

Improving End of Life Care for South Australians:

A Report by the Health Performance Council of SA

September 2013

Health Performance Council



Government
of South Australia

Health Performance Council

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1. Message from the Chairs

End of life is something we all experience, both as community members and as individuals. Quality end of life care is an important measure of a humane society and an essential element of health care systems. The Health Performance Council (HPC) has been privileged to examine the progress of the strategies which address this significant topic in South Australia.

Through this review, the HPC has seen evidence of a lot of good work in end of life and palliative services. The HPC is confident it is possible to align people's wishes with system capacity and resources.

The HPC would like to acknowledge the generous contributions made to this review by all the people who shared their knowledge, experience and expertise. The HPC is grateful to the Palliative Care Clinical Network Steering Committee, especially its Chair, Kate Swetenham, for its active participation, advice and support throughout the review. The HPC also appreciated the efforts of the Palliative Care Council and SA Health staff in supporting the review.

The members of the Health Performance Council commend this report to the Minister for Health and Ageing, Hon Jack Snelling MP.



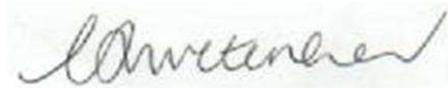
Ms Anne Dunn AM
Chairperson, Health Performance Council
30 / 9 / 2013

The Palliative Care Clinical Network has embraced the opportunity to engage in an independent review of the statewide *Palliative Care Services Plan 2009-2016* with the HPC. This review has afforded a valuable opportunity to assess the strategic directions for relevance and currency in today's health care environment. There is a clear distinction between end of life care which is the responsibility of all health care professionals across all disciplines and specialist palliative care which focuses on the most complex needs of patients living with a life limiting illness.

The standard model of medical care has been to focus on cure. We propose that a more balanced model of care that focuses on the 3 Cs, 'Cure, Care and Console,' will embed the responsibility of providing end of life care across primary and specialist health-related disciplines, so that end of life care is not seen as a failure of good medical care.

Recognition of the impact of unresolved grief on health care utilisation underpins the element of care that is allocated to Console. Bereavement care has a dedicated role within the specialist palliative care service but if end of life care is to be everybody's responsibility, then care after death of those left behind grieving must also be addressed across the health system. The opportunity to partner with non-government organisations to build community capacity in this particular area will go a long way to addressing the death denying culture of the community, remove the mystery, and return dying and death to their accepted place in the life cycle.

The Network has found the external review process to provide a valuable contribution to its work. We welcome the opportunity to work with other Statewide Networks to ensure that end of life care is incorporated as routine care and becomes everyone's business.



Kate Swetenham
Chair, Palliative Care Clinical Network
30 / 9 / 2013

2. Advice to the Minister for Health and Ageing

On 2 July 2013, the Minister for Health and Ageing, Hon Jack Snelling MP, asked the Health Performance Council (HPC) to work with the Palliative Care Clinical Network to review the *Palliative Care Service Plan 2009-2016* (the Plan). The terms of reference were to understand areas that have not progressed and identify the reasons.

This review is a formative review only, as the Plan is four years into a seven year program. The review aims to support system improvements in end of life care in the next three years and, ultimately, quality end of life care for South Australians.

The HPC has concluded that while there is clearly progress being made towards the implementation of the Plan, there are many areas requiring attention. This is a topic that is much larger than can be covered by a review of palliative care arrangements.

There are several components of good end of life care – meeting the community’s expectations of access to quality end of life care services, providing caring and compassionate experiences for patients and their families, and effectively focusing health system resources. The health system and the community have much to gain by a renewed focus on end of life care, and the opportunity to do so presents itself with the impending implementation of the *Advance Care Directives Act 2013*.

To meet this opportunity, the following action needs to be taken by 2016:

- A. Increase identification of the end of life stage
- B. Make advanced care directives work
- C. Do what was intended
- D. Work better together, and
- E. Put people first.

A. Increase Identification of the End of Life Stage

Finding 1. End of Life Pathways: Chronic diseases lead to a large proportion of deaths, yet people with chronic, terminal conditions are under-recognised by health services as entering the end of life stage.

Finding 2. Intensive Care Unit Use: One in eight South Australians are admitted to an intensive care unit in their last year of life, with those who have not been identified as palliative spending significantly more time in the ICU. Better identification of people as being near the end of life would reduce ICU use, saving the public health system up to \$13 million per year.

Advised Actions:

- A1. The Minister for Health and Ageing request the South Australian Health and Medical Research Institute explore factors which contribute to under-identification of people as being at the end of life.
- A2. The Clinical Networks seek to increase recognition of the end of life stage by developing end of life pathways together, especially the Cardiology, Renal and Older Persons Clinical Networks in collaboration with the Palliative Care Services Network.
- A3. The Older Persons and Palliative Care Clinical Networks develop a comprehensive strategy to address the end of life needs of people with dementia and their families, from early diagnosis to the end stages of the disease.

- A4. SA Health implement protocols to reduce reliance on intensive care that does not provide quality of life for people with end stage diseases, particularly end stage respiratory disease.

B. Make Advanced Care Directives Work

Finding 3. Advanced Care Directives: The *Advance Care Directives Act 2013* is a positive move, but in and of itself not enough to effect change. Implementation of the Act requires effective systems and efforts to increase community confidence.

Advised Actions:

- B1. The Department for Health and Ageing initiate a public awareness campaign to encourage people of all ages to complete an advanced care directive and include it on their Personally Controlled Electronic Health Record.
- B2. SA Health deliver comprehensive education to clinicians about the *Advance Care Directives Act 2013* and encourage them to complete a directive themselves.
- B3. SA Health partner with the local government, community and aged care sectors to support South Australians to complete directives.
- B4. The Department for Health and Ageing partner with the Public Trustee, the Law Society, and commercial companies to include a pro-forma advanced care directive in will packages.
- B5. SA Health implement means of easily accessing advanced care directives electronically, including through SA Ambulance emergency call systems (as is being trialled with paediatric palliative patients) and EPAS.
- B6. SA Health develop, implement and resource a clinical planning system with decision-making protocols to support clinicians to make good end of life decisions.
- B7. Local health networks implement protocols for asking patients about advanced care directives if they are transferred from a residential aged care facility or are admitted to hospital twice in twelve months for a chronic disease.

C. Do What Was Intended

Finding 4. Workforce: There is a need to enhance the capability of the generalist workforce to provide end of life care in community, aged care, and hospital settings. The structure of specialist palliative care services should be refined and resourced to deliver equitable statewide services and provide support to generalist services.

Finding 5. Care Coordination: Service delivery arrangements are variable. Coordination of care remains a challenge between primary care, aged care and specialist services.

Finding 6. Clinical Network Development: The Palliative Care Services Network should build on its successes by improving Network visibility and development.

Finding 7. Governance: Governance and accountability for the Plan are generally weak and resources are not clearly allocated.

Finding 8. Reporting systems: Reporting systems for palliative and end of life care are disjointed and do not facilitate easy monitoring.

Advised Actions:

For the Plan's initiatives which have stalled or were not commenced, renewed effort by the SA Health is required, particularly developing the following statewide initiatives:

- C1. Palliative care workforce strategy.
- C2. Reporting cycle to monitor end of life care outcomes.
- C3. Health in grief and loss plan.

To improve governance and accountability, the following is required:

- C4. The Department for Health and Ageing lead discussions to achieve formal agreement about responsibilities under the Plan between: the Department for Health and Ageing, local health networks, the Palliative Care Services Clinical Network and the Palliative Care Council SA.
- C5. The Department for Health and Ageing document responsibilities under the Plan unambiguously in:
 - o Local health networks' service agreements, including actions required to support Level 4 and Level 2 services
 - o The Palliative Care Council SA's service contract
 - o The Palliative Care Services Clinical Network Steering Committee's Terms of Reference.
- C6. The Palliative Care Services Clinical Network Steering Committee implement a comprehensive communication plan which, at a minimum, engages and informs Network members and aims to expand reach among clinicians and other clinical networks.
- C7. The Palliative Care Services Clinical Network consider the feasibility of a statewide model for delivery of palliative care services.

D. Work Better Together

Finding 9. Partnership: A renewed focus is required on partnering with the aged care, not-for-profit and private sectors to ensure seamless transitions within and across sectors, maximise personal choice and best use resources.

Finding 10. Equipment, Pharmacy, 24/7 Support: Improvements in access to equipment, pharmacy and after hours supports will increase congruence between peoples' desired and actual place of death.

Advised Actions:

SA Health actively seek partnership and collaboration with the aged care, disability services and community sectors, including by:

- D1. Supporting South Australians to complete advanced care directives.
- D2. Developing pathways for people to access end of life services, including access to equipment, pharmacy and after-hours advice and support.

E. Put People First

Finding 11. Support and Respite: Psychosocial and respite supports are critical to help people with a terminal illness stay at home if they wish but there is significant confusion about who is to provide this care.

Finding 12. Being Inclusive: Improved planning for South Australia's diversity is required in future implementation of the Plan, particularly for Aboriginal and culturally and linguistically diverse populations.

Advised Actions:

- E1. SA Health explore ways to reduce carer fatigue, including by advocating for improved and more flexible respite arrangements.
- E2. Country Health SA develop an Aboriginal palliative care service in Port Augusta as committed to in the Plan.
- E3. SA Health and the Palliative Care Services Clinical Network work with appropriate community organisations to improve end of life responses for diverse populations.
- E4. SA Health actively recruit staff from diverse populations.
- E5. SA Health train all staff in cultural sensitivities, including by using the Australian Government's 'Cultural Competency in Health' as stated in the Plan.
- E6. SA Health continue to actively promote the principles of its 'Aboriginal Cultural Respect Framework' across health policy and service delivery.

3. Background

The Review

On 2 July 2013, the Minister for Health and Ageing, Hon Jack Snelling MP, asked the Health Performance Council (HPC) to work with the Palliative Care Clinical Network to review the *Palliative Care Service Plan 2009-2016* (the Plan). The terms of reference were to understand areas that have not progressed and identify the reasons.

This review is a formative review only, as the Plan is four years into a seven year program. The review aims to support system improvements in end of life care in the next three years and, ultimately, quality end of life care for South Australians.

Role of the Health Performance Council

The HPC was established under the *Health Care Act 2008* to provide independent advice to the Minister for Health and Ageing.

The Palliative Care Services Plan 2009-2016

In 2009, SA Health released the *Palliative Care Service Plan 2009-2016*. The Plan sets out a comprehensive agenda to redesign health system capacity to deliver on end of life care needs for all South Australians.

The redesigned services were intended to increase support for people to be cared for in the community and their own homes by generalist and specialist services. These changes were anticipated to reduce avoidable emergency department presentations and hospital admissions while improving responsiveness to individual end of life care choices. The Plan's implementation is a shared responsibility of the Department of Health and Ageing, the Palliative Care Clinical Network and local health networks.

Review Process

The HPC is committed to providing independent and evidence-based appraisals of the health system. For this review, the HPC sought to combine high-quality evidence to assess progress against the stated goals and actions of the Plan.

The HPC used a rapid assessment methodology to obtain qualitative evidence on individual, societal and health and aged care system factors. A wide range of expertise was drawn on through: conversations with key informants, group consultation sessions, online surveys and a review of relevant academic literature, legislation and policy. The Palliative Care Clinical Network Steering Committee created a Project Advisory Working Group to support the HPC throughout the review.

The HPC also invited comment from Aboriginal and country Health Advisory Committees and the sixteen bodies prescribed under the *Health Care Regulations 2008*, which collectively represent the organisations most relevant to the South Australian health sector. The full list of those consulted is provided in Appendix D.

Quantitative data were primarily drawn from South Australia's hospital inpatient morbidity database, the Australian Institute for Health and Welfare and a de-identified linkage of data of: deaths recorded in the South Australian Death Registry from July 2003 and June 2011, separations from public hospitals, and presentations at metropolitan public emergency departments. This comprehensive set of data provided evidence of patient journeys and of progress made towards reaching the Plan's goals.

The HPC drew on the combination of the qualitative and quantitative evidence to produce its advice. Where questions remained about the sufficiency or quality of the evidence but the HPC thought an issue was worth further investigation, this is noted in the report.

4. End of Life Care in South Australia

There is a difference between 'end of life care' and 'palliative care'. As defined by the Plan, 'end of life care' is a broad term for care that is planned for, negotiated with or provided to people at the end of their lives (SA Health 2009). 'Palliative care' is a specific type of end of life care provided by specialised teams whose substantive work is with people with terminal illnesses and their families.

As with many other elements of its healthcare system, Australia's end of life care, including palliative care, fares well internationally. Australia ranks second on the Economist Intelligence Unit's 'Quality of Death Index,' which considers the end-of-life healthcare environment and the availability, cost and quality of end of life care. This ranking places Australia second only to the United Kingdom, the home of the hospice movement, and just before New Zealand. Unlike these two countries, and many other countries, though, Australian palliative care does not receive private donations (Economist Intelligence Unit 2010).

The majority of South Australians do not receive inpatient palliation in the twelve months before their death. To gain a true picture of the system's capacity to properly manage end of life care requires consideration of those people who die without receiving palliative care. This review therefore took the broader approach of considering end of life care as well as progress on implementation of the Plan.

Death in South Australia

Dying is part of the life cycle and can occur at any age, although more than half of deaths in South Australia occur at or after 80 years of age (SA NT Datalink 2013, Customised report). More than 12,000 people die every year in South Australia and, due to population growth, the number is increasing annually (ABS 2011c). Overall, just under 1 of every 180 South Australians die each year (ABS 2011d).

Cancer and diseases of the circulatory system, like heart attack and stroke, are South Australia's leading causes of death, followed by respiratory disease, external causes and mental and behavioural disorders (ABS 2011b).

Although the leading causes of death were the same for Aboriginal South Australians between 2006 and 2010, Aboriginal South Australians were 1.6 times more likely to die of circulatory diseases than non-Aboriginal people, 1.2 times more likely to die from cancer, and 2.2 times more likely to die of respiratory diseases (ABS unpublished, cited in Productivity Commission 2013). The highest mortality rate disparity between the Aboriginal and non-Aboriginal population in South Australia was for deaths from kidney diseases, with an Aboriginal person 3.6 times more likely to die of kidney disease than a non-Aboriginal person.

In 2011, the median age at death for South Australian non-Aboriginal women was 85.3 years and 79.6 years for non-Aboriginal men (ABS unpublished, cited in Productivity Commission 2013). That same year, the median age at death for both Aboriginal South Australian men and women was 50.3 years, lower than median ages at death for Aboriginal women and men across Australia of 58.5 years and 55.4 years, respectively.

Hospital, aged care facilities, and private homes are the three most common places of death in South Australia. Over the last several years, there has been a downward trend in deaths in hospital, with a corresponding increase in deaths in aged care. In 2009-10, 46.4% of all deaths were in hospital, down 2.4 percentage points from 2003-04, and 29.0% were in aged care, up 2.6 percentage points (SA NT Datalink 2013, Customised report).

While deaths recorded to be at a private home were down 1.6 percentage points to 16.5% of deaths, given the ageing population, this must be taken in context of the increased percentage of deaths in aged care facilities, which, for many people, are their homes.

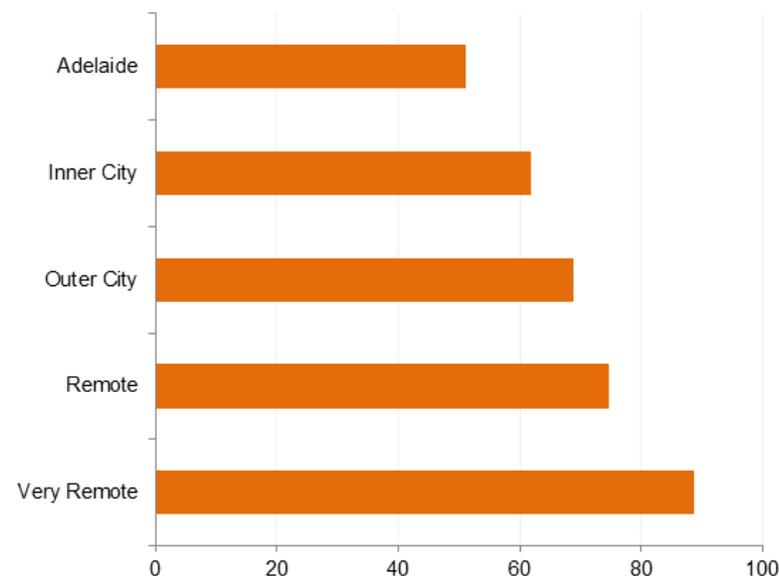
Men were more likely to die in hospital than women, as 50.4% of men who died in 2010-11 died in hospital compared to 42.4% of women (SA NT Datalink 2013, Customised report). Men were also more likely to die in a private home, at 21.3%, compared to 11.7% for women. At the same time, women were more likely to die in an aged care facility, with 36.6% of women dying in aged care facilities, compared to 21.4% of men.

These differences by sex may be related to different average age of death for men and women, as there is a difference in where a person is mostly likely to die at different ages. For example, in 2009-10 the average age at death in South Australia was 77 years (SA NT DataLink 2013, Customised report). However, the average age of death in private homes was just 65 years. Those who died in hospital were closer to the average age at death, with an average age of over 75 years. Those who died in aged care facilities were much older, at over 85 years of age.

The reason behind these marked differences was not explored in depth, but anecdotal evidence suggests that younger people are more likely to die suddenly in accidents, or for expected deaths, to have family and other supports systems for staying at home. The older cohort is more likely to already reside at an aged care facility.

There is also a correlation between a person's residence and the likelihood of dying in hospital. As illustrated in Figure 1, South Australians living in Adelaide are the least likely to die in a hospital, with the likelihood increasing with their residence's distance from Adelaide (SA NT Datalink 2013, Customised report).

Figure 1. Percentage of Deaths in Hospital by Region, 2009-10



Source: Based on SA NT Datalink 2013, Customised Report

The strong increased chance of dying in hospital in remote and very remote regions could be due to aged care facilities being located in hospitals in country areas. The high incidence of death in hospital by those living in remote or very remote areas could also be related to transportation issues, with some country residents finding it difficult to return home from hospital if they require ongoing treatment.

The Plan: Its Context and Vision

In response to the emerging challenges of an ageing, diverse population, *South Australia's Health Care Plan 2007-2016* is committed to developing a plan for South Australian palliative care services to:

- 'Make it easier for all people at the end of life to receive palliative care either at home or in hospital
- Ensure there is an improved focus on providing palliative care services for cancer sufferers and people suffering from renal failure, respiratory disease, cardiac disease and other end-stage illnesses
- Help patients and their families to make the right choices about care needs at the end of life' (Government of South Australia 2007).

In 2009, SA Health released the *Palliative Care Services Plan 2009-2016* (the Plan). The Plan sets out a comprehensive agenda for redesigning the health system's service capacity to plan for, deliver and report on needs and outcomes of care for all South Australians at the end of life, not only those who have been officially recognised as palliative.

The redesigned services were intended to provide end of life care by generalist providers and specialist palliative care service providers for complex needs, while expanding community-based palliative care services and home based packages. It was envisioned this would support palliative care patients to remain at home during the end of life while increasing system capacity.

The Plan aims that 30-40% of people referred to a palliative care service would be supported to die at home by 2012, and that the rate would increase to 45-55% by 2016 (SA Health 2009, p 13). The Plan does not state whether 'home' includes aged care facilities if they are the person's usual place of residence, nor how this would be monitored.

Figure 2. Ideal Patient Outcomes under the *Palliative Care Services Plan 2009-2016*

Advanced Care Planning

- End of life issues identified and accepted by clinicians who initiate discussions with patients and their families.
- People make known their wishes about treatment.
- Treating health professionals are aware of and respect people's wishes.

Access to Services

- Patients and carers have 24/7 access to symptom management, support and advice as needed.
- There is equitable access to end of life care options delivered in the community or hospital by a skilled workforce in accordance with advanced care plans.
- Patients do not have unnecessary visits to hospital or unwanted, invasive treatments.

A Good Death

- A dignified death in a place of the person's choosing.
- Access to grief and bereavement support for carers and family.

Broadly, the Plan aims to achieve the desired outcomes by:

- Consolidating statewide palliative care services and referrals through creation of three levels of specialist palliative services and formal links between country and metropolitan services

- Delivering services to people with complex care needs via regional teams in a range of community and hospital settings
- Increasing the capacity of generalist providers to deliver quality end of life.

During the public consultations for this review, the HPC found broad support for the Plan, its goals and initiatives from consumers, clinicians and service managers. The Plan is broadly seen as a testament to SA Health's public commitment to palliative care.

The Plan's commitment aligns with South Australians' expectations that they will be able to access appropriate services and support when they need them and that their wishes will be respected, allowing dignity at the end of life.

Good implementation of the Plan will deliver on these expectations, leading to improved end of life care and more efficient use of health system resources. Benefits to the community include increased confidence in the health system and a better match between where people wish to die and where they actually do. The congruence between the types of care people wish to receive and do receive will lead to reductions in delivery of inappropriate procedures and avoidable emergency department and hospital admissions.

Conversely, the risks of not getting end of life care right are immense. A poor quality death experience has a lasting effect on the family and friends of the deceased. There is also strong evidence to suggest that calls for euthanasia reflect community concerns about health systems' quality of end of life care (Virik and Glare 2002; MacLeod, Wilson and Malpas 2012; Materstvedt et al 2003).

Since the release of the Plan, there have been significant developments in the palliative care arena. The National Safety and Quality Health Service Standards, published in 2011, outline a mandatory framework for the recognition of and response to clinical deterioration in patients across the health services spectrum, with special reference to palliative care. In 2011 and 2012, the Australian Senate Community Affairs Committee conducted an inquiry into palliative care. Most recently, the South Australian Parliament passed the *Advance Care Directives Act 2013*, leading to a 90 day project to implement clinical protocols.

The Plan: Its Initiatives

The HPC assessed the Plan itself by considering its goals against its initiatives. The Plan was predominately found to be logical, indicating that successful implementation should lead to its stated outcomes. This assessment of the Plan's value was strongly echoed by a range of people throughout the review.

The only frequent concern about the Plan was expressed by clinicians, who were concerned that funding changes may erode the Plan's potential achievements in 2013-2016.

Though the Plan is coherent in its goals and initiatives, it lacks clear accountability. As part of this review, the HPC worked with the Palliative Care Clinical Network and the Department for Health and Ageing to develop an understanding of initiatives' status and responsibility for their implementation. The result of this work is illustrated in Figure 3.

Figure 3. Palliative Care Services Plan: Initiatives by Responsibility and Status

<u>Department Responsibilities</u>	
ACHIEVED	Developing a suite of palliative care packages Establishing a statewide palliative care clinical network
ONGOING	Supporting the work of the Palliative Care Council of SA Strengthening service partnering arrangements across the state Rolling out an Informed Choices Program across the state
COMMENCED	Working with aged care sector to develop their capacity as end of life care providers Putting in place information technology solutions and support
COMMENCED NOW STALLED	Developing a statewide palliative care workforce strategy [shared]
NOT COMMENCED, UNDER REVIEW	Establishing a trained community-based personal care workforce Developing end of life care outcomes surveillance capacity Establishing a statewide reporting cycle
<u>Network Responsibilities</u>	
COMMENCED	Establishing a statewide palliative care community pharmacy network Using a shared model of care and common approach to service delivery across the state Using a statewide approach to education, training support and practice development Reinstating a statewide end of life research collaborative
COMMENCED NOW STALLED	Developing a statewide palliative care workforce strategy [shared]
NOT COMMENCED, UNDER REVIEW	Developing a statewide health in grief and loss plan [scope only]

Local Health Network Responsibilities

ACHIEVED Developing Level 6 Services within Central and Northern local health networks

Implementing a statewide quality program

ONGOING Undertaking capital works

Using rapid response teams

COMMENCED Developing Level 4 services in country SA [Note: Not consistent across areas]

Extending and expanding community based services

Exploring day hospice options

Supporting new regional aged care teams

Working alongside chronic disease services

Working differently in acute settings

Working alongside pain management teams

Expanding and using the General Practitioner with a special interest

Exploring and using new and emerging roles

COMMENCED NOW STALLED

Growing the established workforce

Proliferating advanced practice roles

Growing a Nurse Practitioner workforce

NOT COMMENCED, UNDER REVIEW

Developing an Aboriginal palliative care service in Port Augusta

Reconfiguring bed and hospice units

Differentiating palliative care bed types (nurse led)

A list of the Plan's initiatives with their timeframes can be found in Appendix D.

Palliative Care Services in SA

Under the Plan, specialist palliative care services are categorised into three levels:

- Level 6 Services: Provide palliative care expertise and service to a metropolitan catchment (currently the three metropolitan local health networks) and provide clinical and professional resources to designated level 2 and level 4 services
- Level 4 Services: Provide palliative care to a regionalised or peri-urban service area; includes services in Gawler, Riverland, Adelaide Hills, Port Augusta, Whyalla, Lower Eyre, Fleurieu Peninsular and Mount Gambier
- Level 2 Services: Provide palliative care to a rural area; includes services in Port Pirie, Barossa, Yorke, Murray Mallee, Kangaroo Island and Naracoorte.

The HPC sought to quantify palliative care services within this structure in South Australia and the proportion of people who die who would potentially benefit from a palliative approach but do not receive it. Yet anecdotal information suggests there may be under-reporting in hospital systems of patients receiving palliative treatment.

From evidence available during this review, it is impossible to indicate the proportion of under-reporting or assess the proportion of over- or under-servicing for people not identified as palliative. This warrants further exploration internally or as a research exercise undertaken by an organisation like the South Australian Health and Medical Research Institute.

For the purposes of this review, a range of data sources other than inpatient data were used to gain a more complete understanding of the scope of palliative care.

Inpatient Palliative Care

The relative burden of palliative care services on health services, as indicated by available statistics, is much lower than some stakeholders believe.

Palliative care-related hospital separations account for only 0.6% of all hospital separations and 2.2% of hospital bed days in 2011-12 (Integrated South Australian Activity Collection Database 2013). This is only 3,333 separations at public hospitals and 742 at private hospitals of the total 697,295 hospital separations in South Australia that year. This represents an aged standardised rate of 22.4 palliative care separations per 10,000 South Australians, lower than the Australian average of 23.2 per 10,000 (Australian Institute for Health and Welfare [AIHW] 2012).

As a proportion of all deaths in South Australia, only 16.1% of people who died in 2009-10 received any palliative care in a public hospital in the year before they died, and 97.5% of those had three or less palliative care separations (SA NT Datalink 2013, Customised report).

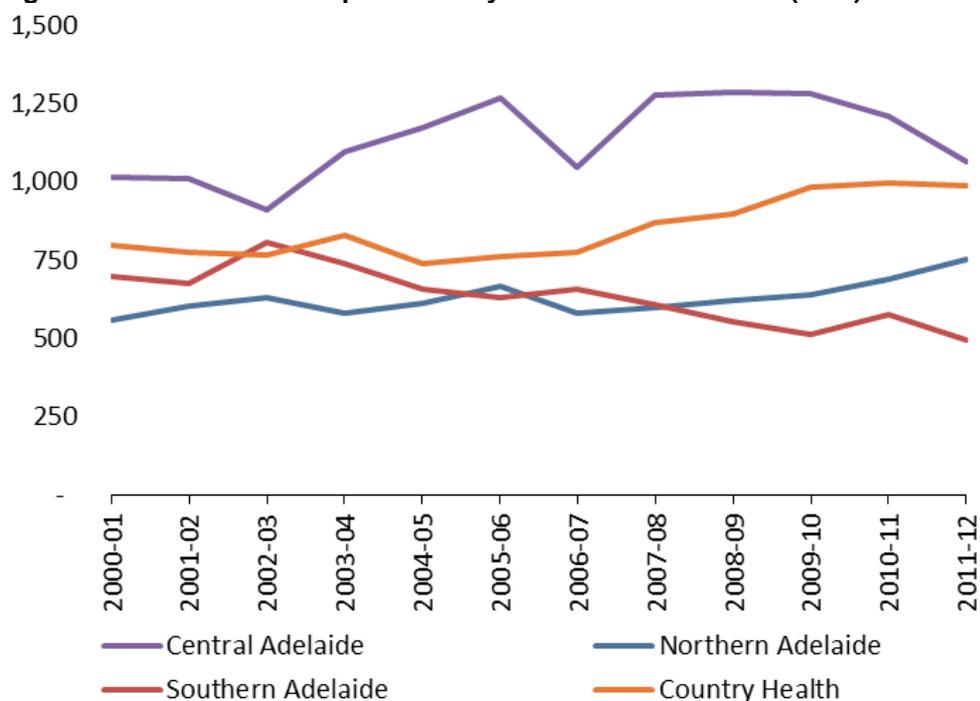
Despite projections that palliative care service use would soar with the ageing of South Australia's population, it has not. Palliative care-related separations grew on average 1.5% per year between 2005-06 and 2009-10 (AIHW 2012), less than half of the 3.9% growth of all hospital separations (Integrated South Australian Activity Collection Database 2013).

Inpatient palliative care in South Australia is also growing slower than Australia-wide, with national average annual growth between 2005-06 and 2009-10 at 5.5% (AIHW 2012).

Growth across individual local health networks (LHNs) has also remained rather stable since 2001, as illustrated in Figure 4 (next page). It is worth noting, though, that there has been growth in country separations since 2004-05 and that separations in Southern Adelaide LHN have been trending down since 2002-03.

There have been shifts in palliative care inpatient separations between hospitals, though. Since 2006-07, as planned, there has indeed been a decrease in palliative separations at the Lyell McEwin, offset by a similar increase at Modbury Hospital (Integrated South Australian Activity Collection Database 2013).

Figure 4. Palliative Care Separations by Local Health Network (LHN)



Source: Based on Integrated South Australian Activity Collection Database 2013

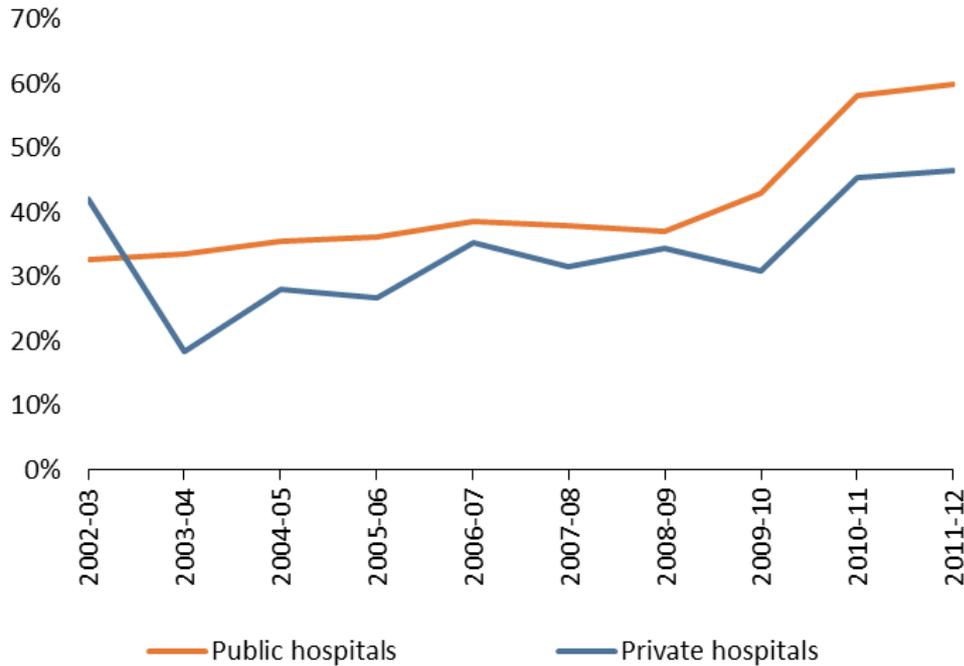
*Note Women’s and Children’s LHN not graphed as paediatric caseload numbers are small.

In 2011-12, palliative care bed days accounted for 2.2% of South Australian hospital bed days (Integrated South Australian Activity Collection Database 2013). While the average length of stay of a non-same day palliative care hospital separation in 2011-12 of 12.8 days may seem high compared to the average 6.2 days for all South Australian overnight hospital separations (Integrated South Australian Activity Collection Database 2013), it is similar to the 2009-10 Australian average of 12.6 days for palliative stays (AIHW 2012). It is also similar to the national average length of stay for all separations (AIHW 2012).

For the small population of palliative care patients in hospital, the burden of procedures is also small.

In 2011-12, inpatient palliative care accounted for 1.5% of all hospital ICU hours and 1.4% of all hospital ventilation hours (Integrated South Australian Activity Collection Database 2013). As can be seen in Figure 5 (next page), there has been a shift in the proportion of palliative inpatients receiving allied health interventions as their principal procedure in hospital during the life of the Plan. This increase coincides in a reduction in imaging, such as CT scans, which may indicate a more palliative approach being taken as opposed to a curative one.

Figure 5. Palliative Care Separations with an Allied Health Intervention as the Principal Procedure



Source: Based on Integrated South Australian Activity Collection Database 2013

Medicare-Subsidised Palliative Care

Another way of quantifying the scope of palliative care in South Australia is by assessing the amount of Medicare-subsidised palliative care-related services South Australians are receiving.

In 2010-11, there were 3,867 Medicare-subsidised palliative medicine specialist services in South Australia (AIHW 2012). This equates to a rate of 170.8 per 100,000 people, lower than the national average of 191.0.

Despite this relative lack of Medicare-subsidised palliative specialist services, South Australia has the second highest rate of PBS palliative-related prescriptions, at a rate of 160.5 prescriptions per 100,000 people, much higher than the national average of 128.9.

Service Activity

SA Health service activity data shows that the number of people being referred to specialist palliative care has been steadily increasing since 2003-04, from 3,664 in 2003-04 to 4,958 in 2012-13 (SA Health 2013, Customised report).

Over the same period, the average of contacts lasting more than fifteen minutes per referral, including care coordination with other agencies, decreased, from 12.9 to 8.4 contacts per person.

The total number of contacts made with palliative care patients has therefore gone down in the last ten years, and by a significant 12.2%.

Scope of Workforce

According to the Australian Institute for Health and Welfare, in 2009 South Australia had 1.0 full-time equivalent of palliative medicine physicians per 100,000 people, slightly above the national rate of 0.8 (AIHW 2012).

At that time, South Australia's rate of palliative care nurses was also higher than the national average, with 29.7 palliative care nurses per 100,000 people, compared to 20.5 nurses per 100,000 people nationwide. This ranks South Australia third, behind Tasmania and Victoria, with rates of 31.0 and 30.3 palliative care nurses respectively. Yet unlike most other states, South Australia's number of palliative care nurses has decreased since 2007.

An audit of the workforce for all adult Level 6 palliative care services in South Australia showed that there were 35.15 full time equivalent positions in December 2010, 33.55 of which were recurrently funded (Palliative Care Clinical Network Steering Committee 2011). These positions consist of consultants, registrars, resident medical officers, an intern and 0.5 of a consultant psychiatrist.

Given their distribution across three local health networks and five hospitals, it appears that some LHNs are resourced with palliative care staffing below the recommended levels in the Palliative Care Australia's Service Provision Planning Guide (2003). Yet the Plan states that the delineation of practice and services would be as per Palliative Care Australia's guidelines (SA Health 2009, p 37). Resources are stretched further as LHNs also support a regional area, each with at least four other services.

There is also one centre for children's palliative services in South Australia, based at the Women's and Children's Hospital. Although it services patients across the state and provides a consultant service for non-palliative clinicians, it is not resourced as a Level 6 service. It currently has 2.1 full-time equivalent positions, with recurrent funding for 1.4.

The children's palliative service lacks a dedicated paediatric palliative medicine specialist and relies on adult palliative care services to consolidate medical input into end of life care for infants, children and adolescents. The children's palliative service also lacks a dedicated bereavement worker, despite this resource highlighted in the Plan as a priority requirement.

On all evidence available, specialist palliative care is a minute part of the health system and is not growing as was anticipated when the Plan was written. A much more significant impact on the health system is made by the 83.9% of South Australians who die without receiving palliative care in a public hospital (SA NT Datalink 2013, Customised report).

End of Life Care in SA

Finding 1. End of Life Pathways: Chronic diseases lead to a large proportion of deaths, yet people with chronic, terminal conditions are under-recognised by health services as entering the end of life stage.

Finding 2. Intensive Care Unit Use: One in eight South Australians are admitted to an intensive care unit in their last year of life, with those who have not been identified as palliative spending significantly more time in the ICU. Better identification of people as being near the end of life would reduce ICU use, saving the public health system up to \$13 million per year.

The end of life care journey begins with recognition by the person and clinicians that the goal of future treatment is maintaining quality of life, not curing the disease. As shown in Figure 6 (next page), the vast majority of South Australians who die do not receive inpatient palliation in the twelve months before their death. Due to the large proportion of people dying who do not receive palliative care, the HPC examined the end of life patient journey, not only that of those receiving palliative care.

With the prevalence of chronic disease continuing to grow, it is clear that end of life care is core business across the health system. Yet there is a lack of established end of life pathways for most diseases other than cancer.

For many chronic diseases, triggers that change the nature of care to a palliative approach can either be sudden, like a revised prognosis or escalated symptoms, or subtle, like a shift in thinking. A clinician stating they would not be surprised if a person died during the next six to twelve months is a frequently cited way of assessing the need for end of life care (SA Health 2009).

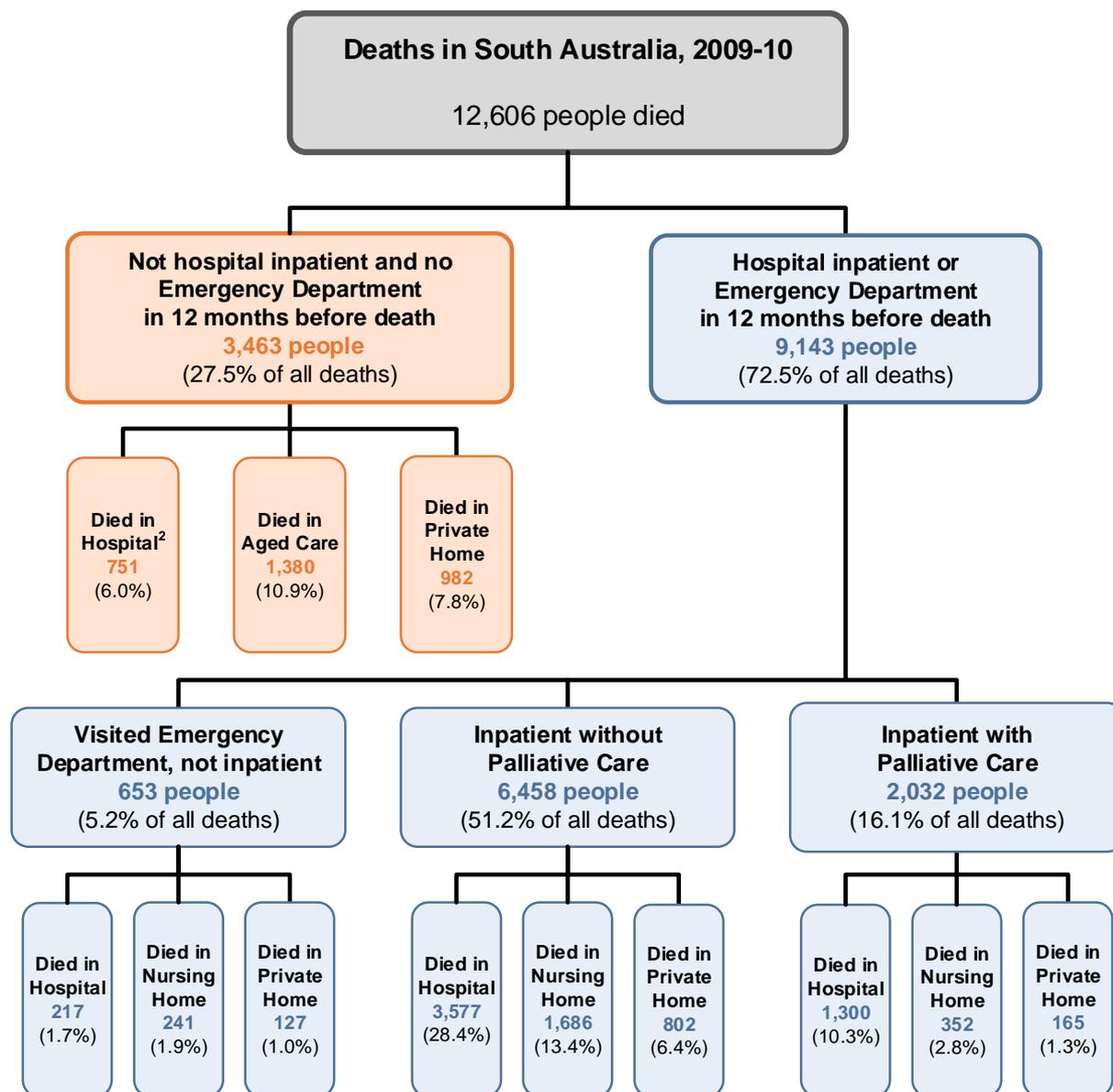
Quality end of life care rests in part on health care providers being alert to these signs and responding appropriately. This includes developing advanced care plans based on recognised good treatment and the person's preferences.

During consultations, community members expressed concerns that people with non-cancer terminal illnesses are less likely to receive appropriate end of life care and access to specialised palliative care.

In South Australia in 2009-10, 81.6% of palliative care separations were for someone whose principal or other diagnosis was cancer, higher than the 76% nationally (AIHW 2011). Nationally, renal failure was a far second at only 13% of palliative separations; heart failure and chronic obstructive pulmonary disease were also a minority of palliative care, at 8% and 6.4%, respectively.

'GP [was] not willing to have Palliative Care staff involvement – 'only for those dying in pain with cancer' (Family member)

Figure 6. Place of Death in South Australia by Public Hospital and Emergency Department Use¹



Source: Based on SA NT Datalink 2013, Customised report

Dementia in particular was frequently mentioned as a terminal illness for which patients do not receive appropriate palliative care. This is partially due to a lack of understanding that dementia is a terminal illness by both the community and the health system, and by other misconceptions, such that dementia is a mental illness or a normal part of ageing (Alzheimer's Australia 2012). These issues are often compounded by cultural differences.

Nationally, only 0.4% of palliative care separations were for people whose principal diagnosis was dementia or Alzheimer's disease in 2009-10 (AIHW 2012). This is significantly disproportionate to the prevalence of dementia, as one in ten Australians 65 or older have dementia, rising to three in ten for those 85 and older (AIHW 2013a). Yet the evidence provided

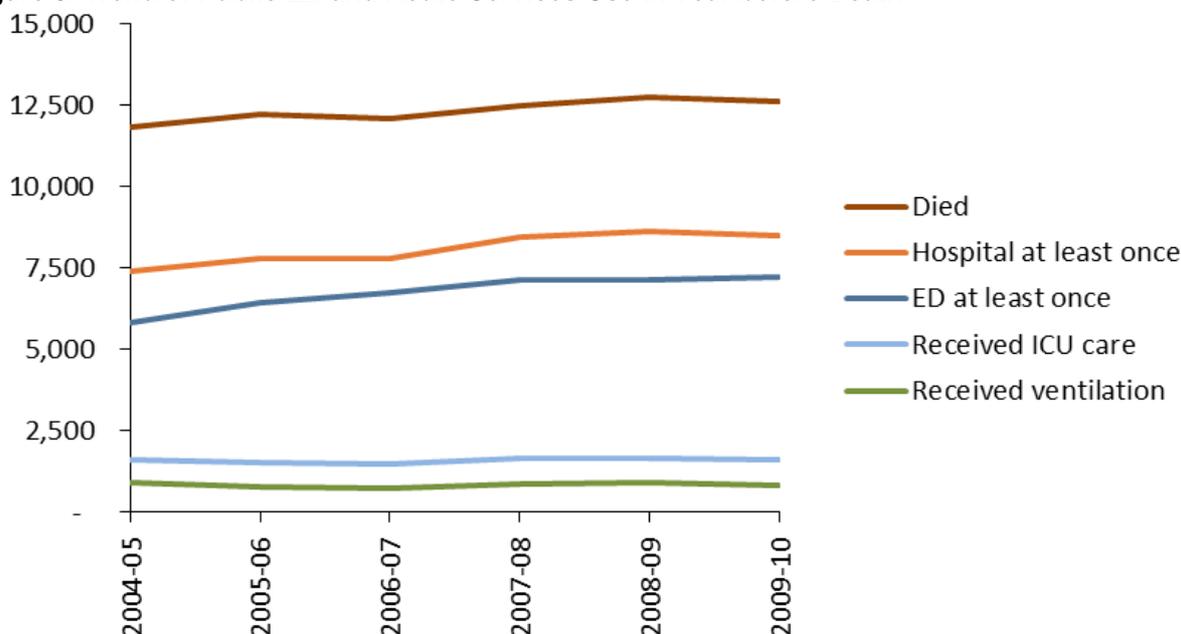
¹ Emergency department data include only metropolitan presentations. Percentages are of all deaths. Place of death includes only three most common places; place of death percentages therefore do not add to 100%.

² Death is recorded at a public or private hospital location but there is no metropolitan, public emergency department or hospital inpatient record for the twelve months prior to death. Person may have been a patient of a private hospital or deceased and was transferred to a hospital for pronouncement of death.

Datalink 2013, Customised report). However, of those 1,593 people that did go to ICU, they spent on average a total of 136.9 hours in ICU in the twelve months before death.

An even larger majority of people who went to hospital before their deaths, 90.4%, had no ventilation hours at all (SA NT Datalink 2013, Customised report). However, of those 818 people that did, they received an average 132.3 hours of ventilation in total in the twelve months before their death.

Figure 8. Trend of Public ED and Acute Services Use in Year before Death



Source: Based on SA NT Datalink 2013, Customised Report

An intensive care unit (ICU) is a specialised ward in a hospital which treats patients with life-threatening illnesses or injuries for which recovery is possible (AIHW 2013b). For patients for whom recovery is not possible, time spent in ICU usually does not contribute to quality of life, can involve multiple invasive procedures, and can be distressing to the person and their family.

In 2009-10, 12.6% of the 12,606 people who died were admitted to an ICU at some stage in the twelve months prior to their deaths (SA NT Datalink 2013, Customised report, see Table 1, next page). Of people who were admitted to ICU before dying, 82.7% were not identified as palliative inpatients in the twelve months prior to their death. A small minority, 17.3%, were identified as palliative yet spent time in ICU.

The average time people spend in ICU is very different depending on whether they have been identified as a palliative inpatient. People who were admitted to ICU before their death in 2009-10 without being recognised as a palliative inpatient spent 6.1 days in ICU on average—the equivalent of 22 fulltime ICU beds a year (SA NT Datalink 2013, Customised report). Palliative inpatients, however, spent on average 37.2% less time in ICU, at 3.8 days on average, equivalent to less than 3 fulltime ICU beds over the year.

SA Health advises that funding for an ICU bed per day is \$4,260 in 2013-14 (Data and Reporting Services, System Performance, SA Health, pers. comm., 17 September 2013). Using these figures, the cost of ICU care for people who died in 2009-2010 was \$38.7 million in today's figures. The large majority, \$34.2 million, was spent on patients who were not identified as palliative inpatients in the twelve months before their deaths. This is due both to the large percentage of deaths which were not identified as being palliative and the increased use of ICU for these people.

Better identification of people as being near the end of life would not only result in significant improvement in the quality of death for patients but also savings to the public health system in ICU costs. For example, if the average time in ICU for all patients who died was reduced to the average of people who are identified as palliative, ICU costs alone would decrease by nearly \$13 million a year. This would also reduce the ICU beds used by patients who were going to die to about 16 fulltime beds per year—a reduction of 9 ICU beds across the state.

While it will not be possible to identify all patients who are likely to die, these calculations indicate an area for further investigation by the department where implementing protocols to identify people as dying and then support quality end of life are likely to result in savings. Ensuring levels of palliative care staff are appropriate and building on their knowledge of end of life will increase in the identification of the end of life.

Table 1. Public Hospital Intensive Care Use in Last Year of Life by Inpatient Palliative Status, 2009-2010

Inpatient Palliative Status	Separated from hospital	Separated from ICU	Average ICU time per patient admitted to ICU	Total annual ICU time and equivalent beds	Total cost, 2013-14 dollars	Total ICU time and equivalent beds if ICU time same as palliative average	Total cost if ICU time same as palliative average
Identified as Palliative Inpatient	2,032 (16.1%)	275 (2.2%)	3.8 days (91.9 hours)	2.8 Beds (1,053 days)	\$4.49 million	2.8 Beds (1,053 days)	\$4.49 million
Not Identified as Palliative Inpatient	6,458 (51.2%)	1,318 (10.5%)	6.1 days (146.3 hours)	22 Beds (8,034 days)	\$34.22 million	13 Beds (5,047 days)	\$21.50 million
Total	8,490 (67.3%)	1,593 (12.6%)	5.7 days (136.9 hours)	24.8 Beds (9,087 days)	\$38.71 million	15.8 Beds (6,100 days)	\$25.99 million Savings: \$12.72 million

Source: Based on SA NT Datalink 2013, Customised Report

*Note percentages are of all deaths

The end of life journey varies for different diseases. The HPC specifically considered the journeys of the top three causes of death in South Australia: cancer, cardiovascular disease and respiratory disease.

Overall, South Australians whose cause of death was respiratory disease are more likely to present to public emergency departments and receive acute care (SA NT Datalink 2013, Customised report, refer to Table 2, next page). Cancer patients are much less likely to be admitted to intensive care units than either group, and if they are, they stay there for less time. They are also less likely to receive ventilation. Although this was not explored in depth, this may indicate that the high recognition rate of cancer patients as palliative impacts the level of resources they use if admitted to hospital.

These data suggest that those with end-stage respiratory disease are either less likely to be identified as being at end of life or that protocols are not in place to support a transition to a palliative approach once it is recognised they are at the end of life.

Table 2. Public Metropolitan Emergency Department and Public Hospital Use in Last Year of Life by Top Three Causes of Death, 2009-2010

Cause of Death	Died	Presented to ED	Average presentations if presented to ED	Separated from hospital	Average separations if separated	Average bed days if separated	Separated from ICU	Average time in ICU if admitted to ICU	Received ventilation	Average time of ventilation if ventilated
Cancer	2,803	1,589 (56.7%)	2.6	1,991 (71.0%)	3.7	38.8	212 (7.6%)	2.96 days (71.1 hrs)	62 (2.2%)	2.8 days (67.8 hrs)
Cardiovascular	2,667	1,356 (50.8%)	2.3	1,549 (58.1%)	3.9	27.2	258 (9.7%)	4.4 days (104.3 hrs)	150 (5.6%)	3.96 days (95.0 hrs)
Respiratory	2,589	1,606 (62.0%)	2.5	1,888 (72.9%)	3.6	38.3	405 (15.6%)	7.3 days (174.2 hrs)	171 (6.6%)	7.4 days (176.9 hrs)
All deaths	12,606	7,219 (57.3%)	2.5	8,490 (67.3%)	4.2	36.1	1,593 (12.6%)	5.7 days (136.9 hrs)	818 (6.5%)	5.5 days (132.3 hrs)

Source: Based on SA NT Datalink 2013, Customised Report

*Note percentages are of all people who died of that cause

In summary, the number of people who have multiple visits to metropolitan public hospitals emergency department or multiple public hospital admissions in their last year of life is increasing. Two thirds of South Australians were admitted to a public hospital in their last year of life; those that were admitted accumulated more than a month in a public hospital in their last year of life; those that were admitted accumulated more than a month in a public hospital in their last year over four separate stays. One in eight South Australians are admitted to an intensive care unit in their last year of life, with those who have not been identified as palliative spending significantly more time in the ICU.

5. Improving System Effectiveness

Against the backdrop of the Plan's intentions and the service activity associated with palliative and other end of life care, the HPC assessed areas where the system could be more effective. In particular, the HPC found that there are improvements to be made to the implementation of advanced care directives, generalist workforce capacity and competency, coordination between services, and governance of the Plan.

The Costs of Dying

As noted by the United Kingdom Department of Health, it is almost impossible to quantify the costs of dying, but key elements include hospital, specialist palliative care services, community nursing and care homes (2008).

For the two leading causes of death in South Australia, cancer and circulatory diseases (ABS 2011b), inpatient costs in New South Wales in the 12 months before death averaged at \$16,853 and \$11,069, respectively, in 2007 (Kardamanidis et al 2007). The imperative to consider the economic costs of end of life is therefore clear.

In addition to these direct service costs, there are the indirect costs of grief and bereavement, the long-term impact on mental health and the associated losses to productivity and community capacity (Genevro and Miller 2010). While these costs may be more difficult to calculate, they are no less real for individuals impacted by them.

The indirect costs of death are also very real for the government and community services to which the cost burden is shifted in cases of poor quality of death. The imperative for quality end of life is therefore just as clear as the economic one.

There is general consensus that congruence between people's preferred place and actual place of death is ideal if possible. Yet studies of the general population internationally show a low congruence. A review of studies on the topic showed 50 to 90% of people who have a preference of where to die prefer to die at home, yet only 10 to 35% of people actually do (Bell, Somogyi-Zalud and Masaki 2010). Interestingly, 18 to 65% of patients in the studies reviewed did not have a preferred place of death, preferring other attributes such as symptom control to place of death.

The only known such study conducted in the South Australian context, incidentally co-authored by HPC member David Roder, suggested 70% of the general South Australian population would prefer to die at home (Foreman et al 2006). Foreman et al found the preference to die at home is inversely related to age and dropped to 58% when weighted to the sex-age distribution of cancer in South Australia.

A flaw with these and most similar surveys is that they consider aged care facilities in a category separate from 'home.' Yet increasingly, particularly in ageing societies such as South Australia, aged care facilities are indeed homes. In addition, qualitative feedback from consumers and clinicians consulted during the HPC's review highlighted that general studies can be misleading, as patients' preferences for place of care can change as an illness progresses.

Although limited and self-selecting, a survey conducted for this review of carers and family of people who had died, only 45% of 114 respondents stated their loved one expressed a preference of where to die. Of those who had a preference, 65% wished to die at home.

In the general public survey regarding end of life preferences, 54% of the 71 respondents preferred to die at home, although several did mention not wishing to be a burden on family.

Palliative care has been found to more than double the likelihood of dying at home (Gomes et al 2013) and reduce health care costs. A review of 36 studies conducted for the UK National Audit Office found that almost all found palliative care, regardless of the model used, is cost-saving, with an average savings of 30% (Haziandreu et al 2008). The savings were primarily from fewer hospitalisations and reduced use of acute hospital resources.

Similarly, studies have found that greater savings can be achieved through models which focus on palliative care home services provided by General Practitioners (GPs) with some specialist palliative hospice beds and community consultation provided by nurse/physician teams, such as the Canadian Edmonton Regional Palliative Care Program (Bruera and Sweeney 2002). This model resulted in a decrease in deaths in hospital from 86% to 49% of deaths in four years and an annual savings of \$1.6 million Canadian.

Silver Chain in the Perth metropolitan area uses a similar approach in its home hospital model, which provides palliative care services in the community. A 2011 review of Silver Chain's home hospital by Pricewaterhouse Coopers found high levels of patient satisfaction with the timeliness and quality of care, the amount and quality of information provided, and access to health professionals (2011). At the same time, there were savings to the health system and improved hospital efficiency. Savings per patient were estimated to be between \$1,069 and \$1,211.

Unlike some elements of the health care system, the evidence indicates a focus on a high level of quality for patients at the end of life will also reduce overall costs. The following sections outline areas for particular quality consideration.

Advanced Care Planning

Finding 3. Advanced Care Directives: The *Advance Care Directives Act 2013* is a positive move, but in and of itself not enough to effect change. Implementation of the Act requires effective systems and efforts to increase community confidence.

The HPC heard throughout the review that there is a lack of clarity about advanced care measures among both clinicians and consumers. Many consumers are not confident that clinicians will respect their wishes. Many clinicians are not confident about when to discuss end of life wishes, or when to stop curative measures.

The South Australian Government has made significant efforts to simplify arrangements for South Australians to document their wishes for future medical care through the *Advance Care Directives Act 2013*.

The argument for the importance of the successful implementation of the Act is clear for both the community and the health system. Advanced care directives provide a framework for clinicians and families to move from a cure to a care approach at end of life, avoid unnecessary and potentially invasive treatment, and plan the quality of life individuals want. Increasing the use of advanced care directives must therefore be a priority for the health system.

The only known randomised control study in Australia on advance care planning interventions showed that advanced care planning facilitated by nonmedical professionals dramatically increased the match between care and patients' wishes (Detering et al 2010). Facilitation resulted in 86% of those who died completing an advanced care plan. According to family members, those wishes were respected for 92% of patients.

In the same study, of patients who died without facilitated advanced care planning, none had an advanced care plan and only 30% had wishes that were known and followed. Those patients were much more likely to die in an intensive care unit and receive multiple invasive procedures until shortly before death, despite evidence that this may have been unwanted. Facilitated advanced care planning also decreased family stress, anxiety and depression and satisfaction with the hospital stay.

Another study conducted in the United States found that less than one third of cancer patients had had end-of-life discussions (Zhang et al 2009). For those who had, though, there was better quality of death and the cost of care was 35.7% lower in the last week of life.

There is limited evidence of the prevalence of advanced care directives in South Australia. Only 25% of the respondents to the HPC's survey about end of life preferences had completed an advanced directive. The survey is a very limited sample, and is likely to be over representative of the general public as respondents to the survey were self-selecting and therefore already had an interest in end-of-life issues.

Ensuring confidence in advanced care directives by the community and clinicians is fundamental to their successful implementation. Throughout the consultations, community members provided examples of patients' wishes not being properly recorded, accessed and followed.

'Dad had a Medical POA, had clear wishes about what treatment he wanted to receive and they were over ridden in the hospital. Dad had frequent admission in the months of his death and each time I as his daughter had to fight for his wishes to be heard.' (Family member)

'It was extremely difficult to find the right person who would take that down [advanced care wishes] and put it in my case notes. Many times I have tried but I don't know someone who does it.' (Community member)

While it could be argued that instilling this confidence is not role of the role of the Government, the efforts and resources behind the *Advance Care Directives Act 2013* will be wasted if it is not effectively implemented. Clinician and community confidence in advanced care directives will also reduce inappropriate and unwanted over-servicing. Instilling this confidence will require:

- Clinical and public awareness
- Support for people to complete directives
- Easy accessibility of completed directives, and
- Data collection and monitoring.

'Patients may perceive that their wishes are not always respected, and they fear that the health system will be unable to maintain their comfort and dignity as they die. The reasons for this can be broken down into two long standing structural challenges, where sometimes there is failure, particularly with regard to:

- Ascertaining patient wishes and converting these into relevant clinical instructions, which can change very quickly as dying becomes close (i.e. decision-making factors)
- The adequate provision of care and resources to maintain the comfort and dignity of patients so that they do not feel abandoned (i.e. care provision factors)

There is a need for a coherent statewide strategy encompassing these two areas rather than piecemeal implementation of strategies.' (Australian Medical Association (SA))

There is also uncertainty among clinicians, largely regarding whether advance care planning should be initiated by health professionals or patients (Rhee, Zwar and Kemp 2011). Yet studies of patients' perceptions have shown patients expect clinicians to initiate this discussion (Detering et al 2010), a view which was echoed in consultations for this review. At the same time, some clinicians reported that they believed their clinical judgement to be more important than a directive.

Clinicians have a role in respecting people's choices and facilitating better outcomes for consumers and their families. SA Health has a role in integrating discussions about directives across the spectrum of health care and ensuring directives are translated into practice.

In its recent inquiry into palliative care, the Australian Senate Community Affairs Committee found that awareness and literacy of advanced care planning and directives are lacking (2012). While that Committee's recommendation for a national public awareness campaign has yet to be implemented, literacy among both consumers and clinicians remain critical to South Australians achieving the quality end of life they desire.

Yet raising awareness is only one step to successful uptake. It was clear from consultation that the community needs support in preparing advanced care directives, with many consumers consulted stating that they did not feel well-informed enough to complete them. An easy to complete pro forma and support in completing it will improve successful uptake of advanced care directives. Partnerships across all three sectors would support this goal.

Studies have also shown that involving family members in end-of-life discussions improves the uptake and implementation of advanced care plans (Tan et al 2013 and Detering et al 2010).

'Really hard to get somebody to sit down with you and talk it through. These forms are complicated. I can't say I want this treatment or that treatment, this is why it needs someone to talk you through the form filling.' (Community member)

Once advanced care directives are completed, accessibility of that documentation is critical for people's wishes to be respected. The documentation must be readily available for all people involved in care, from aged care workers to first responders and clinicians.

Positive moves have been made in this space. For example, the statewide Level 6 Paediatric Palliative Care Service is finalising a process with the SA Ambulance Service. When the process is implemented, do not resuscitate orders will appear on electronic systems when an emergency call is made from a home with a child who is a palliative patient. This process will support families to not experience additional grief from police intervention after a foreseen death, as well as preventing unwanted transfers to hospital. The HPC questions why this innovative process is not also being implemented for adult palliative patients.

Finally, there does not seem to currently be evidence of the uptake of advanced care directives in South Australia. Data collection and monitoring will be critical to monitor uptake of advanced care directives and make adjustments to strategies as appropriate. Implementation of data collection systems must be a priority for implementation of the Act.

Workforce

Finding 4. Workforce: There is a need to enhance the capability of the generalist workforce to provide end of life care in community, aged care, and hospital settings. The structure of specialist palliative care services should be refined and resourced to deliver equitable statewide services and provide support to generalist services.

A key area to support patients to stay at home is a generalist workforce capable of supporting the needs of patients to do so. Our consultations revealed that there is a strong community perception that this is not always available.

The generalist workforce is critical to quality end of life care, but evidence indicates that there are gaps in capacity and skills to manage end of life care. In particular, many clinicians and specialists outside palliative care have difficulties in moving from a curative approach to a palliative approach, which can limit patients' abilities to make appropriate choices and lead to unnecessary and unwanted over-servicing by the health system.

Indeed, it is understandable how the culture of the health workforce is more focussed on curative treatments than palliative care. As noted by the Economist Intelligence Unit, 'the obligations implied by the Hippocratic oath – rightly the starting point for all curative medicine – do not sit easily with the demands of end-of-life palliative care, where the patient's recovery is unlikely' (2010). Other research has shown that the focus of medicine on cure, acute care and technology can lead to death being seen as a failure (Sullivan, Lakoma and Block 2003).

The Plan established an expectation that palliative care services would build non-palliative specialist clinical capacity, but this has proved unrealistic while specialist services were themselves being reshaped and consolidated.

The clinical lack of decision making tools has contributed to ambiguity and clinicians' unease. The Dying Matters 90 day project and the 7 Step Pathway developed by Dr Chris Moy will support this translation, but further work may be needed (see Government of South Australia 2013). The project should be closely monitored to see if additional work will be needed to support clinicians to make the best possible choices.

'[I] would like more access to teleconferencing with specialist palliative care services.' (GP)

'I feel it [palliative care] often needs specialist input and a full team approach.' (GP)

At the same time, we heard from many consumers, community organisations and aged care facilities that the large majority of people with a terminal illness would prefer not to have clinical interventions which do not contribute to the quality of life. In addition, an appropriate palliative diagnosis is critical to allow patients to plan and to allow discussions of appropriate treatment plans. Without this, the choices available to a person are limited.

Clinicians have a clear role to communicate with patients and their families regarding prognosis and their options for care. Yet the evidence compiled during this review suggests that this communication does not always happen, resulting in treatment that may not be adequate or appropriate for the person's situation and wishes.

'Until all medical practitioners who routinely diagnose and "treat" terminal illnesses are skilled in communicating difficult and sensitive news, dying patients will continue to be denied the honesty and dignity they deserve.' (Community member)

A national study of end-of-life education in medical schools across the United States found that there was:

- very little teaching about end-of-life care
- a lack of exposure to caring for dying patients at home or in hospice
- perceptions that end-of-life care is less important than other types of care
- a tolerance for not being prepared for psychosocial issues and communication regarding end-of-life, and
- mixed messages about end-of-life care (Sullivan, Lakoma and Block 2003).

Although there was no comprehensive evidence assessed during this review regarding end of life medical education, the American findings seem to be relevant in the South Australian context from the survey of GPs conducted as a part of this review. Of the 24 GPs who responded, almost 71% said they had no training in palliative care, although 92% of them had treated patients with a terminal illness in the last twelve months.

From community members' experiences and GPs responses, it is clear greater education in the fundamentals of palliative care is required in formal medical education with reinforcement through ongoing training development and palliative placements. A greater focus on the psychosocial aspects of care is likely to improve patients' opportunities and willingness to communicate their wishes regarding what treatment they do and do not want.

Service Coordination

Finding 5. Care Coordination: Service delivery arrangements are variable. Coordination of care remains a challenge between primary care, aged care and specialist services.

Many people would prefer to receive palliative care in their home, whether it is a private home or an aged care facility.

A 2010 review of 18 studies regarding congruence between preferred and actual place of death found that factors increasing congruence were physician support, hospice enrolment and family support (Bell, Somogyi-Zalud and Masaki 2010). That review also found that congruence was improved when patients were given additional skilled care and support to navigate the health system. Negatively impacting congruence were inadequate symptom control, re-hospitalisation and lack of family support.

This finding was confirmed through HPC's survey of 114 family members and carers conducted during this review. Of respondents, 47% said there were always or sometimes problems of coordination or transfer between services. The HPC even heard of a family member paying a broker at his own expense to organise a family member's end of life care. Without these extraordinary interventions by families with the resources to do so, patients will default to the emergency room and hospital.

'Coordination between health-care specialists seemed to be patchy and to rely, to an unacceptable extent, on us (untrained, lay people) carrying messages between them (the medical specialists). It seemed hard, too, to have much confidence that the mass of medications being prescribed were being coordinated to ensure against adverse cross-medication reactions.' (Family member)

'Patients mostly want to die at home and this is a much cheaper option if all the supports are in place. Coordinating the supports has proved difficult.' (GP)

Service coordination is a key element across the healthcare journey, but particularly in end of life services, and even more so if a person is to stay at home near the end of their end of life journey. Coordination is also one of the basic Standards for Providing Quality Palliative Care for all Australians:

Standard 4: Care is coordinated to minimise the burden on patient, their caregiver/s and family (Palliative Care Australia 2005).

Yet lack of coordination between services and lack of clear patient pathways were frequently mentioned as frustrations for health, community and aged care workers. In a survey of 24 GPs undertaken for this review, 80% said coordination between providers was a barrier to providing end of life care to people where they live. Lack of service coordination is also a particularly pertinent issue for the resource-limited health system.

'One doctor didn't know what the other doctor had told us.' (Palliative care patient)

Without adequate knowledge of options, patients needing care will default to the emergency room and the hospital. To reduce admissions, patients and their families need increased information and support to access other services, which would reduce the hospital burden and better meet patients' needs.

'We asked when a palliative care bed will be available. The response given to us that that you will know when the right time is. We turned up at emergency because there was no other option and we were told that we were wasting their time and money.' (Employee, community organisation)

Although work has been done to establish referral pathways for palliative patients, inconsistency in clinicians' knowledge of what services are available and how to access them remains. This results in what feels to many patients to be a disjointed and ineffective system.

Creation of and communication about effective patient pathways was also a priority of the Senate Community Affairs Committee's inquiry into palliative care. That Committee recommended that medical workforce training include education about existing pathways to specialist palliative care and that care be applied effectively (Senate Community Affairs Committee 2012). One way to address this issue would be a clearly designated care coordinator for terminal patients. While the Senate Community Affairs Committee recommended a case management model, this role could be fulfilled by GPs, nurse practitioners, aged care staff, or social workers.

Improvements in service coordination and consumers', families' and health professionals' ability to navigate end of life care services depend on sufficient and sustainable budgets. Consultation with workforce revealed that there are concerns that constraints within overall health budgets, including reduction in funding of sub-acute services and the shift to Activity-Based Funding, could create barriers to achieving these improvements.

Country areas are particularly vulnerable to budget constraints, given their reliance on metropolitan Level 6 services to provide specialist palliative care expertise. Formalising these partnerships will go some way to alleviate country workforce and residents' concerns about not having the same level of support as their metropolitan counterparts.

The public and clinicians also expressed general concerns regarding variations between services in country and metropolitan areas. It has been reported that accessing services in country areas is likely to be easier due to community coherence. Nevertheless, there are relatively fewer community services in country areas and services in country are particularly stretched due to a comparatively older population and higher palliative care service needs.

The end of life care packages developed under the Plan are going some way to address the gaps in service coordination. In particular, the Terminal Care Package is reported by clinicians and aged care sector to be accessible and useful.

It seems other packages have not been as accessible, reportedly due to funding limitations. The lack of the full suite of packages being rolled out is leading to an absence of appropriate supports and patients being admitted to hospital in some instances, as the Terminal Care Package is only available for 7 days and the date of death is difficult, if not impossible, to anticipate.

Throughout the review, extended care paramedics (referred to in the Plan as 'rapid response teams') were universally praised as an effective initiative to improve patient outcomes and reduce unnecessary over-servicing. Extended care paramedics provide the care patients in the metropolitan area need in their place of usual residence without unnecessarily transporting them to hospital. Between December 2008 and June 2009, the 1123 cases with extended care paramedics resulted in 49.4% of emergency department presentations being prevented, and 5.3% of hospital admissions avoided, without any adverse effects (SA Ambulance 2009). This service has not been rolled out statewide, though consumers consulted did specifically mention a desire for this service in country areas.

Another initiative developed under the Plan which may address coordination issues is an app for patients to record symptoms. The app will automatically flag the right area of system and prompt proactive contact from a clinician if a person's symptoms reach a certain threshold. Once implemented, this initiative could address system navigation issues and therefore contribute to better patient outcomes and reduced use of acute services. It should be monitored for these outcomes.

The Clinical Network

Finding 6. Clinical Network Development: The Palliative Care Services Network should build on its successes by improving Network visibility and development.

Finding 7. Governance: Governance and accountability for the Plan are generally weak and resources are not clearly allocated.

Finding 8. Reporting systems: Reporting systems for palliative and end of life care are disjointed and do not facilitate easy monitoring.

Under the Plan, the Palliative Care Clinical Network was given the responsibility of providing clinical leadership for the reshaping and expanding of palliative care services.

Clinical networks can be an effective mechanism to improve patient outcomes by involving the workforce in championing improved clinical practice and facilitating consumer input. Haines et al (2012) argue that clinical networks require three features for success: well-designed quality-improvement programs with explicit implementation plans, effective organisation, and strong support from health system management. Improvements in all three of these areas would increase the effectiveness of the Palliative Care Services Clinical Network and the implementation of the Plan.

Although not developed by the Palliative Care Services Clinical Network, the Plan itself is the Network's key quality-improvement plan. The Plan was developed in 2007 and 2008—a time of expanding Government resources, bolstered by an economy believed to be in boom and a renewed sense of cooperation between state and federal governments.

The Plan's ambitious, comprehensive goals and lack of clarity regarding resources and initiatives' priority reflect this optimism. This ambition and the Plan's aspirational goals are commendable and are widely supported by the Palliative Care Clinical Network and community members.

Since the development of the Plan, though, South Australia's health system has undergone significant structural changes as well as experienced the impact of the global financial crisis and changes in state-Commonwealth financial arrangements. These shifts in political and financial contexts are a large contributor to the deceleration in the Plan's progress. These external factors have been strongly compounded by the Plan's lengthy timeframe combined with its lack of priorities and measures of success. Without these key factors, turnover in leadership and operational staff have led to much of the workforce critical to delivery of the Plan not having a clear understanding of what is expected of it to deliver the Plan. The culmination of these micro and macro factors is evident in a lack of coherence between the Plan, departmental structures, and resourcing decisions.

For progress to be made in 2013-2016, the Health Performance Council strongly recommends an unambiguous implementation plan be created in partnership between the Department for Health and Ageing, local health networks and the Palliative Care Services Clinical Network.

As previously stated, the Plan seeks to address the needs of not only the approximately 16% of people who die after being identified as palliative, but also the general population's end of life needs (Integrated South Australian Activity Collection Database 2013). Actions toward this comprehensive goal will contribute to a higher quality of life for all South Australians, but the Plan does not acknowledge that the differences between the general and specialist palliative populations necessitate some different strategies. It is recommended that in developing an implementation plan for the next three years, strategies take into account these differences.

Through the review, it was evident to the Health Performance Council that the Palliative Care Services Clinical Network Steering Committee has a dedication to not only implementing the Plan but genuinely improving patient outcomes.

The Steering Committee has been innovative and hardworking in its relentless efforts to achieve these goals. Despite this dedication, the Steering Committee has limited levers in the health system. It has no remit to access or allocate necessary resources for the Plan's implementation, for example information technology and workforce.

Successful implementation of the Plan is therefore highly reliant on an interdependent relationship between the Palliative Care Clinical Network, the Department of Health and Ageing, and the local health networks.

There is an urgent need to revisit the Plan and decide priorities for action for the period from 2013-2016. Implementation appears stalled in some areas, responsibility for initiatives is not defined or understood, and resources are not clearly allocated. Without a clear working relationship and a shared understanding of goals and priorities between these three groups, there is little likelihood of further progress.

Effective organisation of the Palliative Care Services Clinical Network is also essential to its success. Although the Network itself acknowledges it is currently underdeveloped, there was little evidence that Network development had been a priority. Improved organisation of the Network is critical not only to the Network's ability to oversee the Plan, but also to its very existence.

As a part of the review, all members of the Clinical Network were invited to comment on the implementation of the Plan via an online survey. Responses to the survey suggest that the role of the Palliative Care Clinical Network is unclear to a significant proportion of its members, with nearly a third of respondents stating they were unaware that they are members of the Network. It was also a recurrent theme in discussions with clinicians and system managers that there is significant confusion between the greater Network and its Steering Committee, with many people thinking the Network *is* its Steering Committee. The lack of awareness of the Network's role undoubtedly has a detrimental effect on members' connection with the Network, and thus the Network's ability to have an impact on healthcare and patient outcomes.

To become a fully developed Network, it is advised that the Palliative Care Services Clinical Network Steering Committee should consider a comprehensive communication plan which builds on its quarterly newsletter and its goal of an annual statewide update day. A necessary part of the Network's development is an effective communication strategy which:

- Leverages on the current energy and commitment of clinicians,
- Provides a support network for professionals,
- Shares expertise among those working in palliative care-related services, and
- Communicates processes, protocols, knowledge, and good practice.

The Network Steering Committee may wish to refer to the International Association for Hospice & Palliative Care's strategies in this area.

Figure 9. Cooperation Required for Progress



Effective external communication is also an important element to continuing the level of workforce commitment to the Plan's goals. During this review, some clinicians, particularly workforce outside specialist palliative care services, stated they wanted to know more about how the Plan is progressing.

Members of the Palliative Care Services Clinical Network Steering Committee not only deliver on the Plan in their professional roles, but also are tasked with overseeing it, monitoring factors impacting implementation and evaluating its impact on patient outcomes. There are evident conflicts of interest in these roles. In addition, the expectation that a small group of people are capable of successfully delivering on all these roles in addition to full-time clinical roles is unrealistic.

Conversations with key informants during the review highlighted that governance of the Plan is generally rated as weak, with significant confusion among the Network members and clinicians regarding who is accountable for overall implementation and individual actions. Without clarity and drivers, there has been significant variation between local health networks.

One way of addressing the variation between local health networks is to consider implementation of a statewide model for palliative care services. A statewide model is likely to not only create a more responsive system but also economies of scale and improved distribution of workforce and funding. Currently, the model is a hybrid, with services delivered by LHNs but other critical aspects statewide, such as referral processes, education, research and all paediatric palliative care. A statewide model is worthy of further investigation by the Clinical Network and the Department for Health and Ageing.

Another governance issue is an overreliance in delivery of the Plan on SA Health resources, particularly the Palliative Care Clinical Network Steering Committee. While specialist palliative care is clearly within the remit of SA Health, non-specialist services critical to end of life care are not only capable of being delivered by the not-for-profit and private sectors, they would be more appropriately delivered by these sectors.

Aged care, primary care, community organisations and the funeral industry all have a role in some aspect of the palliative approach.

The HPC strongly recommends that parties to the discussions regarding responsibilities under the Plan think laterally when assessing which services are most appropriately delivered by SA Health. Specific initiatives recognised through this review which would be better delivered by other sectors are identified in Section 6 of this report.

6. Putting People First

In addition to improvements which can be made within the health system itself, the HPC found that there are areas outside the direct control of the health system which impact on service delivery. These areas require solutions developed with a collaborative approach with others outside health services. Community literacy about death and dying, psychosocial issues, integration with other sectors and addressing diversity in particular require active collaboration with community groups and private businesses to be successful.

Community Literacy

One of the most frequent issues mentioned by consumers was that inadequate awareness and knowledge of end of life care options and services can take a significant toll on patients and their families, and there are additional barriers for culturally and linguistically diverse and Aboriginal clients.

Definitions of key terminology can particularly be a barrier to productive communication, and there is confusion by patients and sometimes clinicians about what palliation is, with some equating it with 'giving up' or even euthanasia.

Throughout this review, the HPC was clear in its use of the palliative approach being both generalist and specialist care which aims to improve the quality of life of patients with life threatening illnesses (World Health Organisation 2013). Similarly, specialist palliative care is that provided by professionals whose substantive work is people with an eventually fatal condition, their families and carers (Palliative Care Australia 2008).

'Mention palliative care and the person immediately think they are going to die in the next two weeks.' (Community member)

'Normalizing death is fundamental to community acceptance and engagement with pall care services. At present there is a lot of wasted energy as oncology and palliative care deliver competing visions and services to many of the same points. Plainly this is a financial and spiritual burden that no society can sustain indefinitely.' (Nurse)

Similarly, there is inadequate community awareness of death and dying, which can lead to a lack of acceptance of death. Throughout consultations there was a strong desire from both clinicians and the community for death to be normalised. The community also expressed confusion about end of life care options and rights.

'My greatest confusion was searching independently, internet search and so on, as to what services are available, how one can call on them, at what stage.' (Palliative care patient)

The Australian Senate Community Affairs Committee's inquiry into palliative care also found information provision about palliative care to be a considerable problem (2012). Recommendation 5 of that report recommends that governments:

Improve the provision and timeliness of information to palliative care patients, their carers and families. Processes should be put in place to ensure that patients, their carers and families are provided with the right amount of information, in the right format, at the right time and that a 'show bag' approach be avoided (2012).

The 'Dying Matters' program run by the United Kingdom's National Council for Palliative Care was frequently mentioned as an effective model of improving public knowledge and acceptance of dying. The model involves collaboration across health, community, private and other sectors. It builds on community capacity through information provision, events such as funeral planning parties, and education for GPs.

Within the South Australian context, the peak body for palliative care, the Palliative Care Council is well placed to address the need for broad community education about dying and end of life options. The Council provides resources for those who are dying and their families and is partially funded by the Department for Health and Ageing. It is better placed to educate the general public and those who are dying than the Department for Health and Ageing or the Clinical Network. Moving forward, mutually agreed clear deliverables on these fronts should support implementation of the Plan.

Working Better Together

Finding 9. Partnership: A renewed focus is required on partnering with the aged care, not-for-profit and private sectors to ensure seamless transitions within and across sectors, maximise personal choice and best use resources.

Finding 10. Equipment, Pharmacy, 24/7 Support: Improvements in access to equipment, pharmacy and after hours supports will increase congruence between peoples' desired and actual place of death.

The Plan is largely focused on the role of the health system and of specialist palliative services. Good end of life care requires effective cross-sector linkages, particularly with the not-for-profit and aged care sectors. These linkages are currently underdeveloped.

The Minister, as the Minister for Health and Ageing, has a unique opportunity to bring together the health and aged care sectors to make significant improvements. During the consultations for this review, the HPC heard from various people that the Plan underestimates the role of non-government partners, particularly residential aged care facilities.

Consultation with aged care facilities revealed that many aged care organisations are willing and capable to have a more active engagement with the health system in end of life care. The HPC saw evidence of some aged care facilities implementing well-structured clinical governance protocols to ensure residents' wishes are met and they are not transferred to hospital inappropriately. Initiatives such as the ACH Group's Namaste sleep promotion program for people with dementia and its comprehensive 'Planning Ahead' guide are not only innovative but also prevent unnecessary burden on the hospital system (ACH Group 2009).

'It is important, in any overall strategy, that primary care and aged care are included in implementation as many of the issues in regard to poor end-of-life care occur outside of hospitals...this will require significant leadership in not just implementing a major change in strategy, but also a change in culture across health and aged care with a focus on the care of patients and the end of life.' (Australian Medical Association (SA))

A major concern for aged care workers, however, is after-hours access to pain relief and other resources to manage symptoms and provide the greatest possible comfort to people at the end of their lives. Aged care workers reported that feeling like the best way to unlock the required resources after-hours is to send residents to hospital.

'Many nights spent begging medical officers in local hospital to please provide analgesic order after hours. High risk for registered nurses and medical officers. Only alternative is to transfer to large public hospital, and left with the potential for resident dying in the ambulance or on a trolley, still in pain!' (Registered Nurse, Aged care facility)

Aged care workers and family members also reported that the Coronial process is an unintentional disincentive to keeping people known to be terminal in their homes. Coronial involvement is a frequent issue for aged care facilities, where residents are often under the guardianship of the Public Advocate. Deaths at private homes can also often precipitate Coronial investigation as medical staff may be reluctant to sign off on the precise cause of death as the person was not under their care at the time, or because the person had been to a hospital or emergency in the preceding day. Families and residents at aged care facilities can find police presence and questioning after a death to be very stressful.

Furthermore, the time to release a body from the Coronial process can add to families' grief. Fear and anxiety about these elements can be a deterrent from deaths at homes, including aged care facilities.

Through discussions with patients with terminal illnesses and their families, it is clear that the most commonly requested supports to facilitate patients remaining in their homes are:

- Easy access to after-hours advice
- Equipment and pharmacy, and
- Psychosocial support, particularly for carers.

These three issues were also on the list of factors whose absence the United Kingdom's Department of Health found to have a 'severe adverse impact on the wellbeing of patients and carers' and which lead 'to avoidable admissions and to prolonged hospital stays' (2010).

Lack of after-hours support and advice was one of the most frequently mentioned reasons from carers to decide to seek another type of care, such as hospital or hospice, for the person for whom they were caring. In the survey of carers and family members, 50% of people noted a different standard or availability of care after hours and on weekends. In the survey of the general public, all of the 71 respondents stated after hours services were important or very important to caring for someone with a terminal illness. In the same survey, 65% of people said they did not receive the support they needed during their loved one's period of care, and 45% said they did not receive the support they needed after the death.

'Weekends were where problems occurred.' (Family member)

'Brochure should say - don't die on a Sunday morning because no care or attention from nursing staff will be provided.' (Family member)

'It would be good if more GPs were willing and able to provide extended care to patients in their homes but this work is poorly remunerated and time consuming.'
(GP)

The Department of Health in the United Kingdom has found that 'provision of 24/7 services can avoid unnecessary emergency admissions to hospital and can enable more people at the end of their life to live and die in the place of their choice' (2008). It is the opinion of the Health Performance Council that programs and services that facilitate easy access to these elements would decrease unnecessary emergency department presentations while improving patient outcomes.

The Palliative Care Clinical Network has purchased a toll-free number, 1300 Palli8, which could go some way to address this issue by being an around the clock single entry-point for generalist clinicians and patients. This initiative has yet to be implemented, though, due to lack of financing.

Access to equipment and pharmacy was another frequently mentioned barrier to dying patients staying at home. Improved access to basic equipment for those who are dying would likely increase the proportion of patients remaining in their home and decrease demand on acute services. Access to palliative pharmacy items are also crucial to patients remaining comfortable and therefore able to remain in their homes longer and more often.

The Plan has resulted in some improvements in this area, with the establishment of advanced practice pharmacy positions to develop a community pharmacy network. This achievement is universally supported, but has yet to be systematically implemented. For its impact to be felt across the state, a statewide community palliative pharmacy network must be implemented to support prescription of medications for end of life symptoms.

Psychosocial Supports

Finding 11. Support and Respite: Psychosocial and respite supports are critical to help people with a terminal illness stay at home if they wish but there is significant confusion about who is to provide this care.

Social support can be as big a contributor to dying a person's preferred place as symptom management. To honour the choice of many individuals to die at home and reduce the end of life impact on acute services, it is necessary to consider increasing support for the full range of current service providers, including support and respite services to support carers to continuing caring.

Building community capacity is critical to supporting people to stay at home. Not all people will be able to stay at home until end of life, but the goal should be to stay at home as long as possible if that is what the person and his or her family want. The need for psychosocial supports is greater with the increase of people living alone and with limited family supports.

One particular psychosocial support that is underdeveloped and requires a more collaborative approach is in the development and implementation of a grief and loss plan. Grief and loss counselling for families while a loved one is ill and after death was also a key theme from consultation and submissions to the HPC, yet there is significant confusion about who is to provide this care. A lack of support for those grieving was seen to contribute to a cycle of poor well-being. It seems that some of the strong consumer support for specialist palliative care comes from its holistic approach to emotionally supporting those close to a patient. This holistic approach could be implemented by other players. In regards to developing and implementing a grief and loss plan, the funeral industry is an obvious option for a partner.

'I felt so alone. I felt we were not understood, felt like a hindrance and a burden to people.' (Family member)

Respite for carers is critical to ensuring their own wellbeing and that they will be able to continue to support the person with a terminal illness. As previously mentioned, there is a strong perception among consumers that end of life support is not available after hours, and this concern extends to support, including respite, for carers outside of business hours. In addition, a few carers commented during the consultations that booking respite in residential aged care for a minimum of a week is often not needed, and requested the option of being able to book respite in day increments.

'My partner was palliative. I cared for [partner] at home for as long as possible. Was working, tried to take care by having my daughter and self on a roster system. Can't ask friends to help at night. As a carer you need to sleep, it's hard when you are the carer and trying to go to work as well. Partner ended up in hospital for last two weeks of life.' (Carer)

Responding to Diversity

Finding 12. Being Inclusive: Improved planning for South Australia's diversity is required in future implementation of the Plan, particularly for Aboriginal and culturally and linguistically diverse populations.

South Australians are incredibly diverse. The Plan has very few actions to address the impact of diversity on patients' needs at the end of life. Yet in the context of a diverse population, the person-centred care the Plan aims to deliver requires recognition of diversity.

For end of life care to be high quality for all South Australians, its delivery will require staff who are culturally competent and capable of being flexible at times. In order for the system to adequately respond to the end of life needs of all South Australians and ensure it is consistently delivering quality care, implementation of the Plan requires a greater focus on appropriate responses to the needs of the diversity of South Australians, including through education of those professionals who are involved in the end of life care, not only specialist palliative services.

The HPC would like to draw attention to two specific population groups that require particular consideration.

Aboriginal South Australians

As presented in Section 3, Aboriginal South Australians die at a higher rate and at a younger age than non-Indigenous South Australians and Aboriginal Australians overall. End of life services therefore must particularly meet the needs of Aboriginal South Australians, and in particular those of relatively younger people.

While anecdotal evidence indicates an increase in access to specialist palliative care services by Aboriginal South Australians, people consulted during this review report the general services available at end of life in hospitals and in the community are not currently meeting cultural-specific needs. Obstacles to a quality end of life experience include a lack of awareness among service providers of the actions to ensure Aboriginal people feel culturally safe, including the presence of potentially large family groups and access to traditional healing or spiritual healing. Mainstream health and aged care facilities are usually not equipped to accommodate large groups of visitors over extended periods of time.

Language barriers can further pose a challenge to patients and family members for whom English is not their first language, for example in communicating with caring and medical staff, accessing health information, and navigating systems. An additional barrier for Aboriginal people feeling comfortable in mainstream services is the relatively low representation of Aboriginal staff.

There is only one diversity-specific initiative in the Plan, initiative 3.3: 'Development of an Aboriginal palliative care service in Port Augusta.' The Aboriginal palliative care service was to support the cultural and spiritual needs of palliative Aboriginal people in that area, particularly those wanting to 'return to country' to die, yet it has not commenced beyond early planning stage.

There are no Aboriginal-specific initiatives in the Plan for other geographical areas. Aboriginal people from southern or eastern communities therefore face barriers to accessing services and returning to their country to die if they so desire. The Plan places little emphasis on Aboriginal peoples' journey to their homes and the establishment of clear pathways for all geographical areas should be a high priority.

'If we [Aboriginal people] go to a hospital or Mary Potter Hospice, it's sometimes uncomfortable, staff are unaware of cultural needs, there are language barriers and judgements are made.' (Community member, speaking as a member of Aboriginal community)

Cultural and Linguistic Diversity

Consumers and staff from community organisations expressed that the ability of the health system to identify and accommodate the diverse needs of South Australians was considered inadequate. Examples were provided such as the lack of awareness of taboo topics and social codes, such as the stigma of mental health issues in some communities, and family structures other than the nuclear family.

The Plan states that palliative services will use the Australian Government's 'Cultural Competency in Health: A Guide for Policy, Partnerships and Participation' and that culturally and linguistically diverse 'service responses will be directed toward collaborative partnerships with community leaders and key workers within cultural and linguistic groups' and that efforts would be made to 'build the capacity of communities to provide their own culturally- and linguistically-specific care at end of life' (SA Health 2009, p. 58).

During consultations conducted for this review, there was little evidence of these two actions being taken. In particular, it was highlighted that religious practices are not well recognised in the South Australian aged and health care systems and that this can particularly be an issue during end of life care.

Palliative Care Victoria recently commissioned comprehensive work regarding the strategies needed to address the needs of culturally and linguistically diverse communities; the Palliative Care Clinical Network may wish to consider UltraFeedback's *Informing a Palliative Care Cultural Responsiveness Strategy* (2012) when further developing its own culturally and linguistically diverse strategies.

In relation to other sections of the diverse population of South Australia, the HPC also received feedback from the following population groups:

- Regional South Australians
The HPC heard that access has improved in these areas, which is of particular importance due to the older populations living in rural areas. This is an area for continued improvement and monitoring.
- Veterans
There are specific end of life issues faced by veterans, including guilt, anger and fear. These issues are not consistently being addressed.
- Gay and lesbian, bisexual, transsexual and intersex community
This group expressed concerns about respect and responsiveness particularly due to blood family being invited to make decisions as opposed to life partners.

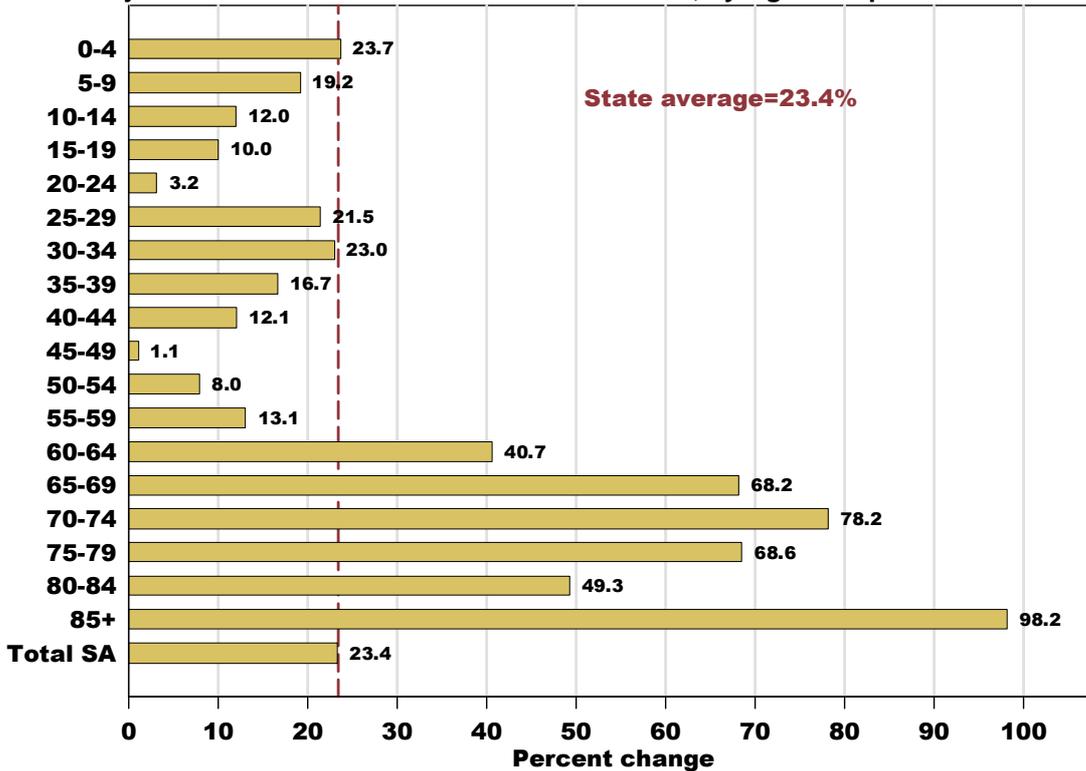
In relation to any specific gender differences, there was no feedback received during consultations, though most carers who provided feedback were women. The HPC did note that there was a slight sex difference in the profile of palliative inpatients, with 42.6% of palliative inpatients female and 57.4% men. The small imbalance in palliative inpatient sex is likely related to the fact that South Australian men are likely to die in hospital than women as noted in Section 3.

7. Appendices

A. South Australia: A Diverse and Ageing Population

South Australians are living longer, resulting in growth in older cohorts (Australian Bureau of Statistics [ABS] 2011e). In the ten years prior to 2011, the number of South Australians aged 55 and over increased by 25.1%, with the number 85 years and older increasing by 50% (ABS 2012). Proportionally, more of the population is now in these older groups, with more than a quarter of South Australians 55 years or older in 2011.

Figure 10. Projected South Australian Growth 2006 to 2026, by Age Group



Source: Based on Department of Planning and Local Government 2010a

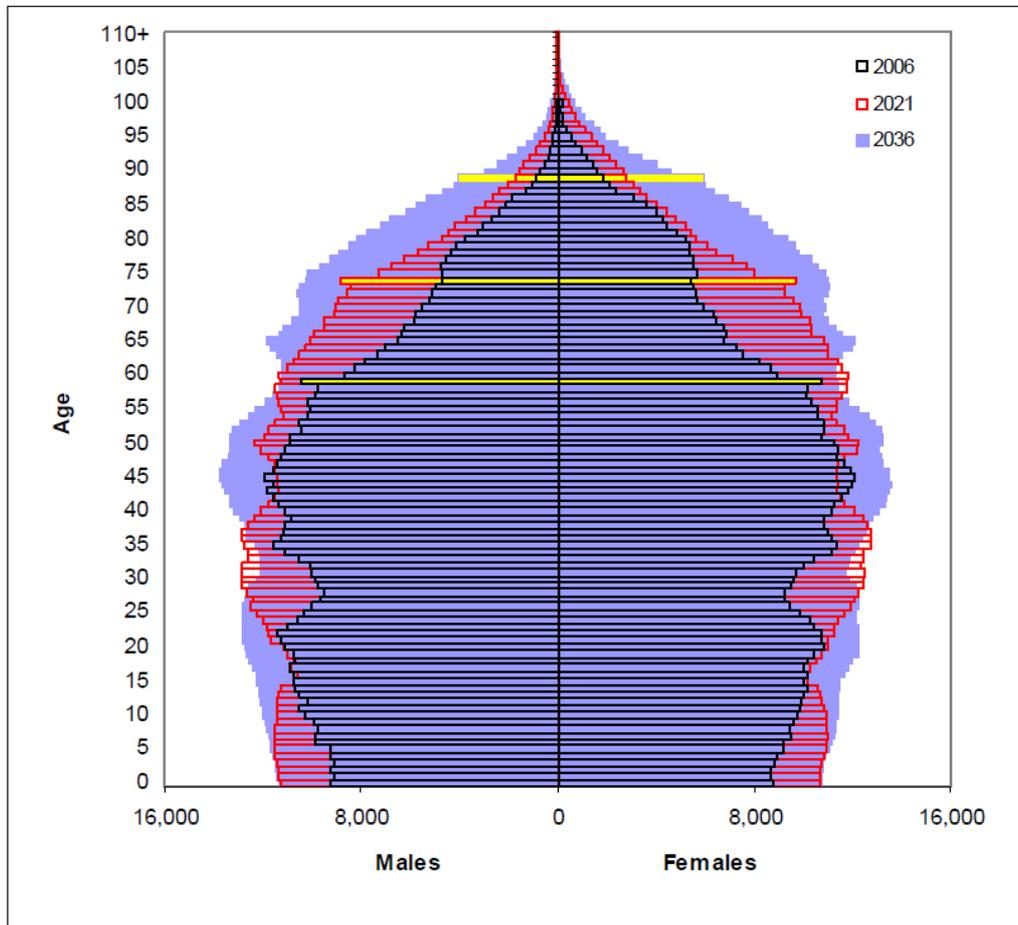
South Australia is also growing. Between 2001 and 2011, South Australia's population increased by 8.4% to over 1.6 million people (ABS 2012c). Thirty year population projections from the Department of Planning and Local Government show that this increase will continue (2010a). The majority of this growth, though, will occur in the older cohorts, with growth in South Australians aged 85 years or older growing by more than 98% by 2026 (see Figure 10).

Longer life expectancy and population growth are expected to compound, resulting in an unprecedented shift in the ageing demographic structure of the population (see Figure 11, next page). In 2011, more than a third of South Australians aged over 80 years old lived alone (ABS 2011a).

South Australia is an incredibly diverse place. In 2011, nearly 30% of South Australians lived in rural and remote areas, with the remaining 70% in metropolitan Adelaide (ABS 2012b). Contrary to some perceptions, metropolitan Adelaide and country SA are growing at similar rates. Between 2006 and 2011, metropolitan and rural areas grew 5.9% and 4.9% respectively (ABS 2012a). The people in those regions are also diverse. Almost a quarter of South Australians were born overseas, 14.4% do not speak English at home and 2.5% do not speak

English well or at all (ABS 2012b). Nearly 2% of South Australians identify as Aboriginal or Torres Strait Islander, approximately half of whom live in the Adelaide area.

Figure 11. Projected South Australian Age and Sex Structure



Source: Department of Planning and Local Government 2010b

*Yellow bars represent the movement of the Post World War 2 generation.

The tremendous diversity of South Australia and its shifting age profile pose challenges at present and into the future for the health care system--public, private and community based. Adequately and appropriately addressing the needs of a diverse, ageing population will particularly be the challenge of end of life services. With fewer available care givers in the future and more people living alone, end of life care will increasingly be provided outside of traditional family structures. Concurrently, South Australia's growing number of older people is likely to increase the proportion of people with comorbidities at end of life.

B. Palliative Care Services Plan: Implementation Status at 29 August 2013

1.0 STATEWIDE INITIATIVES	Time Frame	Responsibility	Status
1.1 Supporting the work of the Palliative Care Council of SA	2009-2016	Dept for Health & Ageing	Ongoing
1.2 Strengthening service partnering arrangement across the state	2009-2016	Dept for Health & Ageing	Ongoing
1.3 Developing a suite of palliative care packages	2011	Dept for Health & Ageing	Achieved
1.4 Establishing a statewide palliative care community pharmacy network	2009-2016	Palliative Care Clinical Network	Commenced
1.5 Establish a statewide palliative care clinical network	2008-09	SA Health	Achieved
1.6 Using a shared model of care and common approach to service delivery across the state	2014	Palliative Care Clinical Network	Commenced
2.0 WHOLE OF SYSTEM INITIATIVES			
2.1 Rolling out an Informed Choices Program across the state	2009	Dept for Health & Ageing	Ongoing
2.2 Developing a statewide health in grief and loss plan (scope only)	2009-10	Palliative Care Clinical Network	Not commenced
3.0 SERVICE REDESIGN INITIATIVES (Note there is variation by local health networks [LHNs])			
3.1 Development of Level 6 Services within Central and Northern LHNs	2009-11	Central & Northern Adel LHNs	Achieved
3.2 Developing Level 4 services in country SA (no consistency)	2009-2016	Country Health LHN	Commenced
3.3 Development of an Aboriginal palliative care service in Port Augusta	2009-10	Country Health LHN	Not commenced
3.4 Extending and expanding community based services	2009	All LHNs	Commenced
3.5 Reconfiguring bed and hospice units	2009-2016	All LHNs	Under Review
3.6 Exploring day hospice options	2010-2015	Pall Care Services/LHNs	Commenced
3.7 Using rapid response teams	2009- 2011	Dept for Health & Ageing	Ongoing
3.8 Differentiating palliative care bed types (nurse led)	2012-2016	All LHNs	Not commenced
3.9 Undertaking capital works	209-2014	All LHNs	Ongoing
4.0 COLLABORATIVE ENABLERS			
4.1 Support new regional aged care teams	2009-2016	Palliative Care Services/LHNs	Commenced
4.2 Working with aged care sector to develop their capacity as end of life care providers	2009-2016	Dept for Health & Ageing	Commenced
4.3 Working alongside chronic disease services	2009-2016	Palliative Care Services/LHNs	Commenced
4.4 Working differently in acute settings	2009-2016	Palliative Care Services/LHNs	Commenced
4.5 Working alongside pain management teams	2009-2016	Palliative Care Services/LHNs	Commenced
5.0 WORKFORCE INITIATIVES AND ENABLERS			
5.1 Developing a statewide palliative care workforce strategy	2009-2016	Dept/Pall Care Clinical Network	Commenced, now stalled
5.2 Growing the established workforce	2009-2016	All LHNs	Commenced, now stalled
5.3 Proliferating advanced practice roles	2009-2016	All LHNs	Commenced, now stalled
5.4 Growing a Nurse Practitioner workforce	2009-2016	All LHNs	Commenced, now stalled
5.5 Expanding the concept of advanced training	2009-2016	Palliative Care Clinical Network	Commenced
5.6 Expanding and using the General Practitioner with a special interest	2009-2016	Palliative Care Services	Commenced
5.7 Establishing a trained community based personal care workforce	2009-2016	Dept for Health & Ageing	Not commenced
5.8 Exploring and using new and emerging roles	2009-2016	Palliative Care Services	Commenced
6.0 QUALITY, DATA REPORTING INIATIVES			
6.1 Developing an end of life care outcomes surveillance capacity	2009-2016	Dept for Health & Ageing	Not commenced, Unlikely
6.2 Implementing a statewide quality program	2009-2016	Palliative Care Services	Achieved
6.3 Establishing a statewide reporting cycle	2009-2016	Dept for Health & Ageing	Not commenced
6.4 Putting in place information technology solutions and support	June 2014	Dept for Health & Ageing	Commenced
7.0 RESEARCH AND EDUCATION INITIATIVES			
7.1 Reinstating a statewide end of life research collaborative	2009-2016	Palliative Care Clinical Network	Commenced
7.2 Using a statewide approach to education, training support and practice development	2009-2016	Palliative Care Clinical Network	Commenced

C. Definitions

The HPC noted significant variation of the use of key terminology during the review. To ensure clarity of HPC's intentions in this report, key terms are defined below.

Advanced Care Directive: an overarching term for any legal document written by a competent adult which outlines his or her directions, wishes and values regarding future health care, accommodation, residential and personal matters or which appoints a substitute person to make these decisions on the person's behalf (Department for Health and Ageing 2013).

Advance Care Plan: Either an advance care directives (see above) or an informal document recording a person's wishes regarding future care and medical treatments in the event he or she is no longer able to make decisions (Department for Health and Ageing 2013).

Dying Process: Death is a normal part of the life cycle and affects people of all ages. Apart from sudden death the last stages of life can be relatively short with rapid decline (some cancers), slower decline with intermittent serious episodes of decline (mostly heart and lung failure) or a prolonged decline associated with increasing frailty. According to the *Palliative Services Care Plan 2009- 2016*, 'End of life care can last for years, days or hours or moments as is the case when life support is withdrawn' (SA Health 2009).

End of Life Care: End of life care is care provided to people who are experiencing a condition which will eventually be fatal. End of life care can be provided by all health care professionals and is not limited to palliative care services or specialists (Health Performance Council 2010).

Quality End of Life: Realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people requiring care (Palliative Care Australia 2008).

Palliative Care: Care whose primary goal is to improve the quality of life of patients and their families facing the problems associated with life threatening illnesses through the prevention and relief of suffering. It includes early identification, assessment and treatment of physical, psychological and spiritual problems (World Health Organisation 2013).

Specialist Palliative Care: Care provided by health or aged care professionals whose substantive work is people with an eventually fatal condition, their families and carers. Their expertise includes the management of complex symptoms, loss, grief and bereavement (Palliative Care Australia 2008).

D. People and Organisations Consulted

Palliative Care Clinical Network Project Advisory Working Group:

Kate Swetenham
Lauren Cortis
Karen Glaetzer
Tiiu Kannussaar
Alexandra Michelmore
Di Moncrieff
Clare Shuttleworth
Lauren Woodford

Organisations Consulted

Aboriginal Health Council of SA Inc
ACH Group Aged Care
Aged and Community Services SA & NT
Alzheimer's Australia SA, including a forum for counsellors and Dementia Behaviour Management Advisory Services staff
Australian Medical Association (SA) Inc
Carers SA
Consultative Council of Ex-Service Organisations (SA)
Council on the Ageing (SA) Inc
Health Consumers Alliance of SA Inc
Multicultural Communities Council of SA Inc
Palliative Care Council SA
Palliative Care Clinical Network
Regional Communities Consultative Council (SA)
Rural Doctors Association of SA Inc
SA Divisions of General Practice Inc
Flinders University of South Australia
Returned & Services League of Australia (SA Branch) Inc
SA Health
South Australian Country Women's Association
University of Adelaide
University of South Australia
Volunteering SA and NT Incorporated

Organisations represented, Access and Equity Forum, 29 July 2013

Aboriginal Aged Care
Alzheimer's Australia SA Access and Equity Unit
Chinese Welfare Services
Croatian Care for the Aged Association
Domiciliary Care
Greek Orthodox Community Care
Home Living Skills, Housing SA
Islamic Information Centre of SA
Multicultural Aged Care
National Aboriginal and Torres Strait Islander Dementia Advisory Group
Uniting Communities

Individuals Consulted

Teresa Burgess, PhD candidate, Adelaide University
Sara Fleming, Nurse Practitioner, Paediatric Palliative Care Service
Dr Christopher Moy, General Practitioner
Dr Lawrie Palmer, Medical Head of Unit, Northern Adelaide Palliative Service
Senior Research Officer, Coroner's Court

Public consultation forums

As part of the review, the Palliative Care Council of SA was engaged to conduct consultation sessions with the general public. 36 people attended public consultation forums between 22 July and 2 August 2013 in the following locations:

- Adelaide CBD
- Elizabeth
- Mount Gambier
- Naracoorte
- Port Adelaide
- Port Augusta
- Port Lincoln
- Stirling
- Victor Harbor

Surveys

A survey regarding perceptions of the implementation of the *Palliative Care Services Plan 2009-2016* was sent to the Palliative Care Clinical Network. Of the 184 who received the email, there were 73 respondents.

The Palliative Care Council of SA was also engaged to conduct surveys of the general public and general workforce. The Palliative Care Council of SA conducted four surveys, with a total of 222 responses:

- For carers and families of people who have died: 113 respondents
- General public regarding end-of-life preferences: 71 respondents
- General Practitioners: 24 respondents
- Staff of Residential Aged Care Facilities: 14 respondents.

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