</tr>
<tr>
<td>Stroke and Other Cerebrovascular Disorders, Died or Transferred &lt;5 Days</td>
<td>739</td>
<td>1,163</td>
<td>265</td>
</tr>
<tr>
<td>Respiratory Infections/Inflammations W/O CC</td>
<td>669</td>
<td>2,760</td>
<td>410</td>
</tr>
<tr>
<td>Respiratory Infections/Inflammations W Catastrophic CC</td>
<td>626</td>
<td>5,331</td>
<td>1,155</td>
</tr>
<tr>
<td>Other Digestive System Diagnoses W Catastrophic or Severe CC</td>
<td>565</td>
<td>3,248</td>
<td>660</td>
</tr>
<tr>
<td>Septicaemia W/O Catastrophic CC</td>
<td>513</td>
<td>2,568</td>
<td>628</td>
</tr>
<tr>
<td>Oesophagitis and Gastroenteritis W Cat/Sev CC</td>
<td>466</td>
<td>1,429</td>
<td>194</td>
</tr>
<tr>
<td>Kidney and Urinary Tract Infections W Catastrophic or Severe CC</td>
<td>465</td>
<td>3,820</td>
<td>707</td>
</tr>
<tr>
<td>Miscellaneous Metabolic Disorders W/O Catastrophic or Severe CC</td>
<td>445</td>
<td>1,171</td>
<td>225</td>
</tr>
<tr>
<td>Kidney and Urinary Tract Signs and Symptoms W/O Catastrophic or Severe CC</td>
<td>423</td>
<td>982</td>
<td>147</td>
</tr>
<tr>
<td>Syncope and Collapse W/O Catastrophic or Severe CC</td>
<td>410</td>
<td>1,037</td>
<td>153</td>
</tr>
<tr>
<td>Red Blood Cell Disorders W Catastrophic or Severe CC</td>
<td>405</td>
<td>2,048</td>
<td>466</td>
</tr>
<tr>
<td>Stroke and Other Cerebrovascular Disorders W Catastrophic CC</td>
<td>398</td>
<td>5,222</td>
<td>1,271</td>
</tr>
<tr>
<td>GI Obstruction W/O Catastrophic or Severe CC</td>
<td>385</td>
<td>1,280</td>
<td>192</td>
</tr>
<tr>
<td>Stroke and Other Cerebrovascular Disorders W Severe CC</td>
<td>371</td>
<td>3,363</td>
<td>631</td>
</tr>
<tr>
<td>Respiratory Signs and Symptoms W/O Catastrophic or Severe CC</td>
<td>364</td>
<td>743</td>
<td>101</td>
</tr>
<tr>
<td>GI Haemorrhage W/O Catastrophic or Severe CC</td>
<td>362</td>
<td>907</td>
<td>127</td>
</tr>
<tr>
<td>Other Respiratory System Diagnosis W/O CC</td>
<td>352</td>
<td>1,188</td>
<td>159</td>
</tr>
<tr>
<td>Other Respiratory System Diagnosis W Severe or Moderate CC</td>
<td>343</td>
<td>1,865</td>
<td>340</td>
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<tr>
<td><strong>Subtotal</strong></td>
<td><strong>19,965</strong></td>
<td><strong>81,938</strong></td>
<td><strong>17,776</strong></td>
</tr>
</tbody>
</table>
Appendix 3. Tools used in the consultation

Consulting with Specialist Palliative Care Services

Introductory letter

Thank you for agreeing to participate in our state-wide consultations with specialist palliative care providers to inform the ACI Palliative and End of Life Model of Care.

The development of this model is led by the ACI Palliative Care Network. The purpose of this Network is to drive continuous improvement in palliative and end of life care for all people approaching or reaching the end of their life in NSW.

What is the NSW Palliative Care Model of Care?

One of the key priorities of the Network is to develop an evidence-based and patient-focused model of care. A model of care broadly defines the way health services are delivered. It outlines best practice care and services for a person, and in this case, their carer or family member, as they progress through the stages of their condition. It aims to ensure people get the right care, at the right time, by the right team and in the right place.

The vision for the NSW Palliative and End of Life Model of Care (MoC) is to ensure that all NSW residents have equitable access to quality care based on assessed need as they approach and reach the end of life.

What is the scope of the interview?

The interview will seek to better understand your views on a range of issues including:

- Strengths in and challenges to providing care.
- Patient reach and access.
- Service coordination.
- Your views on how best to ensure accessible, quality care based on patient need.

To assist us to understand and interpret responses to the upcoming interview, could you please provide us with the following information about your service?

Name of Service: ...................................................................................................................................................................................................................

Local Health District or Region: ...........................................................................................................................................................................................................

Location of Service:  

- Rural  
- Regional  
- Metropolitan

Tick all that apply:

- Inpatient service:

- Community service:

- Consultancy Service  
  - Onsite  
  - In-reach  
  - Outpatient clinic  
  - Other: ............................................................................................................................................................................................................
Do you provide services to RACF?

Does the service provide any form of after hours support?
- After hours visit
- Telephone
- Other

Do you provide any Fly-in Fly-out arrangements to other LHDs?
- To where?
- How often?

Please provide a brief description of the service (ie features of this service you feel would be beneficial to know about prior to the interview)

Do you know what proportion of patients you see have a cancer diagnosis vs a non-cancer diagnosis?

Your name and position: .................................................................

Contact details: ...........................................................................

Thank you again for agreeing to participate.

If you have any questions please contact:

**Rob Wilkins**
ACI Palliative Care Network Manager
on (02) 9464 4637
or the LHD Project Lead.

Please forward these details to: rob.wilkins@aci.health.nsw.gov.au
**Interview questions**

Name of individual or group: ..........................................................

Position(s): ......................................................................................

Date of Interview: ..............................................................................

Service: ............................................................................................

**Context**

1. What is the history or evolution of this service – how has the service grown? In what directions and why?

2. What do you believe are the key strengths of your service?

**Access**

3. How do patients access your service? How do you assess the needs of patients referred to your service?
   - Are there referral protocols, how does referral occur, relationships?

4. What are the challenges or barriers for you in providing palliative care based on assessed need?

5. Are there patient cohorts / population groups who you feel miss out or are underserviced?
   - Why?

Show and describe the “Level of need within the Population of Patients” triangle

![Level of Need within the Population of Patients Approaching and Reaching the End of Life](image)

6. Does your service work within this Model?

7. What are some of the challenges in working within this model?
8. Do you think patients get the appropriate level of care in accordance with their needs?
   • If not, where are they receiving care?
   • Is this appropriate?

9. In your opinion, what needs to happen for this to work better?

**Coordination**

Show and describe the diagram below

![Diagram](image)

*Source: Adapted from the Framework for Palliative Care Service Planning (PCA, 2005).*

10. Does your service work within this model?

11. What are some of the challenges in working within this model?

12. How do you assess high and low patient need?

13. Can you describe the relationships / roles you have with primary care providers?
   *Prompts: generalist nurses, GPs, inreach, outreach, consults*

14. Describe the relationship / roles you have with other specialist providers?
   *Prompts: inreach, outreach*

15. What (if any) structural arrangements support / enable your service to operate under this model?

**Patient, carer and family participation**

16. What programs or activities are you undertaking now to assure patient-centred approaches?
   *Prompts: their values, preferences and unique needs are met, use of assessment instruments.*

**Resourcing and sustainability**

17. If our vision for our model of care is to ensure that all NSW residents have access to quality care based on assessed need as they approach and reach the end of their life, What things need to occur for this to happen locally? Statewide?
Consulting with Primary, Acute, Critical and Community Care Services

Introductory letter

Thank you for agreeing to participate in our statewide consultations with a range of care providers to inform the ACI Palliative and End of Life Model of Care.

The development of this model is led by the ACI Palliative Care Network. The purpose of this Network is to drive continuous improvement in palliative and end of life care for all people approaching or reaching the end of their life in NSW.

What is the NSW Palliative Care Model of Care?

One of the key priorities of the Network is to develop an evidence-based and patient-focused model of care. A model of care broadly defines the way health services are delivered. It outlines best practice care and services for a person, and in this case, their carer or family member, as they progress through the stages of their condition. It aims to ensure people get the right care, at the right time, by the right team and in the right place.

The vision for the NSW Palliative and End of Life Model of Care (MoC) is to ensure that all NSW residents have equitable access to quality care based on assessed need as they approach and reach the end of life.

What is the scope of the interview?

The interview will seek to better understand your views on a range of issues including:

- Strengths in and challenges to providing care.
- Patient reach and access.
- Service coordination.
- Your views on how best to ensure accessible, quality care based on need.

To assist us to understand and interpret responses to the upcoming interview, could you please provide us with the following information about your service?

Name of Service:

Local Health District or Region:

Location of Service:  
- Rural  
- Regional  
- Metropolitan

Please provide a brief description of the service (ie features of this service you feel would be beneficial to know about prior to the interview)

Your name and position:

Contact details:

Thank you again for agreeing to participate.

If you have any questions please contact:

Rob Wilkins
ACI Palliative Care Network Manager on (02) 9464 4637 or the LHD Project Lead.

Please forward these details to: rob.wilkins@aci.health.nsw.gov.au
Interview questions

Name of individual or group: ...........................................................................................................................................................................................................

Position(s): ...........................................................................................................................................................................................................

Date of Interview: ...................................................................................................................................................................................................

Service: ...........................................................................................................................................................................................................

Context

1. Please describe the service.

2. How would you describe your role in providing care to your patients or residents who are approaching and reaching the end of their lives? (ie palliative, refer on, quality end of life care)
   - Is there a service model or overall approach?

Strengths & challenges

3. What do you believe are the key strengths of your service in meeting the needs of people, approaching and reaching the end of their lives, their families and carers?

4. What are the key challenges to providing such care?
   - For community nurses: What are the barriers and enablers to keeping patients at home or in a RACF?

5. Are there patient cohorts/populations groups who you feel miss out or are underserviced?

6. Are there programs you think we should know about that increase access for particular patient cohorts/population groups?

For Primary Care Providers only:

Show and describe the “Level of need within the Population of Patients” triangle.

Level of Need within the Population of Patients Approaching and Reaching the End of Life

NEEDS

- Complex
- Intermediate
- Non-complex

PATIENTS

- Patients with complex, unstable conditions requiring ongoing care. Primary care service would remain involved in care in partnership with specialist service, which would have an ongoing role in care provision.

- Patients requiring consultation-based specialist palliative care on an episodic basis would remain under care of primary care service.

- Patients approaching end of life whose needs can be met by a range of primary care and non-specialist palliative care options.
7. Does your service work within this Model?

8. What are some of the challenges in working within this Model?

9. Do you think patients get the appropriate level of care in accordance with their needs?
   
   - If not, where are they receiving care?
   
   - Is this appropriate?

10. In your opinion, what needs to happen for this to work better?

    **Coordination & transition**

11. What (if any) structural arrangements support /enable your service to provide an appropriate level of care to people approaching and reaching the end of their lives?
    
    (ie skilled and knowledgeable staff, clear procedures for referral based on patients assessed needs, good relationships with other service providers, GPs, Specialist PC Services)

12. Can you describe how patients approaching and reaching end of life, move to and from your service? Are there any bottlenecks? Are there any processes or protocols that assist with this?

    **Capacity building**

13. What programs or activities are you undertaking now to assure patient-centred approaches?
    
    Prompts: their values, preferences and unique needs are met, use of assessment instruments, ACP

    **Resourcing and sustainability**

14. If our vision for our model of care is to ensure that all NSW residents have access to quality care based on assessed need as they approach and reach the end of their life. What things need to occur for this to happen locally? Statewide?
Consulting with patients

Patient, family and carer information sheet

You are invited to participate in an interview as part of the consultation process for developing Models of Care at the NSW Agency for Clinical Innovation. This is an important area of work in which health systems are being redesigned to improve the experiences of patients and their carers. We are interested in hearing about your experience so that we can identify ways to improve it. In this instance, we are focussing our discussions around the experiences of people living with an advanced illness.

Do you think you can help us with these interviews?

What is the Model of Care?

A model of care broadly defines the way health services are delivered. It outlines best practice care and services for a person, and in this case, their carer or family member, as they progress through the stages of their condition. It aims to ensure people get the right care, at the right time, by the right team and in the right place.

The aim is to bring about improvements in the way services are delivered or coordinated.

What is the purpose of these interviews?

We would like to hear about these particular aspects the care provided to you, your family member or the person you cared for:

- Ease of access to care.
- Respect for patient’s values, preferences and expressed needs.
- Coordination and integration of care.
- Information and education provided.
- Transition and continuity.
- Your physical comfort.
- Your emotional support and alleviation of fear and anxiety.
- Involvement of family and friends.

How will the information be used?

Your participation is completely voluntary and the information you provide will not be disclosed to the people providing your care. While we will collect information about you including your name and contact details, the information you provide will be de-identified before we use it. The information you provide will be used to improve the standard and coordination of a range of health services in NSW.

What will the interview involve?

If you agree to participate in an interview, we will arrange a time that is convenient for you. If you are willing to tell us about your experience, we will ask you to sign the Participant Consent Form on the next page.

The interview will take approximately one hour. We will not ask you detailed questions about your medical treatments or results – we want to know about how the health system works and communicates information to you and how you (and your carer) feel about your experiences.

Should you have any further questions or would like to talk to someone about it, please contact:

Rob Wilkins, ACI Palliative Care Network Manager
on (02) 9464 4637 or rob.wilkins@aci.health.nsw.gov.au
or contact your health service manager or nurse in charge.
Patient experience discussion record: introductory comments

- Hello, my name is: (spend a few moments on this and introduce yourself fully – where you work, what that means, why you do what you do)

- Thank you for agreeing to speak with me. Your information will assist in developing solutions to improving experiences of patients and their families and carers.

- We are looking closely at the systems involved in delivering health care – our people, our processes and our technology and how they all work together to provide health care services to you.

- It is very important that we understand how our systems work from the point of view of patients and their carers. Then we can improve them and make the experience of people like you better in future.

- Thank you again for agreeing to speak with me about your health care experiences. Please be as honest and constructively critical as you can, because this will really help us.

- I reassure you that we will protect your privacy. When we describe your experiences to our colleagues, we will do it in a way that protects your privacy. So we will never reveal your name nor where you come from.

  o **Note:** informed consent means the person knows how their information will be used, by whom, where it will be stored and for how long.

Other considerations in opening discussion

- Provide overview of project and reiterate content of Patient Information Sheet

- Refer to contacts within the consent form if they have any questions or concerns

- Confirm their ability to withdraw their story at any time by returning portion of consent form and their information will no longer be used

- Obtain written consent if not already received

- Ask if participant has any questions or concerns prior to conducting the discussion.

Name of interviewee: ...................................................................................................................................................................................................................

Place of interview: ...................................................................................................................................................................................................................

Date interviewed: ...................................................................................................................................................................................................................

Name of interviewer: ...................................................................................................................................................................................................................
Patient interview questions

Opening high level question

1. Please describe your health care experiences from beginning to end.
   *Prompts:* What triggered the need for health care?
   What were the steps along the way?
   What did you see, hear, feel?

2. What were the best or most positive aspects of your health care experience?
   *Prompts:* Was there any part of your experience that was particularly reassuring for you, your family member or your carer?
   How did the situation affect you emotionally and physically?

3. Thinking back over the last 12 months or so, what did not work so well for you during your health care?
   What constructive criticism can you offer us to we can improve things?
   *Prompts:* Was there anything you expected that did not happen?
   What were you most concerned about?
   How did the situation affect you emotionally and physically?
   What would you have preferred?
   How could the situation be changed?
   What could make a difference?
Confirm with patient/family member/carer where their positive experiences “fit” in the Picker Domains:

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Prompts
These questions are only to be considered as prompts if there are gaps in the patients story that don’t cover a particular domain.

Access to care
Thinking back over the last 12 months or so, can you describe what it was like for you accessing care? Then what? What happened next… until you get to the present.

Respect for patient’s values, preferences and expressed needs
Were your values, preferences and expressed needs met? Can you describe how they were or were not met? What happened? Or what did that look like?

Coordination and integration of care
Were you involved in the decisions about the types of care you received along the way? or Did caregivers know about you at each step of the way?

Information and education
Were you given the types of information you needed to make decisions about your care? Was that information provided in a timely way? Was it given in a way that you understood?

Physical comfort
Could you describe your experience of pain and how it was controlled? Did this change over time?

Emotional support and alleviation of fear and anxiety
In what ways did you feel emotionally supported? Did you feel anxious at times? Can you describe how you were supported?

Involvement of family and friends
Were family and friends involved to the extent that you wanted them to be?
Checklist

Signed patient consent

What time period does this interview cover?  Period: .........................................................

Who was the story told by?

☐ Patient  ☐ Carer or family member  ☐ Patient and Carer together  ☐ Other: ............................................

Patient diagnosis (if known): ........................................................................................................

Is the patient...

☐ Male  ☐ Female

What year was the patient born? ........................................................................................................

What is the patient’s place of birth?

☐ Australia  ☐ Other: ..........................................................................................................................

Is the person of Aboriginal or Torres Strait Islander origin?

☐ No  ☐ Yes, Aboriginal  ☐ Yes, Torres Strait Islander

Where does the patient normally live?

☐ Capital city (Sydney)  ☐ Regional city  ☐ Rural area
Consulting with carers and families

Family and carer experience discussion record:
introductory comments

• Hello, my name is: (spend a few moments on this and introduce yourself fully – where you work, what that means, why you do what you do).

• Thank you for agreeing to speak with me. Your information will assist in developing solutions to improving experiences of patients and their families and carers.

• We are looking closely at the systems involved in delivering health care – our people, our processes and our technology and how they all work together to provide health care services to you.

• It is very important that we understand how our systems work from the point of view of patients and their carers. Then we can improve them and make the experience of people like you better in future.

• Thank you again for agreeing to speak with me about your health care experiences. Please be as honest and constructively critical as you can, because this will really help us.

• I reassure you that we will protect your privacy. When we describe your experiences to our colleagues, we will do it in a way that protects your privacy. So we will never reveal your name nor where you come from.
  
  o Note: informed consent means the person knows how their information will be used, by whom, where it will be stored and for how long.

Other considerations in opening discussion

• Provide overview of project and reiterate content of Patient Information Sheet.

• Refer to contacts within the consent form if they have any questions or concerns.

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• Ask if participant has any questions or concerns prior to conducting the discussion.

Name of interviewee:  ...................................................................................................................................................................................................................

Place of interview: ..........................................................................................................................................................................................................

Date interviewed: ..........................................................................................................................................................................................................

Name of interviewer: ..........................................................................................................................................................................................................

Interview questions

Opening High level question

1. Please describe [name]’s health care experiences from beginning to end.
   Prompts: What triggered the need for his/her health care?
   What were the steps along the way?
   What did he/she see, hear, feel?

2. What do you think were the best or most positive aspects of [name]’s health care experience?
   Prompts: Was there any part of his/her experience that was particularly reassuring for you?
   How did the situation affect him/her emotionally and physically?

3. Thinking back over the last 12 months or so, what do you think did not work so well for [name] during his/her health care? What constructive criticism can you offer us so we can improve things?
   Prompts: Was there anything he/she expected that did not happen?
   What was he/she most concerned about?
   How did the situation affect him/her emotionally and physically?
   What would he/she have preferred?
   How could the situation be changed?
   What could make a difference?
Confirm with family member/carer where their positive experiences “fit” in the Picker Domains:

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Prompts

These questions are only to be considered as prompts if there are gaps in the patient's story that don't cover a particular domain.

Access to care

Thinking back over the last 12 months or so, can you describe what it was like for [name] accessing care? Then what? What happened next...until you get to the present.

Respect for patient's values, preferences and expressed needs

Were [name]'s values, preferences and expressed needs met? Can you describe how they were or were not met? What happened? Or what did that look like?

Coordination and integration of care

Was [name] involved in the decisions about the types of care he or she received along the way? or Did caregivers know about [name] at each step of the way?

Information and education

Was [name] given the types of information he/she needed to make decisions about their care? Was that information provided in a timely way? Was it given in a way that you understood?

Physical comfort

Could you describe your perspective on [name]'s experience of pain and how it was controlled? Did this change over time?

Emotional support and alleviation of fear and anxiety

In what ways that you are aware of does/did [name] feel emotionally supported? Are you aware if [name] feels/felt anxious at times? Can you describe how he/she was supported?

Involvement of family and friends

Were you involved to the extent that [name] wanted you to be?
Checklist

Signed patient consent

What time period does this interview cover?

Period: ............................................................

Who was the story told by?

- Patient
- Carer or family member
- Patient and Carer together
- Other: ......................................................

Patient diagnosis (if known): ..............................................................

Is the patient...

- Male
- Female

What year was the patient born?

What is the patient’s place of birth?

- Australia
- Other: ..............................................................

Is the person of Aboriginal or Torres Strait Islander origin?

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander

Where does the patient normally live?

- Capital city (Sydney)
- Regional city
- Rural area
Consulting with key stakeholders

Thank you for agreeing to participate in our state-wide consultations with a range of care providers, patients, carers, families and other key stakeholders to inform the ACI Palliative and End of Life Model of Care.

The development of this model is led by the ACI Palliative Care Network. The purpose of this Network is to drive continuous improvement in palliative and end of life care for all people approaching or reaching the end of their life in NSW.

What is the NSW Palliative Care Model of Care?

One of the key priorities of the Network is to develop an evidence-based and patient-focused model of care. A model of care broadly defines the way health services are delivered. It outlines best practice care and services for a person, and in this case, their carer or family member, as they progress through the stages of their condition. It aims to ensure people get the right care, at the right time, by the right team and in the right place.

The vision for the NSW Palliative and End of Life Model of Care (MoC) is to ensure that all NSW residents have equitable access to quality care based on assessed need as they approach and reach the end of life.

What is the scope of the interview?

The interview will seek to better understand your views on a range of issues including:

- Strengths in and challenges to providing care.
- Patient reach and access.
- Service coordination.
- Your views on how best to ensure accessible, quality care based on need.

Name of Service: ...........................................................................................................................................................................................................

Local Health District or Region: ...........................................................................................................................................................................................................

Location of Service: □ Rural □ Regional □ Metropolitan □ Statewide

Please provide a brief description of the organisation:

Your name and position: ...........................................................................................................................................................................................................

Contact details: ...........................................................................................................................................................................................................
Context

1. How would you describe your organisation’s role in contributing to the provision of quality care to people who are approaching and reaching the end of their lives?

Strengths & challenges

2. In relation to your role, what are some of the challenges or gaps in services for people approaching and reaching the end of their lives?
3. How can these be improved?
4. What is working well that you think we could build on?

5. Optional Question: Describe the “Level of need within the Population of Patients” triangle

![Level of need within the Population of Patients Approaching and Reaching the End of Life](image)

5. What are some of the challenges in working within this model?

Resourcing and sustainability

6. If our vision for our model of care is to ensure that all NSW residents have access to quality care based on assessed need as they approach and reach the end of their life. What things need to occur for this to happen locally? Statewide?
Information for LHD Project Leads

Planning for consultations

Thank you again for agreeing to act as a Project Lead and for agreeing to guide and assist with our consultations in your Local Health District. From July to October 2013, the ACI Palliative Care Network is seeking to consult widely with a range of people who provide care to those approaching and reaching the end of their lives (and not solely specialist palliative care providers). This means that we are looking to interview people across service sectors that span primary, specialist palliative care, acute, sub-acute and community services.

The purpose of this document is to outline the range of people and services we would like to consult with and to propose some ways forward. Ideally consultations would be face-to-face; however we recognise that this is not always possible and are happy to make arrangements to accommodate busy schedules. Semi-structured interviews can be with clinical teams or conducted individually. Ideally, group discussions will be multi-disciplinary.

There may also be opportunity for us to join in with a planned staff meeting and to conduct our consultation within that meeting.

The following is a list of people and services we hope to consult with to inform the Model of Care. We understand that we may not reach all of these in every LHD.

1. Specialist Palliative Care services

This includes inpatient, consultancy and/or community palliative care services. Here we recognise the variety of service models that specialist palliative care providers work under.

2. Critical Care services

A significant amount of end of life care occurs in critical care environments. We hope to consult with such services including (but not limited to) Emergency Departments, Intensive Care Units and Ambulance Services.

3. Acute Care services

Acute Care Services also provide a considerable amount of end of life care. These include but are not limited to specialist medical fields such as Oncology, Cardiovascular, Respiratory, Renal, Geriatrics and Neurology services.

4. Primary and Community Care services

This group provides the first point of contact for the largest cohort of patients approaching and reaching the end of their lives. We would like to seek your advice about the primary and community care providers. A priority of the NSW Government Plan to Increase Access to Palliative Care is the development of an integrated network of primary care, specialist palliative care, aged care and community services, and the need for access to competent and supported primary care providers. The need to consult with Aboriginal Health Workers and/or Aboriginal Medical Services is important for the development of the Model of Care.

5. Patients, families and carers

To ensure that our Model of Care is directly informed by an analysis of a range of experiences of patients, families and carers we plan to conduct interviews with patients in the last year of life, their carers and families.

This understanding will assist us in improving experiences for patients, carers and families in future.

The interviews will be conducted by ACI program staff in partnership with the ACI Patient and Staff Experience Team. This team has extensive statewide experience in profiling the needs of health staff, patients, their families and carers to improve patient-centred care.

Participation is completely voluntary and the information provided will not be disclosed to the people providing the patient’s care. While we will collect participants’ personal information including name and contact details, the information collected in interviews will be de-identified.

Our aim is to make contact with people living with a broad range of advanced illnesses, including those with a non-cancer diagnosis.
To assist with nominating appropriate patients for these interviews, we ask that you consider the following broad eligibility criteria:

1. *Does the patient have a life-limiting illness?*

2. *Would you be surprised if the patient died within the next 12 months or so?*

These questions form part of the Centre to Advance Palliative Care (CAPC) Consensus criteria to assist with identifying patients in need of end of life care (Weissman & Meir, 2011).

We appreciate your assistance in contacting the appropriate health service managers to ensure the purpose for and scope of these interviews is made clear; to provide an overview of the Patient, Family & Carer Information Sheet; to explain the informed consent process and to ensure there is a clear process for post interview de-briefing or follow-up if desired.

Thank you again for your time and willingness to assist the ACI Palliative Care Network to undertake these consultations.

**Reference**

Consulting across NSW to inform the Palliative and End of Life Model of Care

The ACI Palliative Care Network

The ACI’s clinical networks provide a framework for clinicians and consumers to meet across regional and service boundaries with a mandate to drive improvements in care through innovation in clinical practice. The ACI Palliative Care Network has over 300 specialist and primary clinicians, service managers, consumers and researchers from across all care settings where people may receive care as they approach the end of their life. The purpose of the Network is to drive continuous improvement in palliative and end of life care for all people approaching or reaching the end of their life in NSW.

The Co-Chairs for the Network are Dr Ghauri Aggarwal and Ms Sue Hanson.

What is the NSW Palliative and End of Life Model of Care?

One of the key priorities of the Network is to develop an evidence-based and patient-focused model of care. A model of care broadly defines the way health services are delivered. It outlines best practice care and services for a person as they progress through the stages of their condition, and includes the experiences of their carer or family member as well. It aims to ensure people get the right care, at the right time, by the right team and in the right place.

The vision for the NSW Palliative and End of Life Model of Care (MoC) is to ensure that all NSW residents have equitable access to quality care based on assessed need as they approach and reach the end of life.

Seeking support from Local Health Districts (LHDs): the roles of Executive Sponsors and Project Leads in each LHD

In order to consult as thoroughly as possible, we have sought the cooperation of all Local Health Districts. We have asked each LHD for nominations for an Executive Sponsor and a Project Lead. The role of the Executive Sponsor is to authorise access to relevant LHD services and to report the project progress to the LHD Chief Executive. The LHD Project Lead has a broad understanding of the current Palliative and End of Life services in the LHD, can organise meetings between relevant LHD stakeholders and the ACI and is the main contact point for the ACI.

Your cooperation in advising and supporting consultations is greatly appreciated. Two teams will be seeking to visit LHD services:

- A team from the ACI who will be seeking to gain a better understanding of the ways in which a range of services are provided to people approaching and reaching the end of their lives. The scope of this consultation is with specialist palliative care services and a range of other services that provide care for patients as they approach and reach the end of their life. These include services such as ED and ICU units, services provided by generalist community teams and those provided by other medical specialists.

Consulting widely to inform the Model of Care

From July to October 2013, the ACI Network is currently entering a diagnostic phase where we try to better understand the root causes of problems to improve quality care for all people approaching and reaching the end of their lives. This phase will include extensive consultations across NSW in order to to learn about the variety of experiences patients, carers and families have in their last year of life. We are aware of the large amount of programs and plans that focus on some aspect of palliative and end of life care in NSW and we are coordinating our work with the Clinical Excellence Commission, the NSW Ministry of Health and other agencies to prevent any duplication and to ensure an integrated response. We are also aware that some Local Health Districts have significantly progressed innovative work in this area. Our intention is to learn from these so they can inform the Model of Care.

We are seeking to consult widely with a broad range of people who provide care to those approaching and reaching the end of their lives including specialist palliative care providers, primary care providers, General Practitioners, residential aged care facility staff and those who work in acute care facilities.
• In coordination with the ACI team, KPMG has been commissioned to gain an understanding of the capacity and support needs of a range of primary care providers and residential aged care facilities in providing palliative and end of life care.

Consultations can take a number of approaches and can usually involve a mix of:

• One-to-one semi-structured interviews with clinicians, patients, carers or family members
• Site visits involving discussion groups with teams of health workers

How will this information be used?

The development of a statewide Palliative and End of Life Model of Care is a staged and participatory process.

Participation is voluntary and the information your LHD provides will be used to:

• Describe a range of journeys and experiences of patients in their last year of life, their carers and families.
• Showcase innovative approaches to providing care to people approaching and reaching the end of their lives based on assessed need.
• Describe any structural arrangements that support sustained, equitable and coordinated access to such care.
• Identify any challenges or barriers that impede the provision of such care.

Information from these consultations will be considered alongside other forms of evidence. These include an analysis of the costs and current activity associated with the provision of palliative and end of life care, ongoing consultations through the NSW Palliative Care Network and reviews of research-based policy and planning literature.

Later this year a state-wide ACI Palliative Care Network Forum will be held that will present key findings from consultations, data analysis and reviews of evidence. Network members and others will have the opportunity to provide feedback and analysis on the findings to date and to begin to identify key solutions the will form part of the Model of Care.

More information


Thank you again for your assistance and upcoming contributions to the development of this important work.

Should you have any concerns regarding provision of information for this project, please contact:

Rob Wilkins
ACI Palliative Care Network Manager
on (02) 9464 4637
or rob.wilkins@aci.health.nsw.gov.au
### Appendix 4. ACI Contracted Consultations: details of those who participated

<table>
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<tr>
<th>Stakeholder type</th>
<th>Region</th>
<th>Stakeholder</th>
<th>Number of participants</th>
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<td>Anglican Retirement Villages</td>
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<td><strong>Total</strong></td>
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<td></td>
<td><strong>489</strong></td>
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</table>
## Appendix 5. ACI Statewide Consultations: details of those who participated

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Description</th>
<th>Numbers consulted</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Service Providers</strong></td>
<td></td>
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</tr>
<tr>
<td>Central Coast LHD</td>
<td>District End of Life Care / Advance Care Planning Committee</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Multidisciplinary Specialist Paediatric Palliative Care team – John Hunter Hospital</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Consumers: Family Member and Carer</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Consumer: Family member</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Multidisciplinary Specialist Paediatric Palliative Care team – Sydney Children’s Hospital at Randwick</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Multidisciplinary Specialist Paediatric Palliative Care team – Children’s Hospital at Westmead</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Consumer: Family member</td>
<td>1</td>
</tr>
<tr>
<td>Far West LHD</td>
<td>Broken Hill Specialist Palliative Care, Acute and Community Care providers, Ambulance Service</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Far West remote community and chronic care providers, Medicare Local representatives</td>
<td>8</td>
</tr>
<tr>
<td>HammondCare</td>
<td>HammondCare North Palliative Care Standards, Practice and Communication Forum – Multidisciplinary Committee</td>
<td>17</td>
</tr>
<tr>
<td>Hunter New England LHD</td>
<td>HNELHD Multidisciplinary Palliative Care Clinical Stream Leadership Group</td>
<td>15</td>
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<tr>
<td></td>
<td>Calvary Mater Hospice Staff and Outreach Workers – Multidisciplinary Team</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Calvary Mater and LHD Palliative Care Director</td>
<td>1</td>
</tr>
<tr>
<td>Organisation</td>
<td>Description</td>
<td>Numbers consulted</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------</td>
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</tr>
<tr>
<td><strong>Illawarra Shoalhaven LHD</strong></td>
<td>Specialist and Primary Palliative Care Multidisciplinary Team including Alzheimer’s Australia, Medicare Local, Aged Care</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Multidisciplinary staff from ED and ICU</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Multidisciplinary staff from acute services including Renal, Radiation Oncology, Haematology and subacute services including Rehab, Aged Care and Palliative Care</td>
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</tr>
<tr>
<td></td>
<td>Multidisciplinary staff from community, aged care and subacute services</td>
<td>10</td>
</tr>
<tr>
<td><strong>Justice Health and Forensic Mental Health Network</strong></td>
<td>Clinical Director and Quality Systems Manager</td>
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</tr>
<tr>
<td><strong>Mid North Coast LHD</strong></td>
<td>Coffs Harbour – Multidisciplinary staff from acute, critical and subacute services</td>
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</tr>
<tr>
<td></td>
<td>Coffs Harbour – Multidisciplinary staff from community health, chronic care, aged care and a private hospital</td>
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<tr>
<td></td>
<td>Consumers: Patient and Carer</td>
<td>2</td>
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<tr>
<td></td>
<td>Consumer: Family member</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Macksville – LHD Palliative Care Multidisciplinary Team</td>
<td>14</td>
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<tr>
<td></td>
<td>Port Macquarie – Multidisciplinary Community Health, Aged Care, Aboriginal Health and Palliative Care</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Port Macquarie – Multidisciplinary Acute Care including Emergency, Renal, Oncology and Pain services</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Wauchope – Multidisciplinary Subacute Care including GP, NUM and Chaplain</td>
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<tr>
<td></td>
<td>Consumer: Family member</td>
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<tr>
<td><strong>Murrumbidgee LHD</strong></td>
<td>Griffith – Community Health and Palliative Care nurses</td>
<td>6</td>
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<tr>
<td></td>
<td>Leeton – Multidisciplinary hospital, community and aged care staff</td>
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<tr>
<td></td>
<td>District Multidisciplinary Palliative Care Team</td>
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<tr>
<td></td>
<td>Junee MPS – Multidisciplinary Team</td>
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<tr>
<td></td>
<td>Wagga Wagga – Aboriginal Health Worker</td>
<td>1</td>
</tr>
<tr>
<td>Organisation</td>
<td>Description</td>
<td>Numbers consulted</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
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</tr>
<tr>
<td><strong>Murrumbidgee LHD (continued)</strong></td>
<td>Wagga Wagga – Multidisciplinary Acute Care including Surgery, Critical Care,</td>
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<tr>
<td></td>
<td>Paediatrics, Orthopaedics and Discharge Planning services</td>
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<tr>
<td></td>
<td>Wagga Wagga – Multidisciplinary subacute, palliative care and cancer services</td>
<td>7</td>
</tr>
<tr>
<td><strong>Northern NSW LHD</strong></td>
<td>Tweed Heads – Multidisciplinary Palliative Care and Oncology Staff</td>
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<tr>
<td></td>
<td>Tweed Heads – ICU Medical Director and NUM</td>
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<tr>
<td></td>
<td>Murwillumbah MPS – Multidisciplinary acute, subacute and community health services</td>
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<tr>
<td></td>
<td>Lismore – Multidisciplinary Palliative Care team</td>
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</tr>
<tr>
<td><strong>Northern Sydney LHD</strong></td>
<td>District End of Life Care/Advance Care Planning Committee</td>
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<tr>
<td><strong>South East Sydney LHD</strong></td>
<td>Director, Northern Sector (counted in St Vincent’s consultation)</td>
<td></td>
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<tr>
<td></td>
<td>Director, Southern Sector and Calvary Hospital</td>
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<tr>
<td><strong>HammondCare</strong></td>
<td>Braeside – Palliative Care Multidisciplinary Team</td>
<td>13</td>
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<td></td>
<td>Braeside – Community Nurses</td>
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<tr>
<td><strong>Southern NSW LHD</strong></td>
<td>Goulburn – SNSW Palliative Care Multidisciplinary Team</td>
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<tr>
<td></td>
<td>Goulburn, Queanbeyan Acute, Community and Aged Care</td>
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<tr>
<td></td>
<td>Bega Hospital – Multidisciplinary acute and palliative care staff and Medicare Local staff</td>
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<td></td>
<td>Naroooma Community Health staff including Aboriginal Health</td>
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<tr>
<td><strong>St Vincent’s Health Network</strong></td>
<td>Director of Palliative and Supportive Care</td>
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<td></td>
<td>Consumer: Carer</td>
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<tr>
<td><strong>Sydney LHD</strong></td>
<td>District Palliative Care Multidisciplinary Team</td>
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<td></td>
<td>Balmain Hospital multidisciplinary staff</td>
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<tr>
<td><strong>Western NSW LHD</strong></td>
<td>District Palliative Care Multidisciplinary Team</td>
<td>7</td>
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<tr>
<td>Organisation</td>
<td>Description</td>
<td>Numbers consulted</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
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<tr>
<td>Ambulance Service of NSW</td>
<td>Project Manager</td>
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<tr>
<td>Cancer Institute NSW</td>
<td>Project Manager</td>
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<tr>
<td>NSW Clinical Excellence Commission</td>
<td>Clinical Lead, End of Life Care Program</td>
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<tr>
<td>NSW Ministry of Health</td>
<td>Office of the Chief Health Officer</td>
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<tr>
<td>Dying to Know Conference: Integrating Palliative Approaches into Chronic and Life limiting Illnesses, Dubbo</td>
<td>Electronic survey of 137 clinicians from a range of disciplines, primarily in the fields of Specialist Palliative Care and Chronic Disease, including seven face to face interviews with conference attendees</td>
<td>137</td>
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<tr>
<td>Palliative Care Service Development Officer Network</td>
<td>Funded Network established to implement the Palliative Care Strategic Framework 2010 – 2013 and undertake other strategic initiatives</td>
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<tr>
<td>Bereavement Key Stakeholder</td>
<td>Coordinator, Bereavement Counselling Service</td>
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<tr>
<td>Social Worker Practice Group (Palliative Care)</td>
<td>NSW AASW Palliative Care Social Workers Practice Group</td>
<td>25</td>
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<tr>
<td>Palliative Care Outcomes Collaborative</td>
<td>Research team from PCOC – a national voluntary program utilising standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care</td>
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<tr>
<td>Multicultural Health Managers</td>
<td>Statewide committee</td>
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<tr>
<td>Aboriginal Health Workers / PEPA</td>
<td>The Program of Experience in the Palliative Approach (PEPA) is a National initiative that provides opportunities to develop knowledge and skills in the palliative approach. PEPA has a program tailored for Aboriginal Health Workers. 3 participants were interviewed.</td>
<td>3</td>
</tr>
<tr>
<td>Cancer Council NSW</td>
<td>Manager, Cancer Peer Support Unit</td>
<td>1</td>
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<tr>
<td>Northern Sydney Aged Care Palliative Care Nursing Forum</td>
<td>A monthly meeting and online forum set up to support and empower Registered Nurses working in RACFs to deliver quality palliative care.</td>
<td>15</td>
</tr>
<tr>
<td>Organisation</td>
<td>Description</td>
<td>Numbers consulted</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>MND Association of NSW</td>
<td>CEO and Program Manager</td>
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<tr>
<td><strong>ACI</strong></td>
<td></td>
<td></td>
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<tr>
<td>ICCMU</td>
<td>Manager</td>
<td>1</td>
</tr>
<tr>
<td>Palliative Care Network Executive Committee</td>
<td>Multidisciplinary and multi-specialty group that leads and oversees the work of the ACI Palliative Care Network</td>
<td>16</td>
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<tr>
<td>ACI GP Clinical Advisory Group</td>
<td>The GP Advisory Group provides strategic advice to the ACI, reflecting the importance of considering the key role of the primary health sector in the development and implementation of models of care/programs/initiatives</td>
<td>6</td>
</tr>
<tr>
<td>Aged Health Network</td>
<td>Network Manager</td>
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<tr>
<td>Pain Network</td>
<td>Network Manager</td>
<td>1</td>
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<tr>
<td>Palliative Care Network members</td>
<td>“One Critical Question”: electronic consultations through a series of short questions posed to Network members, providing timely evidence to inform the development of the Model of Care.</td>
<td>131</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td>720</td>
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