

NSW Health  
**Palliative Care Roundtables**  
Consultation Paper  
2017

***PROVIDING FEEDBACK***

You may wish to fill in the survey that accompanies this document.  
You can complete the survey online or return it by mail or email.

You can return your survey:

Online: [www.surveymonkey.com/r/NSWpalliativecare](http://www.surveymonkey.com/r/NSWpalliativecare)

Print, scan and email: [palliativecare@moh.health.nsw.gov.au](mailto:palliativecare@moh.health.nsw.gov.au)

Print and return to: Palliative Care Consultation Paper  
Health and Social Policy Branch  
NSW Ministry of Health  
Locked Bag 961  
North Sydney NSW 2059

**CLOSING DATE FOR FEEDBACK 15<sup>th</sup> DECEMBER 2017**



## Minister's foreword



I invite you to contribute your views about the priorities for palliative care in NSW.

Demand for palliative and end of life care is growing.

The NSW Government is committed to ensuring all NSW residents have access to quality palliative care where and when they need it. Quality services are delivered by skilled clinicians working together to provide integrated, coordinated care. Last year the NSW Agency for Clinical Innovation's (ACI) Palliative Care Network launched Palliative and End of Life Care; A Blueprint for Improvement, which provides a flexible guide to assist services and Local Health Districts to better meet the needs of people approaching and reaching the end of their life, their families and carers. Activities to make use of the *Blueprint* are outlined in this Consultation Paper.

Quality care is also about providing patients with choices. As part of the *NSW Government Plan to increase access to palliative care 2012 – 2016*, NSW Health has been working to expand the choices available to enable patients to remain at home for longer and to die at home if that is their wish.

This year I was pleased to announce that the NSW Government will commit an additional \$100 million over four years to further improve palliative care services in NSW. This investment will enable us to build on what has already been achieved, and meet the growing challenge of delivering quality palliative and end of life care across NSW.

To meet this challenge, NSW Health is developing a new policy framework for palliative and end of life care. Earlier this year my colleague Leslie Williams MP, Parliamentary Secretary for Rural and Regional Health, and I convened a series of Roundtable meetings on palliative care across the state. These meetings brought together carers, families, clinicians, service providers and policymakers to provide their thoughts on what works well in palliative care and the priorities for the future.

The purpose of this Consultation Paper is to seek your thoughts. The Consultation Paper outlines the priorities for palliative care identified during the Roundtable meetings, and provides a short survey for you to provide your own response. I look forward to seeing your suggestions, and to working together to ensure that all NSW residents receive world-class care.

A handwritten signature in blue ink that reads "Brad Hazzard". The signature is fluid and cursive, written in a professional style.

**Brad Hazzard MP**  
**Minister for Health and Minister for Medical Research**

## Purpose

NSW Health is developing a policy framework for palliative and end of life care services. The purpose of this consultation paper is to seek suggestions and ideas from the community for this framework.

From April to June this year Roundtable meetings on palliative care were held across NSW to hear directly from communities, clinicians and service providers about what they saw as the priorities for palliative care. The information gained from these meetings will inform the NSW Health policy framework.

The NSW Ministry of Health is reporting to Roundtable participants through this consultation paper, which also provides participants the opportunity to comment on the validity of the analysis and provide input to priority setting. This paper also provides an opportunity for people and organisations who were unable to attend the Roundtable meetings to be included in the process and have their say on priorities for palliative care.

## Where we have come from

The NSW Government has significantly enhanced palliative care services in NSW. The *NSW Government Plan to increase access to palliative care 2012 – 2016* identified four key areas for action:

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

The NSW Government has invested in these areas identifying funds for palliative care in successive State Budgets: \$35M (2012/13-2015/16) and \$32M (2015/16-2018/19), and establishing new community-based palliative care services to support patients and their families and carers.

NSW Palliative Care Home Support Service (*Last-Days-of-Life*) supports patients, families and carers where patients wish to die at home. Services include nursing care, personal care and domestic assistance. Since the program started in December 2013, more than 6,500 people across NSW have been supported with more than 9,000 packages.

The Palliative Care Home Support Service is delivered by Silver Chain, HammondCare and South Western Sydney Local Health District, each under a service agreement with the Health Administration Corporation.

The *Paediatric Palliative Care Program* provides a statewide network of paediatric palliative care services which mobilises specialist supports around the child and their family.

*Palliative Care Volunteer Support Program* is a statewide service to support volunteers in hospital and community settings.

*Palliative Care Flexible Funding* of \$12M (2015/16-2018/19) was allocated to Local Health Districts and other NSW Health organisations to address palliative care needs specific to their communities.

The NSW *Palliative Care After-Hours Helpline* is a state-wide service offering specialised palliative care advice and support to people who are receiving palliative care at home, including a residential facility, along with their carers, and families. The Helpline commenced on 1 March 2016 and is available:

- Weekdays 5pm – 9am
- Weekends 5pm Friday to 9am Monday
- Public Holidays.

Local Health Districts are responsible for planning and delivering services that meet local needs. NSW Health has developed key initiatives to support high quality palliative care.

Existing NSW Health frameworks to guide palliative care service delivery include:

- *Palliative and end of life care – A Blueprint for Improvement*
- *AMBER Care Bundle*, developed by the Clinical Excellence Commission
- *SHAPE end of life conversations, Verification of death, and Managing death and death certification* eLearning modules
- *Advance Planning for Quality Care at End of Life: Action Plan 2013 - 2018*.

Many Local Health Districts (LHDs) have significantly progressed local planning to meet the needs of patients approaching or reaching the end of their life. The ACI Palliative Care Network in collaboration with the Clinical Excellence Commission (CEC) is offering to LHDs a series of planning workshops to make use of the Blueprint. The workshops aim to complement local planning and to work towards building a statewide network for improvement.

## Investing in palliative care

The NSW Government spends approximately \$210 million each year on palliative care. In June 2017, the NSW Government announced major increases in funding for palliative care over four years. The initiatives announced in the Budget include:

- \$1.2 million to provide 300 scholarships for staff in rural and regional areas to enhance their skills in palliative care, with \$300,000 in 2017-2018
- \$3.7 million to provide on-the-job training in palliative care for 300 nurses and allied health staff, with \$900,000 in 2017-2018
- \$3.3 million for two specialist positions to provide relief to other specialists in rural and regional areas, with \$795,000 in 2017-2018
- \$10 million for six additional palliative care specialists in rural and regional areas, with \$2.4 million in 2017-2018
- \$20 million over four years for an additional 30 palliative care nurses supporting care in hospitals, homes and nursing homes, with \$5 million in 2017-2018
- Additional funds for developing and implementing comprehensive and integrated palliative care services in line with community expectations
- \$38.9 million for the community-based palliative care services in Western Sydney, including a 24-hour, seven days a week on-call specialist palliative care service to provide care in homes, with \$6.9 million in 2017-2018
- \$400,000 to improve medication management for palliative care patients through community pharmacy initiatives, with \$200,000 in 2017-2018.

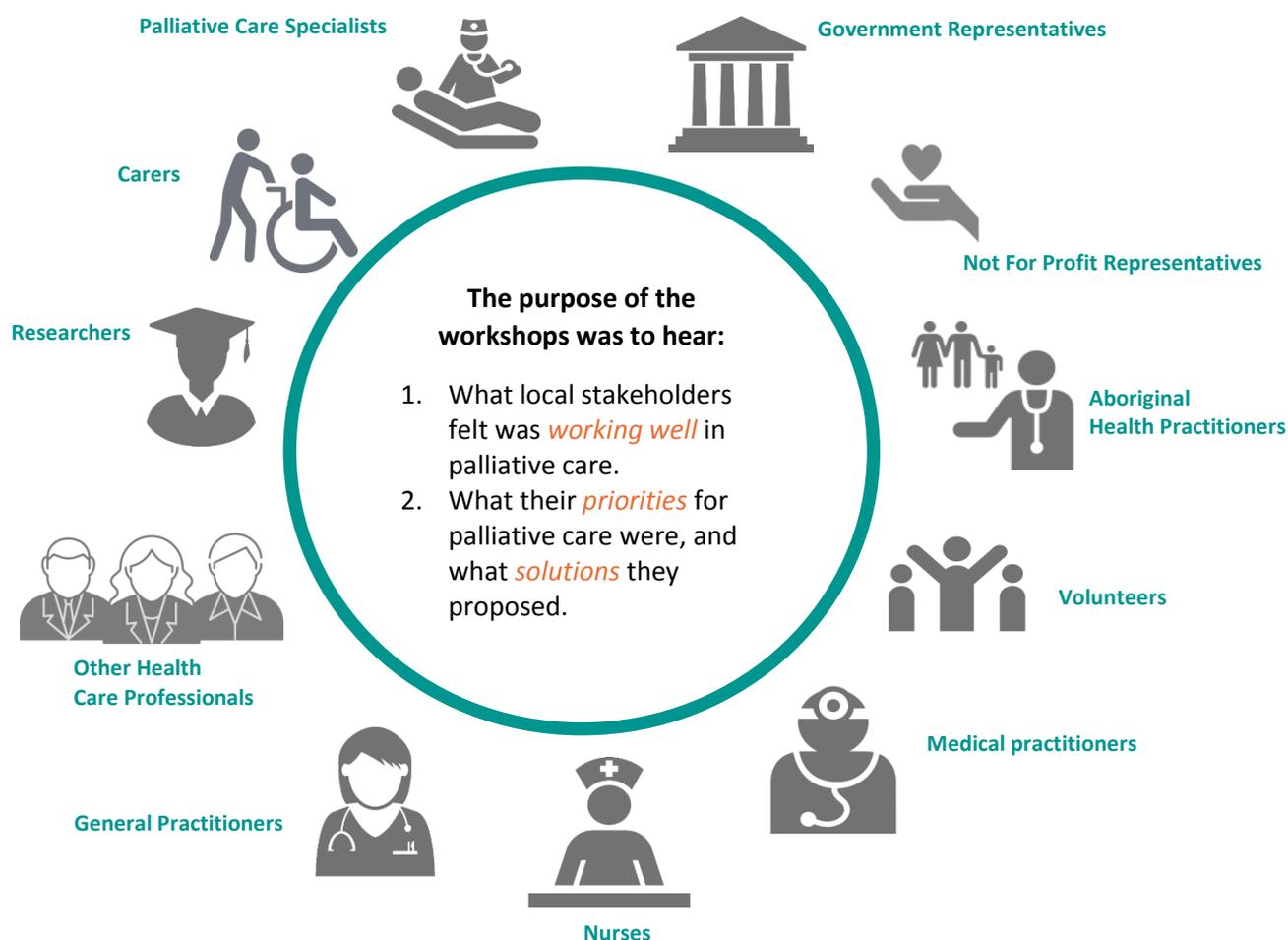
## Planning for the future

After the completion of the *NSW Government Plan to increase access to palliative care 2012 – 2016*, NSW Health is developing a policy framework for palliative care and end of life services. As part of this process, NSW Health is reaching out to the community.

From April to June this year The Hon Brad Hazzard MP, Minister for Health and Minister for Medical Research and The Hon Leslie Williams MP, Parliamentary Secretary for Regional and Rural Health, hosted Roundtable meetings on palliative care in Sydney, Newcastle, Tamworth, Orange, Lismore, Kempsey, Broken Hill, Griffith, Queanbeyan and Kiama. Communities in Dubbo and Gosford were consulted on priorities for palliative care in September and October.

The meetings were facilitated by an independent communications and engagement agency, KJA, with assistance from Local Health District and NSW Health staff.

The meetings were attended by the wide range of people who make palliative care services work:



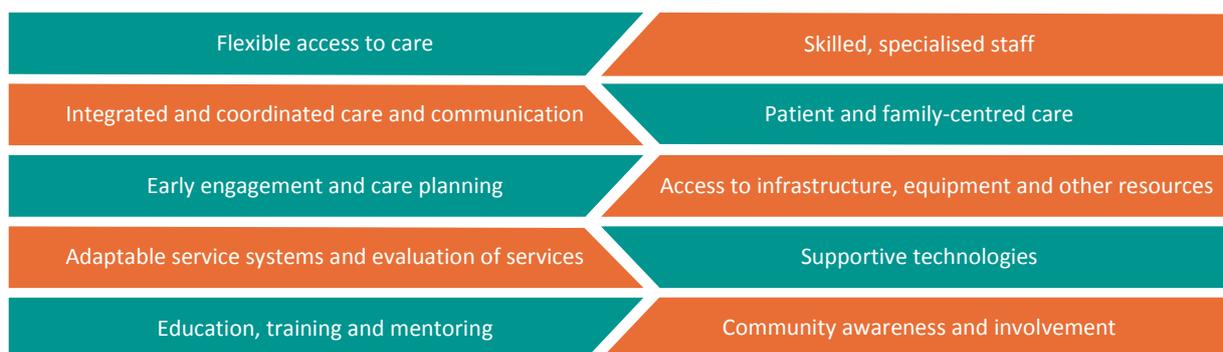
Discussion at the meetings focused on three key questions:

- 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?

Each Roundtable group focused on palliative care in the local community and as a result, each was slightly different. Some issues were raised at more than one meeting and common themes emerged. This paper summarises the common themes that emerged on what works well in palliative care, the priorities, and possible solutions.

## What works well?

These were the things participants felt were important:



## Priorities and solutions

Many of the solutions proposed related to things that participants had seen work well in services either in NSW or elsewhere. The priorities identified, and some of the solutions proposed, are outlined below.

### Providing flexible access to care through a range of strategies

Standard 9am-5pm business hours account for only about 25 per cent of the week. It is important that patients, families, carers and staff have access to support outside these times. This can be more difficult for patients receiving care at home. Providing flexible access might involve a range of strategies, such as specialist phone support being available at any time, improved access to medications in the community, or outreach services to patients being cared for at home, including residential aged care facilities. Telehealth services also play a growing role, particularly for patients in regional, rural and remote communities.

### Care is centred on the patient

Early conversations about death and dying and early engagement with palliative care services mean that patients can be involved in decisions about their palliative care. Advance Care Plans and Advance Care Directives also play an important role in ensuring that a patient's wishes are respected. Patients, their families and carers should be able to easily navigate a system of integrated and coordinated services that puts them at the centre of the decisions being made about care and how it is provided. Health service providers also need to ensure that care is culturally appropriate, including for culturally and linguistically diverse and local Aboriginal communities.

## Integrated and coordinated care, with a focus on good communication

A patient is more likely to experience quality, consistent care if public and private health staff actively communicate with one another, sharing knowledge and resources. Acute care, aged care, primary health, community services and other staff can also work together to enable smooth patient transitions within and between facilities and services. Integrated and coordinated care might be delivered through, for example, multi-disciplinary teams, embedded specialist staff, shared equipment and patient reports, and/or general practitioner (GP) involvement throughout the time the patient is receiving care.

## Early engagement and care planning

All clinicians who provide end of life care – and not just palliative care specialists – should be capable of discussing and planning palliative care with their patients. These conversations might take place in GP clinics, aged care facilities or hospitals. Advance Care Directives help to involve patients in decisions about their care. Early referrals to, and intervention by, palliative care specialists will improve how patients experience end of life care. However, not all patients approaching the end of their lives will need specialist palliative care. There is a range of clinicians who might be involved and they need the skills to initiate and manage conversations and provide advice to patients and their families/carer/s.

## Adaptable systems of care

Different configurations of services can provide high quality care. In some communities, fly in/fly out services are used, while others have employed a 'hub and spoke' model, where specialist support and resources are situated in hubs and accessed by surrounding rural and remote communities. The key focus of such models is ensuring that local clinicians have access to the specialist advice and support they need. It is important to regularly review how services are provided, to identify best practice and opportunities for improvement.

## A skilled and supported workforce

Building and maintaining the palliative care workforce is an ongoing process. More palliative care services are needed, particularly in rural and regional communities. The NSW Government's recent commitment to enhance funding by \$100 million over four years will address some of these needs, providing improved access to specialist palliative care doctors and nurses.

Generalist clinicians also provide care. It is important all health staff are supported and can develop their skills. Staff, graduates and students need to be provided with training, experiences and incentives around palliative care, including in regional areas. The NSW Government's commitment to provide scholarships and on-the-job training will enhance NSW Health initiatives that already support the palliative care workforce, and provide ways for staff to become more specialised in the care they provide.

## Support families and carers

Providing quality palliative and end of life care involves support for patients, families and carers. Many carers who attended the Roundtable meetings spoke passionately about the importance of the support they received from service providers, such as care packages for patients being cared for at home, or help from volunteer services. Skilled and caring staff and volunteers enable families to feel included and supported.

## Providing suitable spaces for care

Everyone should have access to palliative care when they need it, no matter their location, age or situation. Participants in the Roundtable meetings emphasised that appropriate physical environments were needed for palliative care. Caring for a patient as they approach and reach the end of their life is a sensitive time, and patients and their families need to feel comfortable. This may mean providing dedicated palliative care rooms and improved facilities for carers and families, making facilities more home-like, or providing equipment for patients being cared for at home or in residential aged care facilities.

## Increase community awareness of palliative care

The community plays a major role in palliative care, especially in rural and regional communities, yet there remains a stigma around death and dying. Many communities want to be more informed about palliative and end of life care options. NSW Health and other health care providers, such as general practitioners, pharmacists, aged care providers and advocacy organisations, have a role in improving public awareness of palliative care, among patients and the broader community. The Roundtable meetings were a key step in this process. Building community awareness will make it easier for patients and service providers to initiate conversations about palliative and end of life care. It will also help to nurture the volunteer programs and informal community networks that provide crucial support to patients, carers and families.

**You can access a report from each of the Roundtable meetings at**

<http://www.health.nsw.gov.au/palliativecare/Pages/Palliative-Care-Roundtables-2017.aspx>

## References

NSW Health (2012) *NSW Government plan to increase access to palliative care 2012-2016*  
<http://www.health.nsw.gov.au/palliativecare/Publications/palliative-care-plan-2012-2016.pdf>

NSW Health (2013) *Advance Planning for Quality Care at End of Life: Action Plan 2013–2018*  
<http://www.health.nsw.gov.au/patients/acp/Pages/acp-plan-2013-2018.aspx>

NSW Health (2017) Palliative Care Roundtable reports  
<http://www.health.nsw.gov.au/palliativecare/Pages/Palliative-Care-Roundtables-2017.aspx>

NSW Health (2017) NSW Agency for Clinical Innovation *Palliative and End of Life Care A Blueprint for improvement* <https://www.aci.health.nsw.gov.au/palliative-care-blueprint>

Swerissen, H and Duckett, S., (2014), *Dying Well*. Grattan Institute, ISBN: 978-1-925015-61-4;  
<https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>