New South Wales Auditor-General's Report
Performance Audit

Planning and evaluating palliative care services in NSW
NSW Health

audit
office
OF NEW SOUTH WALES

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In accordance with section 38E of the *Public Finance and Audit Act 1983*, I present a report titled **Planning and evaluating palliative care services in NSW: NSW Health.**

Margaret Crawford
Auditor-General
17 August 2017

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Executive summary

Overview

Palliative care is an essential component of modern health care services and an increasingly important part of the wider health and social care systems. Palliative care is healthcare and support for people with a life-limiting illness, their families and carers. It is provided by, or informed by, professionals who specialise in palliative care. 'End of life' care is provided to people approaching the end of life by health professionals, who may work in the health, community or aged care systems. Not everyone receiving end of life care needs palliative care.

NSW Health has a policy and planning role in palliative and end-of-life care, and it coordinates a wide range of service providers. Local Health Districts (LHDs) provide care services in settings such as homes, hospitals and clinics to patients with varying needs. There are several care providers that can be involved.

Due to this shared nature of palliative care — where many people, services and settings are involved in delivering care to the patient — availability and communication of information is critical. For service planning, data and evidence must be drawn from various sources in a timely and efficient way.

This audit assessed whether NSW Health is effectively planning and evaluating palliative care services, in the context of rising demand, increasingly complex needs, and the diversity of service providers.

Conclusion

NSW Health's approach to planning and evaluating palliative care is not effectively coordinated. There is no overall policy framework for palliative and end-of-life care, nor is there comprehensive monitoring and reporting on services and outcomes.

NSW Health has a limited understanding of the quantity and quality of palliative care services across the state, which reduces its ability to plan for future demand and the workforce needed to deliver it. At the district level, planning is sometimes ad hoc and accountability for performance is unclear.

The capacity of LHDs to use accurate and complete data to plan and deliver services is hindered by multiple disjointed information systems and manual data collections. Further, a data collection on patient outcomes, for benchmarking and quality improvement, is not used universally. This limits the ability of districts to plan, benchmark and improve services based on outcomes data.

NSW Health's engagement with stakeholders is not systematic. The lack of an overall stakeholder engagement strategy puts at risk the sustainability and value of stakeholder input in planning and limits transparency.

Over the last two years, NSW Health has taken steps to improve its planning and support for districts. The Agency for Clinical Innovation has produced an online resource which will assist LHDs in constructing their own, localised models of care. eHealth, which coordinates information communication technology for the state's healthcare, aims to invest in integrating and improving information systems. These initiatives should help to address many of the issues now inhibiting integrated service delivery, reporting on activity and outcomes, and planning for the future.

Recommendations

1. By July 2018, NSW Health should develop an integrated palliative and end-of-life care policy framework that:

    *   clearly articulates the interface between palliative and end of life care and outlines the priorities for the respective areas
    *   defines policy goals and objectives, and a performance and evaluation framework for palliative care service planning and delivery
    *   informs a related workforce plan which supports the policy framework and is linked to the Health Professional Workforce Plan 2012–2022
    *   reviews the funding allocation model to ensure future enhancement funds are distributed equitably and transparently based on the need and population of districts.

By December 2018, NSW Health should:

2. assess how the functionality provided in data collection programs such as the Palliative Care Outcomes Collaboration program can be provided across all palliative care services in NSW

3. complete its statewide review of systems and reporting for end of life management including specialist palliative care, and develop a business case to implement a more integrated set of solutions to:

    *   support providers delivering end of life and palliative care
    *   help monitor service quality and quantity
    *   provide comprehensive data for service planning

4. improve stakeholder engagement by:

    *   developing a statewide stakeholder engagement strategy that brings together current activity and good practice, and is transparent and publicly available
    *   defining accountability for overseeing and implementing the strategy at state and district levels.

Key findings

1. Performance monitoring is inadequate

NSW Government policy on palliative care is outlined in the NSW Government Plan to Increase Access to Palliative Care 2012–2016 (the Plan). Under the Plan, the overarching policy is 'to ensure that everyone has access to quality palliative care regardless of their economic or social circumstances, their geographical location or their medical condition.' Some initiatives under the Plan are still being implemented.

NSW Health only has measures in place to assess some processes and activities for individual initiatives under the Plan. There is no tracking of outcomes relating to the policy goals set out in the Plan, such as increased choice to die at home or the location of the patient's choice, and improved access to specialist palliative care services. NSW Health has not conducted an overall assessment of the Plan's outcomes to guide future priorities.

Further, there is no overall performance and reporting framework for palliative and end of life care, meaning there is no monitoring of performance of palliative care services for NSW as a whole. This lack of evaluation and performance measurement impacts on NSW Health's ability to monitor progress and achievements, address gaps in service, and plan for future service enhancement.

2. Statewide planning and evaluation lacks coordination

Currently, palliative care services are complex to plan and evaluate. Many policies, strategies, guidelines, directives and data collections currently inform services. Even definitions of services vary. The split of policy functions for palliative care and end-of-life care between

different branches within NSW Health adds further complexity. These arrangements create the risk of confusion, gaps in advice and support for LHDs.

Consistency is needed in the use of terminology and planning to achieve an integrated approach at all levels, including:

- standard definitions of palliative care and end-of-life care
- planning within a single structured policy framework to help clarify what services are to be delivered, who is accountable for delivering them and how to measure their outcomes.

Workforce planning is also affected. While NSW Health has identified significant gaps in the specialist palliative care workforce (especially in regional and remote areas) and it previously made workforce capacity one of its priorities, limited work has been undertaken in producing a statewide strategy to reduce these gaps.

3. District planning is not systematic and some external providers are poorly managed

An integrated approach would inform district-level service planning for palliative care. Planning in the districts we visited was sometimes ad hoc and accountability for performance unclear. Districts would benefit from:

- better integrating data collection systems with planning
- clearer guidelines, easy-to-use tools, monitoring and accountability systems.

The recently developed guide – A Blueprint for Improvement, from the Agency for Clinical Innovation – should help districts plan more effectively and consistently as it rolls out more widely in 2017. This takes an integrated approach to palliative and end-of-life care. Only one district we visited has finalised a comprehensive plan using the Blueprint.

Issues with district planning extend to external agreements with service providers, as these are sometimes poorly managed and do not support improved patient outcomes. Examples we reviewed showed a significant reporting burden with process-focused reporting. We also found little evidence of monitoring or action as a result of these reports.

4. Diverse information systems mean data collection and use are inconsistent

NSW Health gathers a broad range of data from many collection points and systems to inform palliative care services at hospital, ward or unit level, and community teams. However, the current data is limited because:

- activity is under-reported, particularly in community-based services
- collection is not universal across districts and services.

Districts also struggle with evidence-based planning and service delivery because multiple information systems mean data may be incomplete or inaccurate. Too often, clinicians and service managers rely on manual collection and paper-based systems.

eHealth, which coordinates information communication technology (ICT) for the state's healthcare, is planning a statewide approach to capture information and report on all palliative care activity. The current plans of eHealth to review and improve systems should make data more complete, robust and accessible for quality improvement and planning.

5. An overarching stakeholder strategy would strengthen engagement

Just as data is central to effective planning and evaluation, so too is stakeholder engagement. However, there is currently no explicit stakeholder strategy, which means consultation is inconsistent across the state and not systematic at a district level.

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While NSW Health uses a range of platforms to consult, the purpose and value is often not clear to stakeholders. Individual districts have some good practices, but there are limited mechanisms to identify and share these with other areas. A state-wide strategy would improve the quality and consistency of engagement, which will in turn inform service planning and delivery.

A stakeholder engagement strategy would integrate current initiatives, such as the two major networks that consult with health planning staff and clinicians. But it will also need to extend the feedback gathered from families, carers and volunteers, and from the peak bodies that represent them.

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1 Introduction

1.1 About palliative care

Palliative care has different meanings

Palliative care means different things to different people. NSW Health has adopted the World Health Organization definition[1]:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care is based on people's needs rather than their diagnosis or possible time to death. Health and community providers deliver it in hospitals, residential aged care facilities, community clinics, hospices or the home.

Despite this broad definition, in practice it is often seen as care from designated, specialist services or professionals whose main work is with patients at the end of life.

Closely linked to palliative care is end-of-life care. All health professionals may deliver this care, whether they work in the health, community or aged care systems. Palliative care is part of the continuum of end of life care – not everyone involved in end of life planning and care needs palliative care.

Demand for quality palliative care services will increase

As the population ages and chronic diseases become more common, demand is growing for quality care at the end of life that is person-centred and provides choice. In NSW alone, the number of deaths each year will more than double by 2058. As a result, more people will require social, aged care and health services and support.

The Grattan Institute[2] estimates the health and social care costs of dying will double to more than $10 billion a year in the next 25 years, as the death rate increases. The costs of dying in hospital far exceed those of dying at home supported by community palliative care services.

Coupled with this increase, some 70 per cent of people in Australia now want to die at home rather than in a hospital. Yet only about 14 per cent do. People are twice as likely to die at home in countries such as New Zealand, the United States, Ireland and France compared to Australia.

In NSW, around 50 per cent of deaths happen in hospital[3], despite an increased policy focus to support people staying at home or in a place of their choice. Wherever people choose to die, safety and clinical care needs are critical.

NSW Government policy is to increase access to quality palliative care

The NSW Government Plan to Increase Access to Palliative Care 2012–2016 (the Plan) outlines the state's policy on palliative care:

> To ensure that everyone has access to quality palliative care regardless of their economic or social circumstances, their geographical location or their medical condition.

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[1] WHO (2014a) WHO Definition of Palliative Care, accessed 7 January 2017, from http://www.who.int/cancer/palliative/definition/en.

[2] Grattan Institute (2014) 'Dying Well' Grattan Institute Report No. 2014-10, September 2014.

[3] ACI (2015) Fact of Death Analysis 2011/12 – Use of NSW public hospital services in the last year of life by NSW residents. Health Economics and Evaluation Team, and Palliative Care Network. 2015 updated edition.

The NSW Government Plan identifies four priority action areas:

Action area	Examples
Expanded community-based palliative care services	Expanded services, especially in rural areas and for populations with special needs.
	New providers, particularly private and non-government organisations.
Greater integration of services across NSW	Better links between palliative care specialists and general practitioners, community nurses and aged care services.
Expanded support for families and carers	Increased access to information, advice, after-hours phone support and other help with day-to-day living, such as domestic help.
Extended capacity of palliative care services in NSW	Building workforce capacity through training, employment and retention of specialist palliative care physicians, nurses and allied health workers, GPs, indigenous workers and volunteers.

NSW Health has done significant work planning for expanded palliative care services since 2012. New programs have been funded and started, and some of these formally evaluated.

Community demand is growing for safe and high-quality care at the end of life that is person-centred and provides choice for patients and their family and carers. Although not everyone who is dying needs specialist palliative care, improving access is a NSW policy goal.

Service delivery in NSW is diverse and devolved

In the devolved NSW health system, Local Health Districts (LHDs) decide how to deliver services that meet local needs under service agreements with the Ministry of Health.

Palliative care services depend on the patient's needs and what is available in their area. Specialist services support other care services, including GPs, allied health clinicians and hospital staff in the overall network. The private, not-for-profit, community and voluntary sectors also provide care.

How this works in practice varies. For some patients, their GP and other non-specialist providers will fully support them. As care is provided based on need: many patients are cared for by GPs and non-specialist providers because these providers can fully meet their needs. For others, a specialist will manage their care and coordinate other services. As palliative care often involves a range of clinicians, linkages and relationships between these clinicians are critical.

Various policy frameworks and plans guide services

Many policies, strategies, guidelines and directives govern palliative care at state and district levels. Within the NSW Health system:

*   the Ministry of Health, the Agency for Clinical Innovation and the Clinical Excellence Commission issue policy for palliative care services
*   NSW Ambulance issues policy for its own operations.

National frameworks also guide state services. For example, the National Palliative Care Strategy 2010 promotes coordinated and consistent delivery of high-quality care. A 2016 evaluation of this strategy made a range of recommendations for governments, including on the need for nationally consistent data on the quality and effectiveness of services in the community and primary care settings. National standards for high-quality palliative care have also been in place since 2005, with various supporting planning guides. A review of the standards began in 2016.

In 2015, the Australian Commission on Safety and Quality in Health developed the National Consensus Statement on End-of-Life Care for acute facilities. Australian health ministers endorsed this statement, which:

- has 10 essential elements for delivering high quality and safe care
- gives clinicians, health service managers, policy-makers, educators and training providers guiding principles to improve care.

1.2 About the audit

This audit assessed whether NSW Health is effective in evaluating and planning the state's palliative care service delivery. We examined whether NSW Health:

- collects robust data
- uses data and evaluations to plan and deliver high-quality, safe and appropriate palliative care services
- works collaboratively with other stakeholders in this area.

As part of the audit, we:

- interviewed people from the Ministry of Health, eHealth NSW, NSW Ambulance, the Palliative Care Network Executive Committee, NSW Agency for Clinical Innovation, Primary Health Networks and contracted service providers
- interviewed staff from the Palliative Care Outcomes Collaboration at the University of Wollongong, and the Australian Institute of Health and Welfare
- met with expert clinicians and academics, peak bodies, consumer advocacy groups and consumers
- reviewed systems and data collections, tools and benchmarking reports as well as various systems in use at a local level
- reviewed policy and evaluation documents, plans and guidelines.

We also visited sites and interviewed staff in three LHDs – Northern Sydney, Illawarra Shoalhaven and Western NSW – including visits to:

- Royal North Shore Hospital
- Greenwich Hospital
- Wollongong Hospital
- Port Kembla Hospital
- David Berry Hospital
- Dubbo Base Hospital
- Lourdes Hospital
- Orange Health Service
- community health service hubs.

Please see Appendix 3 for more on the audit scope, criteria and methods.

2 Planning at the state level

NSW Health is responsible for the state's palliative care services but its approach to planning and evaluating service delivery is not effectively coordinated. This chapter assesses:

1. statewide planning and evaluation systems
2. workforce planning and service funding.

There is no defined policy framework for palliative and end-of-life care, nor is there comprehensive monitoring or reporting. The lack of an overarching performance framework or public reporting for palliative care limits understanding of the quantity and quality of palliative care services across the state.

While NSW Health uses some data and formal evaluations to inform service planning for initiatives, it does not do so for palliative care service as a whole.

There is also no statewide workforce strategy supporting ongoing delivery or the NSW Government Plan, and the rationale for recent enhancement funding is not transparent. These issues mean the state is not currently addressing gaps in services.

Recommendations

By July 2018, NSW Health should develop an integrated palliative and end-of-life care policy framework that:

- clearly articulates the interface between palliative and end of life care and outlines the priorities for the respective areas
- defines policy goals and objectives, and a performance and evaluation framework for palliative care service planning and delivery
- informs a related workforce plan which supports the policy framework and is linked to the Health Professional Workforce Plan 2012–2022
- reviews the funding allocation model to ensure future enhancement funds are distributed equitably and transparently based on the need and population of districts.

2.1 Statewide planning and evaluation

The NSW Government Plan states that the overarching policy for palliative care is 'to ensure that everyone has access to quality palliative care regardless of their economic or social circumstances, their geographical location or their medical condition.' However, our audit found that:

- this policy does not establish consistent objectives or definitions
- key functions are split within NSW Health and past recommendations have not been adopted
- performance monitoring is limited, making it difficult to assess the effectiveness of the state's services and plan for the future
- an integrated statewide policy framework would help to address these issues.

The links between palliative and end-of-life care are unclear

The NSW Government Plan does not explicitly address the relationship between palliative and end-of-life care. Currently, different definitions and objectives are used across NSW Health.

The Agency for Clinical Innovation, for example, has developed the Palliative and End of Life Care: A Blueprint for Improvement 2016 which aims to guide services and LHDs in

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constructing their own, localised models of care. It defines care operationally based on who is providing it.

Various 'enablers' support palliative care data collections, district and facility plans, actions, tools and resources. Within these, the integration or distinction between palliative care, specialist palliative care and end-of-life care is less clear and limits effective coordination across different activities.

Central planning and evaluation could be better coordinated

Related to these definitional issues, central policy and planning functions for palliative and end-of-life care are spilt within NSW Health. The Office of the Chief Health Officer manages the Advance Planning for Quality Care and End of Life Action Plan 2013–2018. The Health and Social Policy Branch, the Agency for Clinical Innovation and the Clinical Excellence Commission are responsible for aspects of palliative care policy.

These arrangements require internal and external coordination, and may lead to:

- gaps in advice and support to districts
- confusion for external stakeholders in identifying the right point of contact.

There is also significant complexity in planning and evaluating palliative care services with many policies, strategies, guidelines, directives and data collections affecting services at state and district levels.

A 2016 evaluation looked at initiatives funded under the NSW Government Plan to extend palliative care services, particularly in the community. NSW Health drafted a summary of activities against the plan at January 2017, but there remains no overall assessment to guide future priorities.

NSW Health advised it is currently developing a strategic plan for palliative care services. This plan will take into account initiatives from the Ministry of Health, the Agency for Clinical Innovation, the Clinical Excellence Commission, Ambulance NSW, Palliative Care Australia, and the Australian Government, as well as the outcomes of the consultation process currently being conducted through statewide roundtables. This is aimed at:

- clarifying how these agencies work together to support high-quality care
- addressing concerns about the lack of coordination and a statewide strategy for palliative and end-of-life care.

Lack of an overarching policy framework affects performance monitoring

Without an overall policy framework for palliative and end-of-life care, the monitoring of how NSW services perform as a whole is affected. The NSW Government Plan has no overarching performance framework, nor was one developed during its implementation. As such, it is not possible to identify gaps or achievements statewide.

Under the Plan, lead agencies and districts self-report on their actions, with no further strategy for measuring performance or ensuring accountability or transparency. Services for specific populations (such as Aboriginal people) are not highlighted despite being a plan priority.

While NSW Health does monitor processes and activity for particular initiatives, there is no performance framework that reflects the plan's various policy objectives, such as:

- increased choice to die at home or a location of the patient's choice
- improved access to specialist palliative care services.

Without these measures, it is difficult for NSW Health to evaluate, track and report on progress and effectiveness.

Exhibits 1 and 2 provide examples of measuring policy effectiveness.

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Exhibit 1: How would you measure policy effectiveness?

A leading clinician and academic speaks on KPIs

For the current policy agenda, the main measure of policy effectiveness would be whether people die where they choose, and if at home, is the trend going up or down. But it would need to be more nuanced than just actual place of death.

He gave the example that a good death would be staying at home for as long as possible and going to a hospital or hospice for the last two days.

The better indicator would be to look at the last 100 days to see where the patient received care, not just where they died. This 'last 100 days' experience would measure policy effectiveness.

Other relevant indicators would be:

- Is the person sick if they are in hospital?
- How many of those dying in hospital are ill?
- How many have high dependencies?

The clinician can report on these measures, but it is not possible statewide, mainly due to system interface issues.

Source: Audit Office interview with a NSW palliative care clinician and academic.

Exhibit 2: Victoria's high-level performance framework

The following table outlines how Victoria uses data from information systems to measure progress in achieving goals across all priority areas through its high-level performance framework for palliative and end-of-life care.

Goals	Measures
People experience optimal end-of-life care	Client and carer experience survey data
People's pain and symptoms are managed with quality interventions	Benchmarked patient outcomes
People express and record their values and preferences for end-of-life care	Documented evidence of advance care plans in patient records
Carers are supported	Client and carer experience survey data
People are cared for in their place of choice	Care delivered in the person's place of choice
Where possible, people die in their place of choice	The person dies in their place of choice

Source: Department of Health and Human Services (2016) Victoria's end of life and palliative care framework.

An integrated policy framework, would benefit performance

Integrating policy and planning activities into a single policy framework would clarify:

- service development roles and responsibilities
- points of influence for patients, carers, advocates and policy makers.

Victoria's June 2016 framework for palliative and end-of-life care defines the relationship between these types of care, sets priorities, and gives a single matrix for performance and accountability against policy goals. A specific framework for palliative care service delivery then supports this framework.

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NSW may benefit from a similarly integrated palliative and end-of-life care policy framework as shown in Exhibit 3. At a minimum, it should include:

- standard definitions for both types of care and specific palliative care services
- a high-level performance and evaluation framework, with outcomes, KPIs and accountabilities
- a requirement linking all guidelines, tools and resources to the strategy.

Exhibit 3: Audit Office example of a possible model for the NSW Palliative and End of Life policy framework
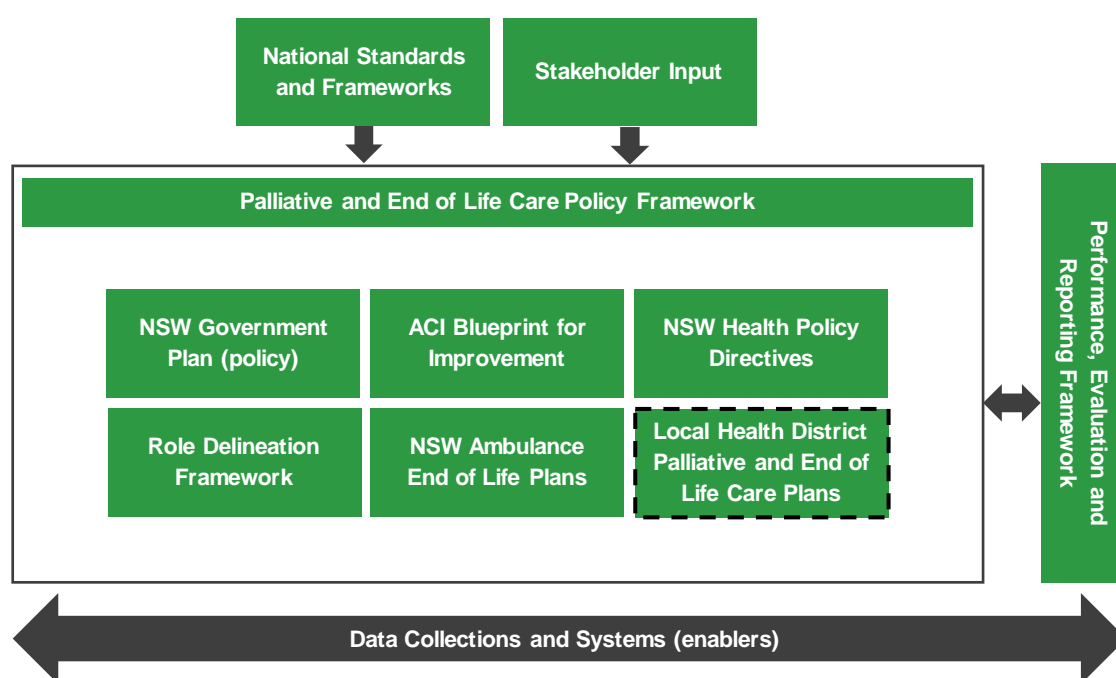
Source: Audit Office research.

2.2 Workforce planning and funding service growth

The lack of an explicit strategy for addressing workforce shortages and needs-based approaches to allocating new funding puts at risk the principle of equitable service delivery.

There is currently no detailed workforce planning to target strategic priorities. Advocates and peak bodies have resorted to collecting data on workforce supply in the absence of centrally available information. Further, service enhancement funding allocations under the four-year plan have not been transparently based on need.

Workforce shortages create a risk to service sustainability and equity

Several reports to government have highlighted workforce shortages and the likely challenges in meeting growing demand for palliative care. In 2010, NSW Health made workforce capacity one of its four priorities up to 2013. A 2012 expert committee advising the Minister for Health concluded there were significant gaps in the specialist palliative care workforce, especially in regional and remote areas[4].

The NSW Government Plan[5] commits to 'build workforce capacity through support for the training, employment and retention of specialist palliative care physicians, nurses and allied health workers (including those specialising in paediatrics), GPs, indigenous palliative care workers and volunteers'.

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[4] Palliative Care Expert Advisory Group (2012) 'Improving Palliative Care for people in NSW'. Report to NSW Minister for Health. April.

[5] NSW Government Plan to Increase Access to Palliative Care 2012–2016.

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However, no overall workforce strategy supports the plan. While the LHDs we visited have identified a need for more staff in palliative care, they are not doing detailed workforce planning against a statewide strategy or priorities. This makes it difficult to target areas of need to sustain existing services and provide equitable access where services are affected by a limited workforce.

NSW Health advised that since 2012, an additional nine palliative care physician training positions and four new rural generalist training positions in palliative care medicine have been funded. Since 2013, an additional 39.5 FTE end of life palliative care nurse educator and clinical nurse specialist positions have been funded, including six FTE for rural and regional areas in 2016. In addition, five FTE nurse practitioner positions specialising in palliative care have also been funded. The government also announced an additional $100 million in funding for the palliative care workforce in June 2017.

Consumer advocates have analysed workforce data to highlight need

During the audit, consumer advocates and peak bodies repeatedly raised the issue of workforce supply as their top priority.

A palliative care advocacy group gave the Minister for Health a detailed business case for enhancing services in 2013. This was supported by another submission in 2016 that analysed the current supply of specialist palliative care physicians by district, including funded positions, vacancies and roles filled by non-specialists. NSW Health could not supply this workforce data so the advocacy group did a telephone survey of all districts.

The NSW Cancer Council also analysed this data against recommended population ratios from both the Australian and New Zealand Society of Palliative Medicine and Palliative Care Australia. The data, with similar analysis for palliative care nursing supply, has formed the centrepiece of a community campaign to boost services and specialist workforce capacity.

This type of analysis seems essential for the NSW Government Plan, yet it was not done during the Plan's implementation planning. NSW Health advised it has conducted analyses of workforce data and is currently conducting an audit of the palliative care workforce.

Funding allocations may not be based on need

Under the NSW Government Plan, LHDs could access a flexible fund to enhance their palliative care services through an expression of interest model. However, this 'bidding' approach may not support equitable service delivery, particularly for regional and remote populations.

NSW Health advised that funds in the flexible funding pool were distributed to LHDs with a weighting towards rural and regional districts and that the expression of interest process was designed to respond to locally identified priorities. However, the funding allocations are not clear to district executives. For example, are they based on measures of relative population need, or do they best serve those with the greatest skill in demonstrating need or innovation, further entrenching inequity?

A funding model based on population and need may provide greater opportunity to address equity in service provision. The Victorian Auditor-General's report on palliative care refers to the Palliative Care Resource Allocation Model. This has a formula for a fairer allocation of new funding based on the needs of the population in a defined catchment. Future planning should assess whether the Victorian approach would suit NSW.

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3 Planning services at the district level

Planning and evaluation of palliative care services at the district level is the responsibility of Local Health Districts.

This chapter assesses:

- planning and evaluation at a district level
- agreements the districts manage with external service providers.

In the three districts we visited, planning is generally ad hoc with plans in draft form or non-existent and accountability for performance unclear. Only one district we visited has finalised a comprehensive plan. Districts would benefit from:

- better integrating data collection systems with planning
- clearer guidelines, easy-to-use tools, monitoring and accountability systems.

Issues with district planning extend to external agreements with service providers, as these are sometimes poorly managed.

3.1 District planning and evaluation

As with planning and evaluation at the state level, LHDs face similar issues from the lack of an overarching policy framework. In our review of three LHDs, our audit found that:

- district planning is often ad hoc, with plans in draft form or missing altogether
- accountability for performance is unclear.

District planning is not driven strategically and is often ad hoc

The (then) Department of Health has required district-level service planning for palliative care since 2010. However, we found little evidence of comprehensive, finalised plans. Districts we visited are at different stages in developing service plans under the new Blueprint. Annual operational plans to support these broader strategic plans are only in draft or non-existent.

The NSW Government Plan and Blueprint both guide district planning. The Blueprint helps LHDs develop comprehensive palliative care and end-of-life care plans, and should improve consistency as the Agency for Clinical Innovation rolls it out to more districts in 2017. But use of the Blueprint has been limited to date, with only one of the LHDs we visited producing a plan using its integrated framework (Western NSW LHD Palliative and End of Life Care Plan 2016–2020).

There was also no evidence that the state monitors the development of district plans, and the Ministry of Health could not report on their status. Districts can still access enhancement funds under the NSW Government Plan without completing a district plan. For district services to improve, the Ministry of Health needs to close the loop on planning activities, approve and support plans, and link them to funding.

Without this oversight, district service planning has not always been implemented within a strategic framework. As Exhibit 4 shows, responding to local needs and priorities can also lead to services operating outside best practice or to districts duplicating effort.

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Exhibit 4: Duplication of after-hours telephone support

In the NSW Government Plan, the government committed to extending after-hours phone services, so the Ministry of Health contracted Healthdirect Australia to launch the statewide Palliative Care After Hours Helpline. This provides professional information, support and advice for patients, families and carers where similar services do not exist. It aims to give people more choice in the care they receive at home.

But when the rollout of the statewide helpline was delayed, the Western NSW LHD funded its own after-hours service for its registered palliative care patients, and continues to do so. Specialist nurses staff the helpline to integrate existing care plans and provide continuity of care. Support, advice and interventions can also be recorded on the patient's electronic medical record, boosting the quality of patient records and capturing data on local demand for after-hours support.

Both helplines have the same aims. The duplication potentially confuses patients about which service to use. Running dual services is also not an efficient use of funding.

Accountability for performance is missing

Evaluation activity within districts is mainly at the service or unit level, and generally reflects the interests of local clinicians. Examples of this include research projects clinicians run at individual services, which compile and analyse data to justify extra resources.

The 2016–17 service agreements between the Ministry of Health and LHDs do not include targets and indicators for palliative and end-of-life care. While it would not be feasible to report on all service types at this level, districts are not reporting on performance through palliative care service planning cycles either. Without some kind of performance monitoring, accountability for service delivery has broken down.

To build accountability and transparency in the outcomes it achieves, each district should:

•   complete a comprehensive, district-wide plan
•   take part in a performance framework that links this plan to the statewide policy framework.

These elements would form the basic architecture for accountability. But they should also incorporate accountability frameworks for external providers, as they make up a substantial part of service delivery in some districts.

3.2 Performance frameworks in external agreements

As districts take a more strategic, consistent approach to planning and evaluation, they also need to consider their agreements with external service providers. We found that agreements:

•   are sometimes poorly managed, with little monitoring and unclear accountabilities
•   require reporting against opaque performance measures that do not target patient outcomes.

Some service agreements are poorly managed

Affiliated organisations are the not-for-profit religious, charitable or other non-government organisations that provide health services and form part of the public health system. They are key service providers in two of the three districts our audit examined.

Although services are ongoing, LHDs enter into annual service agreements with these organisations. This has led to 'planning fatigue' with very little effort or attention given to the annual review and renewal. For example, we found some draft unsigned service agreements well into the life of the agreement.

Program initiatives also use service agreements. The Ministry of Health has contracts with established not-for-profit providers in aged care and palliative care for the NSW Palliative Care Last-Days-of-Life Home Support Services.

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For both types of agreements, we found:

- examples of poorly constructed or excessively process-focused activity reporting
- little evidence of monitoring or action stemming from this reporting within the district or Ministry of Health
- a disconnect in the accountability model. For example, in one program the providers must manage performance against activity targets but they do not control the number of patients referred to them, which has led to funded places being underused.

Examples show poor performance measures in external service agreements

Exhibit 5 shows two examples of performance frameworks. Example 1 relates to an affiliated organisation providing an ongoing service in a district. The agreement is renewed annually and negotiations focus on activity. However, performance is poorly managed and not linked to existing benchmarks. Performance measures are opaque and provide no basis for reporting or accountability, except for the number of occasions of service.

Example 2 relates to the NSW Palliative Care Last-Days-of-Life Home Support Services with three-year funding, where the Ministry of Health requires a quarterly report. The number of process measures far exceeds outcome measures **(marked in bold)** and the burden of reporting is significant. As the program moves from Year 1 reporting to future years, this balance should change.

Exhibit 5: Examples of current performance monitoring

Example 1: Performance framework between LHD and an affiliated organisation	
Palliative care service indicators	**Performance measures**
90% of referrals contacted within 3 business days	Quarterly review and negotiated action
Preferred place of death at end of life compared to actual	As above
100% of patients assessed regarding their suitability for a specialist palliative care medical review	As above
75% of carers satisfied with the service	Annual review and negotiated action
1,780 occasions of service per year	Monthly performance monitoring and negotiated action

Source: Affiliated Health Service Organisation Agreement: An Agreement between Western NSW and Lourdes Hospital and Community Health Services, 1 July 2015 – 30 June 2016.

Example 2: Palliative Care Last-Days-of-Life Home Support Services	
Service indicator	**Measures**
Relationship management	• Data on package use and trends • Update on risk identification, mitigation strategies and program improvement opportunities • Staffing movements • Proportion of clients and carers engaged in a satisfaction/experience survey and reported to the Ministry (including survey process, volumes and key themes of experience)
Demand management	• Percentage of packages used compared to those available or projected
Service response	• Percentage of referrals accepted within 12 hours • **Percentage of eligible clients whose service starts within 24 hours of referral (PCOC benchmark)** • Number of clients deemed ineligible and why • Equitable access to services by palliative care patients of all ages
Funding and financial management	• Submission of quarterly agreed service activity and performance reports • Submission of a financial acquittal certificate
Organisational quality	• **Number and percentage of client deaths at home** • **Patient and carer experience for at least 10 per cent of clients receiving services** • Summary of continuous quality improvements started, and their progress • Progress with the evaluation plan and any emerging findings • Summary of identified local and system level risks and opportunities, with management strategies
Education and training	• Training activities conducted, including the volume and frequency • Professional education services offered and a summary of statewide participation • Evaluation activities in progress

Source: NSW Palliative Care Last-Days-of-Life Home Support Services 2016/2017 Quarter 1 Agreed Service Activity and Performance Measures Report.

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4 Collecting and using data

Collecting service data is key to effective planning and evaluation, and NSW Health gathers a broad range of data from many collection points and systems to inform services at hospital, community team, and ward or unit level.

This chapter assesses:

- the challenges with current data collection methods
- current data initiatives to improve quality of care
- planned improvements to integrate data systems.

Current data are limited because activity is under-reported, particularly in community-based services, and collection is not universal across Local Health Districts (LHDs) and services. Districts also struggle with evidence-based planning and service delivery because multiple information systems mean data may be incomplete or inaccurate. Clinicians and service managers often rely on manual collection and paper-based systems.

Some more formal systems are in place across the state, including:

- an app to monitor hospital performance against process indicators
- a collaborative program – the Palliative Care Outcomes Collaboration – where participating services use standard tools and training to capture patient outcomes.

In 2016, eHealth also started a statewide review of systems and reporting for palliative care, aiming to provide a single, integrated approach across NSW. This should help improve many of the system and data issues our audit identified.

Recommendations

By December 2018, NSW Health should:

- assess how the functionality provided in data collection programs such as the Palliative Care Outcomes Collaboration program can be provided across all palliative care services in NSW
- complete its statewide review of systems and reporting for end of life management including specialist palliative care, and develop a business case to implement a more integrated set of solutions to:
  - support providers delivering end of life and palliative care
  - help monitor service quality and quantity
  - provide comprehensive data for service planning.

4.1 Data collection challenges

NSW has a number of data collecting systems, but data on palliative care services can be:

- under-collected and under-reported, leading to issues with planning, evaluation and patient care
- disjointed or incomplete as it is stored separately in information systems that do not 'talk' to each other
- variable in quality because of resource-intensive manual entry that increases the risk of errors.

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Information systems must capture accurate data for planning and quality care

Across the health settings and sites we visited, information systems do inform planning, support clinical and financial management, and help monitor activity. However, as these systems are not usually purpose-designed for palliative care, they do not necessarily capture all relevant information for palliative care services.

Palliative Care involves many people, services and settings delivering care to one person. For services to meet the needs of patients, families and carers, even after a patient has died, it is essential that information systems support this breadth of activity. Information must be available to everyone involved.

More broadly, reporting activity accurately is also fundamental for planning services, assuring quality, equity and efficiency in allocating resources.

Diverse delivery points mean activity is not always accurately and fully recorded or reported. Some districts, for example, provide integrated services and other programs (such as volunteer coordination) that are not reported outside the team delivering the service. This has led to under-collection and under-reporting of activity, making it difficult to quantify past service delivery activity when planning for the future.

Another risk of poor data collection is that the clinical care of patients may be affected. For example, one hospital service noted that referral forms were sometimes left unattended on a fax machine. Where clinical notes are not shared between the systems for inpatient care and community care through electronic medical records (eMR), continuity of care may be compromised and the potential for human error increases.

Many clinicians and service managers manually enter data on paper or in local spreadsheets. This inefficient, resource-intensive approach delivers variable data and increases the risk of human error. Data collection should be aligned with state and national standards of care. Ideally, clinicians would contribute through standardised real-time reporting (bedside documents or mobile devices) and business processes.

Diverse systems across the districts create 'silos' of information

Districts often use different systems or the same systems but in different ways. There is then inconsistency in how these systems line up.

Districts buying or developing local solutions to collect and report data has led to challenges with integrating care systems. In some districts, local solutions do integrate data across activities and sectors in a single application, but these have limited capacity to interface with other systems.

In other places, systems collecting data do not 'talk' to each other between hospital and community services. Hospitals use a central electronic reporting system supported by policy directives, education and feedback. For community services, districts might have a different system to capture activity and clinical notes. Within a district, community-based systems may also vary, with data not being available to all parties involved in care elsewhere.

These issues mean information falls into silos, restricting its value for planning and clinical needs. Some local systems have recently been abandoned as a result.

Where consistent approaches do exist, such as shared templates and forms, structural barriers can create other problems. For example, Lourdes Hospital is an affiliated health organisation that provides palliative care inpatient beds and community outreach for Western NSW LHD's western sector, but it:

- does not have access to NSW Health systems
- cannot access or update eMRs from the nearby Dubbo Health Service when patients are referred
- cannot participate in benchmarking against other NSW services through the SNAP app (see 4.2).

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The services, which lie just one kilometre apart, send faxes or hand deliver paper records to share patient information.

Finally, the challenge of integration extends to systems that help manage cancer patients or prescribe medication. Even though these might allow specific data on the palliative phase of care to be extracted, they do not align with other information systems.

4.2 Current data initiatives

While data collection systems vary significantly between districts, more standardised statewide data collections are improving monitoring, particularly for hospital services. Our audit found that the:

- Sub-Acute and Non-Acute Patient Classification (SNAP) system and app are helping to track hospital activity and boost compliance with patient classification processes
- Palliative Care Outcomes Collaboration (PCOC) offers a systematic way to collect outcomes data using standardised tools
- PCOC functionality could drive significant improvements in the quality of the state's care if it is expanded to cover more services.

SNAP data collection has improved the capture of hospital activity

SNAP is the mandatory statewide data collection for sub-acute and non-acute patient groups in hospital care, including palliative care. Participating hospitals submit data to the Ministry of Health. SNAP is used at state and district levels to drive performance in hospitals through activity targets and processes, such as updating patient classifications as their status changes to trigger different funding allocations.

For a patient receiving palliative care in a hospital, the clinician will contribute to SNAP during their usual 'bedside' documentation process, by using standard assessment tools that identify the patient classification.

The Ministry of Health has developed the interactive SNAP app to:

- capture inpatient activity at hospitals that meet a given threshold of activity
- collect some outpatient activity, but not activity delivered in the community
- monitor district activity against forecasts and agreed performance measures.

These performance measures are related to processes, such as the percentage error rate in updating a patient's classification as their status changes (which leads to differential funding).

The app delivers a monthly monitoring report on performance by district, calculating estimated loss in income from Commonwealth funding where forecasts are not met. LHDs are then benchmarked against the NSW average and designated as high or low performers. This has the benefit of encouraging districts to better comply with defined processes.

AIHW and PCOC reports cover national and state data

For national data, the Australian Institute of Health and Welfare (AIHW) reports on palliative care services each year. It breaks some data down by state and territory, mainly for hospitals. Appendix 2 outlines AIHW's most recent national highlights.

It is possible to match AIHW data collections and NSW health administrative data sets to analyse healthcare utilisation patterns and trends. Appendix 2 contains highlights of the recent Agency for Clinical Innovation 'Facts of Death' analysis which does this.

The Palliative Care Outcomes Collaboration (PCOC) measures and benchmarks patient outcomes in palliative care. This is a voluntary, national program that uses standardised clinical assessment tools to measure and benchmark patient outcomes. It aims to help service providers improve practice and meet national standards, through data development, training, reports and research.

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National or statewide reporting on outcomes is not possible as PCOC is not universal or mandatory and in NSW mainly covers specialist palliative care services in hospital settings.

The PCOC dataset:

- gives clinicians a way to systematically assess individual patient experiences
- defines a common clinical language to streamline communication
- facilitates the routine collection of national data to drive quality improvement through reporting and benchmarking.

Although we were given many examples of the use of PCOC for quality improvement, only a small number of service leaders are using it to its full potential for district planning.

The Australian Health Services Research Institute at the University of Wollongong delivers the PCOC program, funded by the Australian Government. It produces national, state and local service reports every six months.

The program collects data on specialist hospital and some community-based palliative care services. In NSW, it mainly covers specialist inpatient services with 27 of approximately 30 NSW palliative care units reporting data. Half of community based palliative care services and 2 of 14 inpatient consultative services also report to PCOC.

In other states, coverage is more balanced. For example, Victoria reports on 22 specialist palliative care services: 12 for inpatients, 9 for community services and 1 integrated service.

Expanding participation in the PCOC program would improve outcomes data and may improve patient care

During our visits to LHDs, we saw examples of the three main PCOC dataset functions (mentioned above) in various hospital services and one integrated service. A non-government organisation providing in-home support was also using PCOC tools and benchmarking.

We visited two other services providing an integrated specialist palliative care service (inpatient beds, consultancy and community-based delivery) that used PCOC data more broadly to cover:

- service level planning
- performance monitoring to improve clinical processes
- evaluation, research, auditing and clinical redesign projects.

NSW Health could gain further value from the resources current participants invest in the PCOC, and extend it to cover additional specialist hospital and community-based services. This would require engagement with the University of Wollongong and district services to address perceived limitation. The main issues NSW Health staff reported to us were:

- some benchmarks are not appropriate for use in community services
- operating systems are not always compatible between community services and hospitals.

Data collected using standard assessment tools and compared with benchmarks can not only affect decisions about the care of individual patients, but also outcomes at a population level. The expansion of the PCOC approach would help drive improvements in the quality of the state's palliative care services.

4.3 Planned data integration

As these formal systems are rolled out more broadly, work is also underway to:

- integrate existing information systems so a range of care providers can more effectively contribute to a patient's care
- roll out a statewide system to collect robust data for state and district planning.

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Planning to integrate information systems is underway

Integration is a key concept for contemporary heath service delivery. The recent eHealth Strategy for NSW Health 2016–2026 emphasises the importance of integrating information and communication technology to support patient care. This priority aligns with the goal of delivering effective, high-quality and safe palliative care in all health settings.

The eHealth Strategy includes developments that will improve the piecemeal systems and collections at district level. For this audit, the relevant ones relate to:

*   accurate and consistent core clinical systems served by integrated 'paper-lite' information systems covering the eMR, electronic medication management and incident management
*   communication and information systems that support integrated care and enable shared care plans to be recorded and transmitted
*   health data analytics that support decision-making and organisational performance
*   integrated core information systems that give better access to data, including:
    –   the eMR, a patient details database available to clinicians in the hospital
    –   the national My Health record system, with patient information from multiple sources
    –   HealtheNET, which integrates disjointed health systems and the My Health record.

An integrated approach to palliative and end-of-life care broadens the number and type of providers who can contribute to a patient's care, such as:

*   their GP, who has detailed knowledge of their medical history
*   disease specialists and palliative care clinicians in hospital
*   patient support groups
*   hospice, home and community clinicians.

Reporting should cover multidisciplinary care and other activity, including support to family and carers before and after the person has died.

Statewide solution to capture information is in design stage

An integrated clinical system to support community health and outpatient care – including palliative care – has only just been rolled out statewide. It is not yet working in all districts and has some limitations for collecting and reporting on palliative care.

This new system improves access to clinical information across hospital and community services within LHDs by adding functionality to the eMR. However, improvements in reporting on non-inpatient activity and outcomes are yet to be fully realised.

eHealth NSW is also developing functions for palliative care in the eMR, to provide a statewide solution for integrating data collection and use. Five LHDs are using specific functions already, but the eMR's continued expansion in NSW will improve it. The record will eventually include care provided in inpatient (general and specialist), outpatient and community settings, and end-of-life care and advance care plans.

Work has also started on a statewide approach to capture information and report on all palliative care activity. A project underway through eHealth will address the flaws and lack of function in the information systems for palliative and end-of-life care. It is in the scoping and high-level design stage.

Adopting this project is fundamental to improving the delivery of high-quality care through robust, accurate data. This in turn will aid planning at ward, unit, service and district levels.

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5 Engaging stakeholders

NSW Health and the Local Health Districts (LHDs) work with stakeholders to plan and evaluate palliative care services. Stakeholders include primary care providers, patients, carers and advocates. For example:

- at the state level, networks of providers and peak bodies consult on key issues and share information
- at the district level, patients, carers and peak bodies have input through community groups, committee representation, surveys and forums.

However, these arrangements are generally informal and not part of an overall stakeholder engagement strategy. Ongoing engagement is therefore not systematic and lacking a clear purpose. There are limited mechanisms to share good practice.

This chapter considers engagement at three levels:

- for the state as a whole
- with primary care providers
- with patients, families, carers and the community.

Recommendation

By December 2018, NSW Health should improve stakeholder engagement by:

- developing a statewide stakeholder engagement strategy that brings together current activity and good practice, and is transparent and publicly available
- defining accountability for overseeing and implementing the strategy at state and district levels.

5.1 State-level strategy for engagement

NSW Health currently has no explicit strategy for engaging palliative care stakeholders to support planning, and this has led to:

- inconsistent engagement across the state
- processes which are not systematic at the district level.

A statewide strategy would reduce confusion and boost long-term engagement

The lack of a strategy means consultation is often directed at a homogenous set of 'stakeholders', when diverse groups should instead be approached using different methods and set different goals.

NSW Health uses a range of platforms to involve people but sometimes:

- the purpose of the consultation is unclear for those it seeks to involve
- its value to them is not specific
- they join the process late and have limited influence.

Planning forums should involve broad stakeholder participation, in line with Agency for Clinical Innovation processes around models of care. The project plan for each piece of work should be explicitly developed and communicated widely.

Without an overarching strategy to define good practice, the state risks losing key contributors to its planning and policy-setting, and buy-in when it then adopts these plans and policies.

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District processes would benefit from statewide guidance

As well as supporting planning and policy at the state level, an overarching strategy would guide district engagement. The districts have some examples of good practice, including:

• councils and committees for planning that involve consumers, external providers, community and advocacy groups

• feedback mechanisms, such as surveys, forums and the 'patient journey' (a process that seeks feedback on a patient's experience through the health system).

A statewide strategy would prompt districts to consider essential elements, such as routine feedback processes, representation in committees and advisory bodies, and support for community-initiated forums.

5.2 Primary care providers

While a statewide strategy would guide engagement going forward, it should also integrate current initiatives, such as those for primary care providers like GPs and community nurses. These providers play a key role in community-based palliative care. Their representatives currently contribute through:

• two large state networks

• formal structures at the district level.

Statewide networks allow broad consultation

NSW Health advised us that the following forums are influential in policy development and planning.

Forum	Description
NSW Palliative Care Network, established by the Agency for Clinical Innovation	The network has more than 470 members. To produce the Blueprint, the Agency for Clinical Innovation consulted LHDs and key stakeholders such as residential aged care facilities, carer organisations, and primary care and specialist palliative care providers.
NSW Palliative Care Service Development Officers Network	Representatives come from each LHD and the Ministry of Health. Service development officers are the ministry's primary LHD contacts for palliative care. The network meets regularly to consult and exchange information.

A statewide working group, widely representative of providers, consumers and carers, has been formed to review the outcomes of the 2012–2016 Plan and plan for the future.

District networks need a clear purpose to be effective

Primary Health Networks represent primary care providers and they have strong, structured relationships with LHDs on palliative care.

When interviewed, staff from the Primary Health Networks also reported formal and project relationships with individual LHDs. For example, Northern Sydney has:

• a joint Chief Executives' committee

• a Health Pathways project

• project work with the Director, Performance, Integration and Innovation

• some data linkage projects

• shared planning informed by the Agency for Clinical Innovation project on Integrated Care of the Older Person.

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In the Illawarra, the Primary Health Networks and LHD have several structures for joint planning, such as:

- using a strategic alliance where senior leaders meet about joint strategic projects, avoiding 'business as usual' planning
- planning infrastructure for integrated service delivery
- sharing some GP activity data.

However, some district-level planning mechanisms do not have a strategic planning purpose. For example, the Northern Sydney LHD network on palliative care, which includes local external providers and partners, is the major vehicle for planning and collaboration but its functions mainly involve sharing information.

5.3 Patients, families, carers and the community

Although statewide and district networks serve important functions, they are dominated by health planning staff and clinicians. The voices of patients, families and carers, although included, are not central to deliberations. Our audit found that:

- families, carers and volunteers play a key role and must have a say in palliative care services
- some districts need to engage people more systematically using a range of methods
- relationships with peak bodies also require further development.

Engagement must include families, carers and volunteers

Families and carers play an essential role in palliative and end-of-life care, and they must be involved in formal, planned consultation.

Like the patients themselves, they receive support from health and community services in the sector to help them as they have a critical support role. Services include psychosocial care and advice, respite and bereavement services.

Bereavement services, for example, are prescribed in the World Health Organization's definition of palliative care and in national standards. They form part of palliative care service delivery in districts.

Volunteers are another important part of a quality service, and should be included in engagement strategies. The NSW Government Plan has funded volunteer program coordination in some districts.

District strategies should use a mix of activities to engage the community

It is fundamental to planning and ongoing service delivery that LHDs engage with patients, families, carers and other advocates, and collect feedback on their service experiences. However, this does not always happen systematically.

Although districts have ways to gather feedback, such as surveys, forums and patient journeys, some health services need to engage people more systematically and continuously in a range of activities.

The south-eastern sector of Western NSW LHD, where consumer groups have been particularly active, provides a useful example. It has a Palliative Care Community Consultative Committee, which includes three community members. A coalition of consumer groups also held an open community forum in 2016 to discuss priorities in palliative care. Around 350 people attended and contributed to a list of strategic priorities, some of which will involve community action and funding outside the Health portfolio.

Various measures that could make up a district's engagement strategy include:

- routine feedback on patient and client experiences (such as patient journeys and surveys)
- consumer councils and advisory bodies

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- community representation on key review and planning committees
- support for forums, initiated by consumers or the community, that help raise awareness, fundraise or identify planning priorities.

Peak bodies have limited representation on key committees

Unlike the networks for primary care providers, relationships with peak bodies in the sector are under-developed. There are some examples of good practice, including standing committees for planning involving peak bodies or advocate groups. But consultation often happens 'as required' or project by project.

Carers NSW, for example, reports no specific mechanisms to support consultation and collaboration, although it does work with NSW Health on some projects at the district level. NSW Health and LHDs could consider including a carer, or representative of a carer organisation, on relevant committees.

Health Consumers NSW is represented on some committees, such as the End of Life Implementation Advisory Committee. It reports it sometimes has contact with specific facilities or districts, but it too notes there is no consumer voice on the advisory committee that will oversee planning following the expiry of the 2012–2016 NSW Government Plan. This committee, set up in 2016, will set strategic priorities for the state's palliative care for the immediate future.

Roundtable meetings improve stakeholder engagement

The Minister for Health convened a series of Roundtable meetings on palliative care, with ten meetings being conducted across NSW between April and June 2017. The purpose of these meetings was to consult with stakeholders about what is working well in palliative services, current priorities and possible solutions. Attendees include medical practitioners, nurses, aged care services, researchers, NGOs, carers and families.

NSW Health advised that following completion of the roundtable meetings, a discussion paper will be produced and made available for public comment.

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Appendices

Appendix 1: Response from Agency

NSW Health

Ms Margaret Crawford
Auditor-General
Audit Office of New South Wales
GPO Box 12
SYDNEY NSW 2001

Your ref PA6598
Our ref S17/346

Dear Ms Crawford

Final Performance Audit Report on Planning and evaluating palliative care services in NSW

I am writing in regard to your letter of 6 July 2017 providing a copy of the final performance audit report on *Planning and evaluating palliative care services in NSW*.

Supporting patients with life-limiting illnesses is important and at times challenging work. Providing care involves a range of clinicians and services working in partnership with patients, families and carers. NSW Health is committed to providing high quality care to all NSW residents as they approach and reach the end of their lives. As your report highlights, demand for palliative and end of life care is growing as our population ages.

This performance audit confirms the priority being placed on improving palliative care in NSW. NSW Health supports the report's recommendations as they complement the work that NSW Health has under way to enhance planning and evaluation of palliative care services. As you will be aware, the Minister has announced a commitment of an additional $100 million over four years to further improve palliative care services in NSW.

Attached to this letter is a table outlining NSW Health's response to the individual report recommendations. I note that this letter and the attached table will be incorporated in the published report, which will be tabled in Parliament on 17 August 2017.

I would like to thank you and your team for working with NSW Health over the course of the audit program.

Yours sincerely

Elizabeth Koff
Secretary, NSW Health

4/8/17

Audit Office Recommendation	NSW Health response

By July 2018, NSW Health should:

1. Develop an integrated palliative and end-of-life care policy framework that:

   - Clearly articulates the interface between palliative and end of life care and outlines priorities for the respective areas
   - Defines policy goals and objectives, and a performance and evaluation framework for palliative care service planning and delivery
   - Informs a related workforce plan which supports the policy framework and is linked to the Health Professional Workforce Plan 2012 -2022
   - Reviews the funding allocation model to ensure future enhancement funds are distributed equitably and transparently based on the need and population of districts

Supported

NSW Health supports the development of an integrated palliative care and end of life policy framework.

NSW Health has made substantial achievements in the area of palliative care and end of life over the last five years, expanding community based services and increasing choices for patients. These achievements supported the goals of the *NSW Government Plan to increase Access to Palliative Care 2012-2016, Advance Planning for Quality Care at End of Life Action Plan 2013-2018* and *Palliative Care and End of Life Care Blueprint.* The Government's recent announcement of $100M over four years for palliative care builds on three previous rounds of enhancement funds to address priorities in this area.

The new policy framework will guide service and workforce planning, and inform funding allocations for the delivery of palliative and end of life care.

By December 2018, NSW Health should:

2. Assess how the functionality provided in data collection programs such as the Palliative Care Outcomes Collaboration program can be provided across all palliative care services in NSW

Supported.

eHealth NSW is currently addressing the design and development of palliative and end of life care functionality within the Cerner Electronic Medical Record (eMR). This work includes an assessment of options for outcomes monitoring within the eMR and related data collection systems.

By December 2018, NSW Health should:

3. Complete its statewide review of systems and reporting for end of life management including specialist palliative care, and develop a

   business case to implement a more integrated set of solutions to:

   - Support providers delivering end of life and palliative care
   - Help monitor service quality and quantity
   - Provide comprehensive data for service planning

Supported.

eHealth NSW will complement the above work through the establishment of the End of Life Management Design Working

Group (DWG) which includes representatives from across NSW.

Outcomes from this process will inform a more integrated set of IT solutions to support providers in delivering palliative care and to monitor outcomes.

Audit Office Recommendation	NSW Health response	
By December 2018, NSW Health should:		
4. Improve stakeholder engagement by: • Developing a state-wide stakeholder engagement strategy that brings together current activity and good practice, and is transparent and publicly available • Defining accountability for overseeing and implementing the strategy at state and district levels.	Supported.	NSW Government has recently completed extensive stakeholder engagement through the Roundtable Meetings which were held around the state. As a result of the Roundtables NSW Health is committed to ongoing state-wide stakeholder engagement. NSW Health will embed Stakeholder and Consumer Engagement within the new policy framework. The new framework will also articulate arrangements for governance and oversight at State and District/Network levels.

Appendix 2: National and NSW data on palliative care activity and outcomes

National snapshot data 2013–14

149,800 people died in Australia and over 74,200 (50%) of these people died in hospital (as an admitted patient)

Less than 1% of hospitalizations are palliative–care related

People aged 75 and over accounted for just over half (51%) of all palliative care-related hospitalisations

44% of patients who died as an admitted patient received palliative care

Over half (53%) of palliative care hospitalisations involved cancer as the principal diagnosis

4% of residential aged care residents were assessed as requiring palliative care

1 in 1,000 GP encounters were palliative care-related

59,000 prescriptions that were palliative care-related were provided to almost 29,800 patients

Source: AIHW www.aihw.gov.au Episodes of admitted patient palliative care occurring in hospitals, using data on palliative care-related hospitalisations from the National Hospital Morbidity Database (NHMD).

Australia and NSW hospital activity 2013–14

Activity indicators	National palliative care activity	NSW palliative care activity
Hospitalisations which were palliative care-related:		
− number	62,200	18,010
− increase from 2009–10	11%	n.a
− proportion of all hospitalisations	<1%	<1%
− rate per 10,000 pop	24.1	26.7
− ALOS	11.2	10.9

Source: AIHW www.aihw.gov.au Episodes of admitted patient palliative care occurring in hospitals, using data on palliative care-related hospitalisations from the National Hospital Morbidity Database (NHMD).

NSW Snapshot data from linked data sets: Facts of Death 2011–12

> Of 49,801 deaths in NSW in 2011/12, 76% presented to emergency departments and 77% of people were hospitalised at least once in the last year of their lives. This represents165,000 hospitalisations using 1.4 million bed-days.

The average number was 4.3 admissions per person. 27% of people who died had only one admission but 24% had more than 10 hospitalisations.

The average length of stay (ALOS) in hospital was 13 days, which is three times longer that the average for all patients.

Only 7% of those hospitalized (and who died in that year) received designated palliative care services. About 23% of admissions for those receiving designated palliative care services were on an emergency basis.

Of those admitted to hospital at some time in their last year of life, 61% died in hospital (15% in their first and only admission, and 46% in a subsequent admission) and 39% outside hospital.

People with cancer were more likely than people with other diagnoses to receive designated palliative care services on admission. The most common non-cancer-related reasons for admission to designated palliative care services were congestive heart failure, pneumonitis, pneumonia, and stroke, not specified as haemorrhage or infarction.

The total cost of hospitalisations and non-admitted emergency presentations was about $1 billion. Of the total cost, around $977 million was for inpatient admitted care and $32.5 million was for non-admitted presentation to ED. The average price per separation was $7,482.

Source: ACI (2015) Fact of Death Analysis 2011/12 – Use of NSW public hospital services in the last year of life by NSW residents. Health Economics and Evaluation Team, and Palliative Care Network. 2015 updated edition, accessed on 12 January 2017 at www.aci.health.nsw.gov.au.

Appendix 3: About the audit

Audit objective

This audit assessed the effectiveness of evaluating and planning palliative care services in NSW.

Audit criteria

We addressed the audit objective with the following lines of inquiry and criteria:

1. Does NSW Health collect and use data to inform the planning of high quality, safe and appropriate palliative care services?
    – The information needs are known.
    – The right information is available and provided in a timely manner.
    – There is access to and use of information at all levels.
    – Data reporting is used to identify trends, risks and issues with service delivery.
2. Is service planning and delivery informed by evaluation and data?
    – Strong evaluation and performance reporting framework is in place.
    – Data is being used to identify unmet need.
    – Planning is evidence-based and supports meeting predicted future demand for services.
3. Does NSW Health work in collaboration with other stakeholders in evaluating and planning palliative care services in NSW?
    – There are programs to develop the evaluation and planning capacity of stakeholders to contribute to effective evaluation and planning.
    – NSW Health consults with stakeholders in the evaluation and planning of palliative care services in NSW.
    – NSW Health collects information from stakeholders to assist in statewide coordination of palliative care services.

Audit scope and focus

In assessing the criteria, we checked the following aspects:

*   information quality, collection and use
*   service delivery and planning
*   collaboration with stakeholders.

The audit did not seek to assess:

*   clinical practice in delivering palliative care
*   paediatric palliative care
*   the Justice Health and the Mental Health Forensic Network.

Audit approach

Our procedures included:

*   interviewing staff from the Ministry of Health, eHealth NSW, NSW Ambulance, members of the Palliative Care Network Executive Committee, NSW Agency for Clinical Innovation, Primary Health Networks and contracted service providers
*   interviewing staff from the Palliative Care Outcomes Collaboration (PCOC) at the University of Wollongong, and the Australian Institute of Health and Welfare
*   interviewing individual expert clinicians and academics, peak bodies, consumer advocacy groups and individual consumers
*   conducting site visits and interviewing staff in three LHDs – Northern Sydney, Illawarra Shoalhaven and Western NSW— including visits to Royal North Shore Hospital,

Greenwich Hospital, Wollongong Hospital, Port Kembla Hospital, David Berry Hospital, Dubbo Base Hospital, Lourdes Hospital, Orange Health Service and community health service hubs in the districts

- reviewing systems and data collections, tools and benchmarking reports as well as various systems in use at a local level
- reviewing policy and evaluation documents, plans and guidelines.

Examining documents

We examined documents, including:

- documents setting out overall objectives for palliative care
- documents setting out future planning for palliative care
- documents detailing engagement and collaboration
- reporting and evaluation
- data collection and use frameworks.

Analysing data

We reviewed reporting systems, including SNAP, CHOC, CHIME, eMR as well as recent evaluation/research data that is not ongoing but provides a valuable planning tool – e.g. the Facts of Death report.

We will also examined:

- documentation from other stakeholders obtained during the audit such as research and studies, statistical data and analysis
- information from other jurisdictions for comparison.

The audit approach was complemented by quality assurance processes within the Audit Office to ensure compliance with professional standards.

Audit methodology

Our performance audit methodology is designed to satisfy Australian Audit Standards ASAE 3500 on performance auditing. The Standard requires the audit team to comply with relevant ethical requirements and plan and perform the audit to obtain reasonable assurance and draw a conclusion on the audit objective. Our processes have also been designed to comply with the auditing requirements specified in the *Public Finance and Audit Act 1983*.

Acknowledgements

We gratefully acknowledge the co-operation and assistance provided NSW Health. Particularly we would like to thank our liaison officers in the Ministry of Health and the three Local Health Districts we visited as well as staff who participated in interviews and provided material relevant to the audit. Additionally, we wish to thank the many clinical experts and academics who gave their time to contribute to the audit.

We would also like to thank our consultant, Ms Michelle Wheeler of Michelle Wheeler Consulting, who advised and assisted throughout the audit.

Audit team

Michael Thistlethwaite conducted the performance audit. Kathrina Lo provided direction and quality assurance.

Audit cost

Including staff costs, printing costs and overheads, the estimated cost of the audit is $170,000.

Performance auditing

What are performance audits?

Performance audits determine whether an agency is carrying out its activities effectively, economically and efficiently, and whether it is complying with all relevant laws.

A performance audit may examine a NSW Government program, all or part of a NSW Government agency, or consider issues that affect the entire public sector. We do not question the merits of NSW Government policy objectives.

The *Public Finance and Audit Act 1983* sets out the Auditor-General's mandate for performance audits.

Why do we conduct performance audits?

Performance audits provide independent assurance to parliament and the public about government activities. Their recommendations seek to improve the efficiency and effectiveness of NSW agencies so that the community receives value for money from government services.

Performance audits also strengthen accountability by holding managers to account for agency performance.

The Auditor-General selects activities to audit with input from parliamentarians, the public, agencies and Audit Office research.

What happens during a performance audit?

Performance audits have three key phases: planning, fieldwork and report writing. These can take up to nine months to complete.

During planning, the audit team develops an understanding of agency activities and defines the objective and scope of an audit. We also identify the audit criteria, which are the standards we will use to assess the performance of an agency or program activities. Criteria may be based on best practice, government targets, benchmarks or published guidelines.

At the end of fieldwork, the audit team discusses with agency management all significant matters emerging from the audit. We then prepare a draft performance audit report.

The audit team next meets with agency management to confirm that the facts in the draft report are correct and that our recommendations are practical and appropriate.

We then provide a final report to the CEO for comment, and copies to the relevant minister and the Treasurer. When tabled in parliament, the report includes a response from the CEO about its conclusion and recommendations. When performance audits involve multiple agencies, there may be responses from more than one agency or from a nominated coordinating agency.

How do we follow up on performance audit reports?

After a report is tabled in parliament, we ask agencies to advise the Audit Office on actions taken, or proposed, against each of the report's recommendations. Usually, agency audit committees monitor progress in implementing recommendations.

The parliament's Public Accounts Committee (PAC) also reviews or holds inquiries into matters raised in our performance audit reports, usually 12 months after a report is tabled. Its reports are available on the parliamentary website.

Who audits the auditors?

Our performance audits are subject to internal and external quality reviews against Australian and international standards.

Internal quality control review of each audit ensures we comply with Australian assurance standards. Periodic review by other audit offices tests our activities against best practice.

The PAC also oversees the performance of the Audit Office and reviews our operations every four years. This report is tabled in parliament and available on its website.

Who pays for performance audits?

NSW Parliament funds performance audit services, so there is no fee for agencies audited.

Where are performance audit reports available?

For more information, including copies of performance audit reports and a list of audits currently underway, please see our website – www.audit.nsw.gov.au – or contact us on 9275 7100.

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Our vision

Our insights inform and challenge
government to improve outcomes for citizens.

Our mission

To help parliament hold government
accountable for its use of public resources.

Our values

Purpose – we have an impact, are
accountable, and work as a team.

People – we trust and respect others
and have a balanced approach to work.

Professionalism – we are recognised
for our independence and integrity
and the value we deliver.

Professional people with purpose
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