NSW Health
Western NSW Local Health District
Palliative Care Regional Workshop – Dubbo
18 September 2017

Final Report
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1. Introduction

On Monday 18 September 2017, NSW Health hosted a workshop in Dubbo 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, including in the Western NSW Local Health District (LHD). 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 18 September 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 Richard Cheney, ED Allied Health of Western NSW LHD. Participants also heard from the Honourable Troy Grant MP, Minister for Police, Minister for Emergency Services and Member for Dubbo, as well as Scott McLachlan, CE of Western NSW LHD.

Mardi Daddo, Acting Director Primary and Community Care Unit of NSW Ministry of Health, presented a summary 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, a session will be hosted in Gosford in early October and 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.

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<tr>
<th>Theme</th>
<th>Feedback and comments</th>
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| **Providing flexible access to care through a range of strategies** | Participants suggested that, as part of providing flexible access to care, the sector needs to:  
- Understand **the aim and complexity** of the treatment  
- Set **clear goals** of care  
- Consider **how the community will access** the generalist model  
- **Sydney Metro** needs to be part of local telehealth services and recognise the needs of rural health delivery  
- **Upskill** residential aged care staff and General Practitioners (GPs)  
- Recognise that there might **not always be suitable room** to cater for the Multipurpose Services model  
- Link this flexibility with **early engagement and care planning**  
- Aim to provide care **wherever the patient wants** to receive it  
- Provide **24 hour** care and advice  
- Recognise **respite care** as an essential component  
- Recognise that palliative care is **not limited to ‘end of life’**  
- Consider **patient preferences** (e.g. patient aged under 65 may not want respite in an aged care facility)  
- Support and advise **community groups** that are keen to provide assistance  
- Provide rural and remote patients with **adequate access to financial support** for transport and accommodation so that they can readily access health support |
| **Care is centred on the patient** | One participant offered the metaphor of the **patient experience as a flowing river**. They suggested it is important that health care practitioners do not simply focus on the ‘banks of the river’ (i.e. controlling the patient) but rather on **empowering the person** by wrapping services around their and their carer’s aspirations and needs. |
Participants also suggested that, as part of centring care on the patient, the sector needs to:

- Recognise patients and their families as the **primary unit of care**
- Provide **psycho-social care** for families
- Offer **24/7 advice and support** for carers
- Acknowledge **varying patient definitions of the community** who provide support
- Prevent patients and carers from feeling isolated due to not knowing who to approach or how to obtain support and advice

### Integrated and Coordinated Care, with a Focus on Good Communication

Participants were particularly interested in the theme of integrated and coordinated care. The feedback and comments provided by participants can be organised under the following subheadings:

**Buy-in across health disciplines**

- Maximise the use of telehealth services for palliative care across health disciplines
- Increase admitting rights for GPs
- Explore funding for Residential Aged Care (RAC) patients in federal facilities to receive telehealth services directly, rather than going via an acute care setting
- Gain clarity around how the palliative care and primary workforces will work together, including the ‘boundaries’ of the services each team provides
- Work on Multidisciplinary Team Care
- Invest time in maintaining relationships with other health care staff, especially in rural areas

**Data and shared plans**

- Use a platform (e.g. My Health Record, Argus) to provide visibility of shared care plans across health disciplines, including Ambulance NSW
- Address the challenges around data collection, including:
  - Sharing data between different systems, public/private entities and health areas
  - Allowing paramedics to view palliative care plans before arriving at the scene (since these plans are not currently scanned into the system)
- Balance clinician control in the system with significant patient access, including the ability to view and add to their records
• The system should be **responsive and localised** within the LHD

**Leadership and governance**

• Consider who should **manage the integration** of services
• Consider who would **complete assessments** as patients move in and out of a range of settings or services
• **Provide governance** to:
  - Support better integration of health partners providing palliative care
  - Consider a palliative care approach in acute presentations to health facilities

**Focus on patient and community**

• Increase **focus on the patient**
• Develop **community understanding**
• Focus on **networks of care** in the community
• Assist people in dying in an **appropriate place** (i.e. not in an emergency department)
• Provide open **communication channels with carers**
• Provide **timely access** to equipment and medications in the home

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<tr>
<th>Early engagement and care planning</th>
<th>Participants suggested that, as part of early engagement and care planning, the sector needs to:</th>
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<td>• Decide whether to encourage health practitioners to refer patients to palliative care specialists early or when/as needed (e.g. should palliative care services be sufficiently involved so that they do not become ‘crisis management’ services), with consideration for resourcing limitations (e.g. in rural areas)</td>
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<td>• <strong>Place Aboriginal people in positions</strong> to liaise with Aboriginal patients and communities to achieve early engagement</td>
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<tr>
<td>• Recognise that palliative care is <strong>not limited to ‘end of life’</strong></td>
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<tr>
<td>• Appoint a <strong>specific care coordinator</strong> or navigator to support people with care planning</td>
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<tr>
<th>Adaptable systems</th>
<th>Participants suggested that, as part of adaptable systems of care, the sector needs to:</th>
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<tr>
<td>• Appoint a <strong>specific care coordinator</strong> or navigator to support people with care planning (as above)</td>
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| • Identify the **limitations of telehealth** in palliative care  
• **Tailor different models of care** to meet each person's needs  
• **Allow for personal connections** to develop between palliative care nurses and patients across the journey  |

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<th>A skilled and supported workforce</th>
<th>Participants spoke of the need for better upskilling and supporting the workforce, because:</th>
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| • Medical practitioner **experience in dealing with death varies**  
• The size of the **workforce needs to increase** in order to deliver on best practice models of care  
• **A gap exists in availability** of palliative care staff in rural communities  
• **Flexible training avenues do not exist**, especially for GPs  
• **Patients will benefit** from investment in upskilling staff  |

Participants suggested that, as part of upskilling and supporting the workforce, the sector needs to:  |
| • **Measure the patient’s, carer’s and professional’s experience**  
• Ensure that palliative care teams have a **minimum level of palliative care-specific workforce** (i.e. medical, nursing, allied health)  
• Have the **palliative care team in one site** to achieve greatest capacity for efficiency and responsiveness  
• **Include Aboriginal people** within the palliative care workforce  
• **Offer tangible benefits and reasons** why staff should upskill  
• **Provide flexibility in training provision**, including training that is locally available and that – in the case of GPs – leaves them with sufficient time to keep their practice running  
• **Tailor training approach for new GPs** who may have pre-existing knowledge and experience in palliative care  
• **Explore possible links** between Health, Education & Training (HETI), The Royal Australian College of General Practitioners (RACGP) and other training providers  
• **Extend training and support to volunteers**  |

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<th>Support families and carers</th>
<th>Participants suggested that, as part of supporting families and carers, the sector needs to:</th>
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| • Recognise that **communication with families and carers is vital**  
• **Address health literacy** issues  
• **Ensure patients and carers understand** Advanced Care Plans and other documents  
• Improve volunteer services to **encourage Aboriginal people to engage** with them, including in hospitals and in the community  |
| Providing suitable spaces for care | Participants suggested that, as part of providing suitable spaces for care, the sector needs to:
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<tr>
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<td>• Ensure suitable spaces for care are available locally</td>
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<td></td>
<td>• Ensure spaces are welcoming for families, including for them to stay and accompany the patient at end of life</td>
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<tr>
<td></td>
<td>• Provide comfortable settings for the family to grieve in private</td>
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<td></td>
<td>• Provide access to respite care in acute care facilities</td>
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</table>

| Increase community awareness of palliative care | Participants suggested that, as part of increasing community awareness of palliative care, the sector needs to:
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<td>• Invest in the use of the arts to attract a greater proportion of the community to engage with palliative care</td>
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<td></td>
<td>• Broaden community understanding of palliative care beyond cancer</td>
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| Other | Feedback and comments outside the scope of a particular priority theme can be organised under the following subheadings:
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<td></td>
<td>Context</td>
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<td>• Clarity needs to be provided around the overlap between the work of the Agency for Clinical Innovation (ACI) and the work on palliative care currently being completed by NSW Health</td>
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<td>Funding</td>
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<td></td>
<td>• Funding is generally based on KPIs that may not match the patient’s needs (e.g. patients will benefit from funding for upskilling staff)</td>
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<td>• Funding in 12 month cycles means that staff are constantly in ‘start-up’ mode</td>
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<td></td>
<td>• A strong Memorandum of Understanding (MOU) for Advanced Care Planning (ACP) conversations will help provide clarity around remuneration</td>
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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:

- A skilled and supported workforce
- Integrated and coordinated care, with a focus on good communication
- Support families and carers
- Care is centred on the patient

In small groups, participants discussed possible local actions against each of the first three priority areas. The fourth – ‘care is centred on the patient’ – they elected to integrate across all conversations. Summaries of each group’s recommended actions are provided below.

### A skilled and supported workforce

- **Provide flexible GP training avenues**
  - Provide training locally that is orientated for medicine
  - Consider how to support and formalise the training
  - Provide tangible benefit to the training to motivate GPs (e.g. greater formalisation of a Diploma in Palliative Care)
  - Train GPs to the point that they can provide palliative care advice to other GPs
  - Build on the rural generalist training program
- **Explore possible models for a working relationship** between nurse practitioner and palliative care physician
- **Build up the skills and the skill mix of the primary workforce** to promote a multidiscipline, ‘whole team’ approach
- **Reach clarity around roles in acute and education spaces**, for the Specialist Palliative Care team, to maintain efficiency
- **Establish ‘rural’ and ‘palliative care’ item numbers** to be used for remuneration by GPs, Practice Nurses and others
- **Explore MOUs and/or formalised networks** with partners that have the tools required to deliver necessary services
- **Consider providing a mentor service** as an LHD that results in service provision, education or clinical placements
- **Incentivise staff** to attract them to rural and regional areas (e.g. housing allowances, education)
- **Ensure staff are located in the most appropriate places**
Integrated and coordinated care, with a focus on good communication

- **Improve information exchange between services** (e.g. building capacity for palliative care in My Health, encouraging/training GPs to use it and ensuring Ambulance NSW can add records through the system)
- Provide Ambulance NSW and GPs with **visibility of Electronic Medical Records** (EMR)
- **Better integrate Ambulance NSW** into inpatient and outpatient record keeping processes
- **Simplify advanced care directives/plans** and ensure they are scanned in
- **Structure guidelines around role capacity** for various agencies
- Provide a **single point of access for patients/community** to engage with palliative care, similar to centralisation of aged care services at the local level
- **Provide a care navigator role** and/or case management model to support integration and coordination of care
- **Appoint a care manager**, trained in the use of the Palliative Care Outcomes Collaboration (PCOC) system, to guide assessment
- **Track patient journeys** by having skilled assessor register in EMR and the Community Health and Outpatient Care (CHOC) program so that the information follows the patient
- Consider **upgrading EMR** so that patient sits at the centre of care
- Identify and increase involvement of relevant **Non-Government Organisations (NGOs)** in discussions about palliative care

Support families and carers

- **Improve education and communication**, with access to the following for health practitioners across the LHD:
  - Carer support groups
  - CALD-appropriate and translated resources
  - Culturally appropriate resources
  - Health literacy resources
- Prepare a **Communication Plan** for the LHD, with guidance from the Communications team and in partnership with the Palliative Care stream and key stakeholders (e.g. shopping centre table promotion to link communities with palliative care information)
- Explore partnerships for providing **appropriate environments/designated areas** for people to grieve in peace and promote these to the community via ‘open days’
- Take a proactive approach to **advanced care planning** and ensure the family/carer(s) have input
- Use an **app** (i.e. VITA) that **collects patient information** (e.g. their likes, dislikes) to improve understanding of the person’s wants and needs
- Promote to the Aboriginal community avenues for **assistance with wills, advanced care plans and funerals** (including funds)