



NSW Health
Central Coast Local Health District
Palliative Care Regional Workshop – Gosford
13 October 2017

Final Report



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1. Introduction

On Friday 13 October 2017, NSW Health hosted a workshop in Gosford with health sector representatives and other critical stakeholders to further inform the development of a policy framework for palliative care and end of life services in NSW.

The NSW Government Plan to increase access to palliative care 2012-2016 identified four key areas for action:

1. Expanded community-based palliative care services, especially in rural areas and for special needs populations
2. Integration of primary care, aged care and specialist palliative care services across the state
3. Expanded support for families and carers
4. Extended capacity of palliative care services in NSW.

To support the development of a policy framework for the future, a series of Roundtable meetings have been held across NSW. Discussions at these meetings focused on three key questions:

- What is working well in palliative care?
- What are the priority issues in relation to palliative care that need addressing?
- What are the potential solutions to these issues?

The purpose of the 13 October workshop was to test the findings from the Roundtable meetings, undertake a gap analysis, and seek input into local priorities and actions. The workshop was facilitated by Ian Colley from independent communications and engagement agency, KJA, and commenced with a welcome address from Dr Andrew Montague, Chief Executive Central Coast LHD. Participants also heard from the Honourable Adam Crouch MP, Member for Terrigal, and Scot MacDonald MLC, Parliamentary Secretary for Planning, the Central Coast and the Hunter.

Mardi Daddo, Acting Director Primary and Community Care Unit of NSW Ministry of Health, presented a brief overview of the nine key themes that emerged from the Roundtable sessions (see Appendix 1), which will guide improvements to palliative care in NSW. These include:

1. Providing flexible access to care through a range of strategies
2. Care is centred on the patient
3. Integrated and coordinated care, with a focus on good communication
4. Early engagement and care planning
5. Adaptable systems of care
6. A skilled and supported workforce
7. Support families and carers
8. Providing suitable spaces for care
9. Increase community awareness of palliative care

Workshop participants were given the opportunity to:

- Provide feedback and comment on each of the above themes
- Identify any gaps or omissions
- Indicate those themes that they felt were of the greatest priority
- Suggest actions that could be taken within the LHD to address the priority themes

The insights gained from this workshop, which are summarised in the following sections of this report, will inform the development of a broader policy framework for palliative care and end of life services in NSW. In addition to this workshop and the recent workshop hosted in Dubbo, NSW Health will release a survey to gather broader input on the key themes identified in the Roundtable meetings.



2. Workshop Outcomes

2.1 Feedback on the themes

The following table represents a summary of participant comments and feedback against each of the key themes identified out of the Roundtable meetings.

Theme	Feedback and comments
Providing flexible access to care through a range of strategies	<ul style="list-style-type: none"> • Define care and map where it is available • Offer accessibility and choice <ul style="list-style-type: none"> ○ Take a holistic approach to care (e.g. spiritual, social care) ○ Ensure health professionals, service providers and communities know what is available ○ Coordinate access to care ○ Recognise varying patient preferences for end of life care (including differences between patient and their family or carer) ○ Support the choices of the patient and their families or carers ○ Support care in the community and in the home ○ Provide local respite care and/or local hospice ○ Offer appropriate care, when needed, at a reasonable price ○ Employ range of care providers, where appropriate • Consider similarities with midwifery, including flexibility around care ‘checkpoints’ and responsiveness
Care is centred on the patient	<ul style="list-style-type: none"> • Determine principles for involving patients in their own care <ul style="list-style-type: none"> ○ Empower clinicians with these principles ○ Work with patient to wrap services around them rather than thinking of services in terms of the institution in which they are provided (e.g. ‘hospital-based’) ○ Involve patient and carer in development of care plan and future reviews ○ Identify goals of care ○ Support each other (i.e. other services) to maximise capacity to deliver care ○ Connect in with broader national conversations about patient enablement, health literacy and shared decision making • Consider cultural and religious sensitivities, including for Aboriginal peoples



	<ul style="list-style-type: none"> ○ Investigate impact of caring on Aboriginal peoples, including educational, work and financial impacts ○ Improve transport services for Aboriginal peoples (e.g. providing ambulance rather than community transport) ○ Address funding limitations when Aboriginal peoples move to nursing homes ● Consider age sensitivities, including for those under 65 years <ul style="list-style-type: none"> ○ Ensure patients under 65 years do not fall between gaps in services ○ Focus conversations on care patient needs rather than on services a given provider can fund ● Capture data to evaluate care <ul style="list-style-type: none"> ○ Increase focus on patient-reported outcomes ○ Use data to inform quality care
<p>Integrated and coordinated care, with a focus on good communication</p>	<ul style="list-style-type: none"> ● Guide integration with principles and goals <ul style="list-style-type: none"> ○ Use shared principles of care as means of better integration and communication across teams ○ Use care plan as means of identifying goals of care ○ Allow for flexibility in planning ● Identify care team <ul style="list-style-type: none"> ○ Integrate palliative care specialists into other services ○ Include staff who can provide spiritual care ○ Assemble teams so that consumer are receiving the care they need ○ Consider practical application of integrated teams ● Clarify role of Care Coordinator <ul style="list-style-type: none"> ○ Determine who is coordinating care (i.e. carer, GP, service provider) ○ Consider role of GP in initiating end-of-life discussions and navigating system ● Identify opportunities for integration <ul style="list-style-type: none"> ○ Collect feedback from chronic care program nurses about community services that could be integrated in patient's daily care ○ Improve workforce capacity so that people can move from hospital to home to die ○ Involve more than one service in conversations about a person's care ○ Maximise use of available support (e.g. Commonwealth Home Care Support package)
<p>Early engagement</p>	<ul style="list-style-type: none"> ● Allocate necessary resources to engage patient early, rather than resorting to crisis management ● Encourage health professionals to engage in early conversations (e.g. through legislation or GP item number)



and care planning	<ul style="list-style-type: none">• Empower community groups to educate people about advanced care planning
Adaptable systems of care	<ul style="list-style-type: none">• Ensure systems are flexible and agile so that actions can be taken quickly once a decision is made (e.g. moving patients)
A skilled and supported workforce	<ul style="list-style-type: none">• Enable whole workforce<ul style="list-style-type: none">○ Connect whole workforce to care plan○ Overcome unwillingness, in the medical profession, to discuss death and dying○ Train whole workforce to care for someone who is going to die• Connect specialist staff with rest of workforce<ul style="list-style-type: none">○ Identify triggers for engaging specialist staff○ Investigate international research into trigger points○ Respond swiftly when staff indicate that they need assistance, even for basic conversations• Upskill staff through training<ul style="list-style-type: none">○ Provide training on a patient's spiritual needs○ Provide training on dealing with conflict within a family○ Nurture staff interest and skills in palliative care to help identify prospective specialists○ Include volunteers in education and training
Support families and carers	<ul style="list-style-type: none">• Establish principles of care that reinforce family and carer involvement<ul style="list-style-type: none">○ Empower clinicians with principles○ Work with families and carers to provide support○ Identify goals of care, including the needs of the family○ Perform comprehensive capacity assessments, including separate family assessments○ Set expectations with families and carers○ Provide care when families and carers need it, not just when they decide they need it○ Help patients and family feel safe and comfortable
Providing suitable	<ul style="list-style-type: none">• Design appropriate and accessible spaces<ul style="list-style-type: none">○ Design spaces that facilitate confidential and private conversations

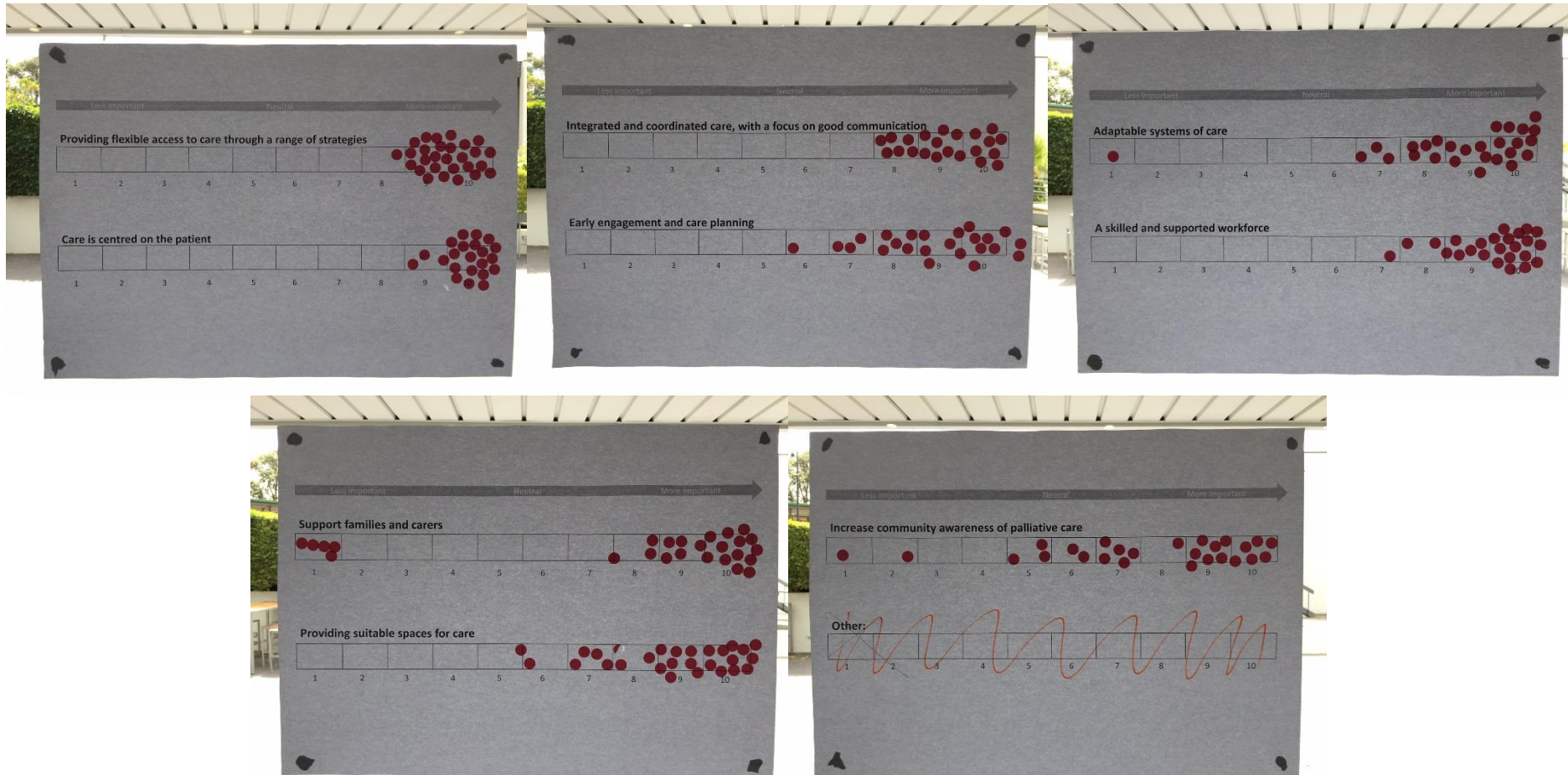


spaces for care	<ul style="list-style-type: none"> ○ Ensure spaces and services are age-appropriate across different care environments ○ Create spaces that act as ‘one stop shops’ for palliative care, including for care, education, allied health, pain relief, family and social support ○ Consider how to make spaces safe ○ Provide designated palliative care beds
Increase community awareness of palliative care	<ul style="list-style-type: none"> ● Normalise end of life conversations <ul style="list-style-type: none"> ○ Start conversations early (e.g. at school) ○ Run community campaign (e.g. through Facebook, TV, ambassadors) ○ Help all health professionals feel more comfortable with conversations, in workplaces and through training ○ Empower junior health staff to have conversations, not just senior staff ○ Emphasise support to help people live fully, as well as to die ○ Confirm approach for explaining palliative care to consumers and families ○ Ensure patients and families are well informed, to make good choices and decisions
Other	<ul style="list-style-type: none"> ● Collect quality data <ul style="list-style-type: none"> ○ Use data to measure quality of work being done ○ Use data to identify opportunities ● Consider impact of palliative care on children, as patients or carers ● Consider safety aspects of palliative care in hospital and community settings ● Establish tailored palliative care pathways for particular disease populations ● View all themes through the lenses of: <ul style="list-style-type: none"> ○ Cultural sensitivity ○ Consideration for carers



2.2 Local priorities and actions

Participants were asked to prioritise these key themes by placing dots, as they saw fit, along Likert scales accompanying each theme. The 1-10 digit scale ranged from 'Less Important' up to 'More important'. Each participant was issued with 9 dots to use across all scales. The exercise was not intended to provide a statistical analysis of prioritisation but rather to provide a general visual indication. The completed scales can be seen in the images below.





Overall, the top priority themes identified by the group were:

- Providing flexible access to care through a range of strategies
- Care is centred on the patient
- Integrated and coordinated care, with a focus on good communication
- A skilled and supported workforce

Informed by these priority themes, as well as key points raised repeatedly during the first session, the Lead Facilitator identified the following topics for small group discussion:

- Support for families and carers
- Early engagement and intervention
- Integrated and coordinated care
- Miscellaneous

Summaries of the groups recommended actions, within each of these areas, are provided below.

Support for families and carers

- Improve **access to support**
 - Identify what support is available
 - Ensure families and carers are aware of these support services and how to access them
 - Assist families and carers to identify services that they want for their patient
 - Design support so that it is flexible, through the different stages of the end-of-life process
 - Support families and carers with anxiety and other social needs, which can affect decision making
 - Provide after-hours support and identify who would be trusted by families and carers to offer this support
- Empower **health professionals to link** families and carers to support
 - Improve health professionals' understanding of what is available
 - Increase their capacity for holding palliative care conversations
 - Heighten their awareness of the language used and the meanings different people attach to terms (e.g. respite)
 - Better utilise digital applications, media and documentation



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- Recognise challenges specific to **demographic groups**
 - Identify – and improve access to – support for those aged under 65 years
 - Address impact caring for their elderly family members has on the career progression of young Indigenous people
 - Recognise the role of cultural differences and trust issues in the way people access support
 - Coordinate **timely referrals**
 - Have future services set up when one service ends to continue support seamlessly
 - Identify appropriate triggers for the introduction of services
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Early engagement and intervention

- Improve the **referral process**
 - Confirm when referral should happen
 - Identify challenges and barriers to referrals (i.e. in chronic diseases other than Cancer)
 - Clarify patient needs at the point of initial diagnosis
 - Confirm whether palliative care team involvement is required
 - Plan for referrals from a variety of sources, as people increasingly visit health centres rather than GPs
 - Clarify **definitions and roles**
 - Align definitions of ‘palliative care’ throughout the workforce
 - Link the term ‘palliative care’ to specific patient and carer needs
 - Confirm the roles of GPs, families and other stakeholders in the patient journey
 - Support **advanced care planning** conversations without locking patient in
 - Normalise conversations in society
 - Assist people in defining their needs during the planning process since they may not know what to ask for when engaged early
 - Regularly re-evaluate a person’s needs so that they are not locked into plans developed during early engagement
 - Have ‘values-based’ conversations about palliative care
 - Recognise that each patient is on their own pathway to understanding
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Integrated and coordinated care

- Place the patient at the **centre of care**
 - Support holistic care for patient and families, including spiritual, social, emotional, physical and clinical needs
 - Improve interfacing of clinical roles (e.g. social workers, chaplaincy, counselling services)
 - Recognise that, to the families, it does not matter who provides the care, only that it is provided
- Honour the **person's desires**
 - "I want to tell my story only once"
 - "I want care to be flexible to my needs at any given time"
 - "When I want urgent help, I want it quickly"
 - "I want choice about where I am going to die"
 - "If my needs change, I want to be able to discuss the plan"
 - "I want to make my own decisions but to receive information and guidance"
 - "I want my experience to feel seamless"
- Provide **timely guidance** for patients navigating **appropriate services**
 - Determine what other services exist and what they can and cannot do
 - Determine the best time and place for each stage of care to be delivered and who should deliver it
 - Manage transitions so patient can make decisions, with appropriate support and guidance, but does not have to coordinate care
- **Empower the workforce** to provide guidance
 - Use an electronic platform with access for all relevant services at all touch points (including Ambulance)
 - Develop workforce skills, including 'soft skills' (i.e. communication)
 - Promote joint training and knowledge sharing across care environments

Miscellaneous

- Improve **inpatient palliative care**
 - Build the capacity of palliative care services to respond to inpatient needs
 - Extend palliative care services availability beyond Monday – Friday, 8.30am – 5pm
 - Re-design palliative care services to be an inpatient, as well as a community service



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- Support people through **grief and loss**
 - Offer ongoing counselling to families and carers
 - Provide people with links to mental health services
 - Embrace learnings from the paediatric model in relation to follow-up services
 - Assist people in **navigating services**
 - Keep health pathways up to date
 - Integrate technology systems
 - Hold workforce accountable to connecting people to services
 - Provide access to **palliative care spaces and personnel**
 - Provide dedicated specialist palliative care wards in hospitals
 - Explore opportunities to work with 'Hospital in the Home'
 - Promote **advanced care planning** and directives
 - Raise community awareness to increase early uptake of advanced care planning
 - Ask those who complete plans to encourage their family or friends to do the same
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