



Government of **Western Australia**  
Department of **Health**

**WA End-of-Life and Palliative Care Strategy 2018–2028**

# Implementation Plan One 2020–2022 (IP1)

**Produced by the WA Cancer and Palliative Care Network,  
Western Australian Department of Health 2020**

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**Using the term Aboriginal**

Within Western Australia, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. Aboriginal and Torres Strait Islander may be referred to in the national context and Indigenous may be referred to in the international context. No disrespect is intended to our Torres Strait Islander colleagues and community.

**Contact information**

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# Contents

<b>Acknowledgements</b> .....	<b>ii</b>
<b>Foreword</b> .....	<b>iii</b>
<b>Executive summary</b> .....	<b>1</b>
Context .....	1
Implementation Plan One 2020–2022 (IP1) .....	1
<b>Overview</b> .....	<b>2</b>
Implementation planning cycle .....	2
Strategic alignment .....	4
Approach to developing IP1 .....	6
<b>How to use the IP1</b> .....	<b>7</b>
Statewide responsibilities .....	7
Local responsibilities .....	7
<b>The implementation plan</b> .....	<b>8</b>
<b>Priority One</b> – Care is accessible to everyone, everywhere .....	8
<b>Priority Two</b> – Care is person-centred .....	12
<b>Priority Three</b> – Care is coordinated .....	16
<b>Priority Four</b> – Families and carers are supported .....	21
<b>Priority Five</b> – All staff are prepared to care .....	23
<b>Priority Six</b> – The community is aware and able to care .....	27
<b>Acronyms</b> .....	<b>30</b>
<b>Appendices</b> .....	<b>31</b>
<b>Appendix One</b> – End-of-life and palliative care snapshot references .....	31
<b>Appendix Two</b> – End-of-life and palliative care recommendations of the <i>My Life, My Choice</i> Report of the Joint Select Committee on End of Life Choices .....	32
<b>Appendix Three</b> – Strategic alignment of the priorities and building blocks to the end-of-life and palliative care recommendations of the <i>My Life, My Choice</i> Report of the Joint Select Committee on End of Life Choices .....	33
<b>Appendix Four</b> – Action plan template .....	34
<b>Appendix Five</b> – Key action areas and measures aligned to the Strategy's priorities .....	36

# Acknowledgements

The *WA End-of-Life and Palliative Care Strategy* Implementation Plan One 2020–2022 (IP1) is the result of extensive consultation and commentary from a significant number of people and organisations including consumers, Health Service Providers, health professionals and public and private organisations from across the Western Australian (WA) health system, non-government service providers and the broader community. We would like to sincerely thank all of the people involved in the consultation process that led to the development of IP1.

We would also like to thank the consumers and health professionals who provided their own insights, either in respect to their lived experiences, or through caring for people and their families/carers within their respective health services. Your insights and your comments, which are included in IP1, have assisted in bringing the plan to life. Your reflections provide a focus for the true meaning behind the priorities and building blocks identified for action. Your participation in the End-of-Life and Palliative Care Strategy Implementation Forum in May 2018, the Citizen Space Strategy Implementation Plan 1 consultation in July 2019, the Health Consumer Council WA consumer survey in August 2019 and the Palliative Care Summit on 24 August 2019 is appreciated.

We would also like to thank the End-of-Life and Palliative Care Advisory Committee, which was the overarching governance group contributing to the development of IP1.

## **WA Cancer and Palliative Care Network**

Western Australian Department of Health

<sup>1</sup> In this document, Health Service Provider (HSP) refers only to public health services that deliver clinical services.

# Foreword

I am pleased to introduce Implementation Plan One 2020–2022 (IP1) that underpins the [WA End-of-Life and Palliative Care Strategy 2018–2028](#) (the Strategy).

End-of-life and palliative care is a priority for the Department of Health and the Implementation Plan reflects our commitment to operationalise the strategy across the WA health system in collaboration with our valued partners.

Improvements to access are vital, particularly regional access and equal access for vulnerable, marginalised and unrepresented people. Equally important is the provision of optimal care for children with life-limiting conditions and their families/carers, across the spectrum from neonates to adolescents. Actions and improvements that place the person and their family/carer at the centre of individualised, well-designed, coordinated and integrated care, including access to bereavement support, are also essential.

IP1 provides the WA health system, spanning the public, private, community and non-government sectors, with a structure from which to plan, deliver and evaluate innovative care aligned to the Strategy. It identifies priorities for action and the foundations for improving end-of-life and palliative care for all West Australians.

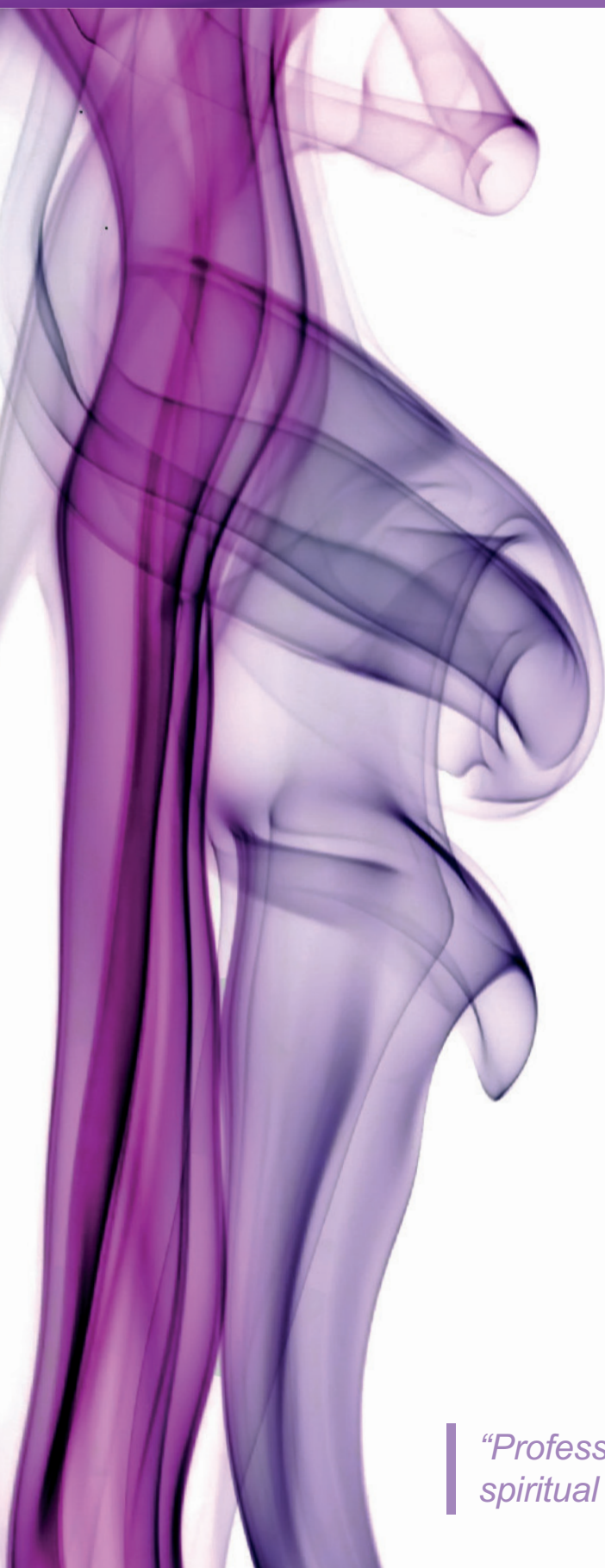
It is important to note that IP1 is the first in a series; the subsequent Implementation Plan Two (2023–2025) and Implementation Plan Three (2026–2027) will follow to build upon the actions and outcomes from earlier years. This allows for flexibility within the changing landscape and to ensure we keep pace with contemporary practice and service provision.

The Department of Health has worked closely with key stakeholders and undertaken extensive consultation with individuals and organisations to ensure people and their families are at the centre of IP1. It is through these partnerships and continued collaboration that we as a health system can strengthen end-of-life and palliative care via the Strategy and structure provided in IP1.

**Dr D J Russell-Weisz**

Director General

WA Department of Health



*“Professional and caring support for medical, spiritual and mental health is important to me.”*

# Executive summary

While the inevitability of death and dying is something that we all share, the impact of symptoms, the effects of treatment and the value we place on quality of life, are different for all of us. *WA End-of-Life and Palliative Care Strategy 2018–2028*

## Context

End-of-life care is everyone's business. Policy-makers, executives, health professionals, researchers and the wider community all have a crucial role to play to ensure that people and their families/carers have access to high-quality evidence-based care, systems and services.

In WA, as elsewhere in Australia, there are still many who, despite knowing they have a life-limiting illness, do not receive palliative care. From our research and consultation we understand that people have unmet needs at end-of-life for many reasons, one of which is that they are not referred early enough in their disease trajectory to benefit from the supportive services of palliative care clinicians.

*"The last weeks or days should be celebrated; family and comfort, support and care are so very important for all."*

The WA health system must enhance and strengthen the way it delivers end-of-life and palliative care to those who require it. This includes providing optimal care for children with life-limiting conditions across the spectrum from neonates to adolescents and their families/carers; addressing the increase in demand for end-of-life and palliative care services in general; and meeting the needs of an ageing population.

Health reform that ensures the highest possible level of end-of-life and palliative care to people and their families/carers by utilising innovative service pathways and integrated, coordinated, and collaborative system models to improve the quality of end-of-life and palliative care is the way forward.

## Implementation Plan One 2020–2022 (IP1)

Implementation Plan One (IP1) is the first in a suite of documents to guide the priorities and building blocks of the *WA End-of-Life and Palliative Care Strategy 2018–2028* (the Strategy). Extensive and considered consultation has ensured that the views of the health, community and aged care services is reflected in IP1 and has assisted in identifying realistic and achievable actions and measures of success.

The Strategy provides a high-level structure for a shared vision of the values and priorities required to provide people and their families/carers with the best possible end-of-life and palliative care in WA. It places people and their families/carers at the centre of care, within a culture of compassion and commitment to excellence.

IP1 provides a vital link, and builds on the Strategy, to establish direction for health systems and services to lead, convene and coordinate local initiatives to implement the priority areas and associated building blocks. Additionally, it encourages services to take shared responsibility and action to find new and innovative ways to establish partnerships and work collaboratively to provide integrated high quality care.

# Overview

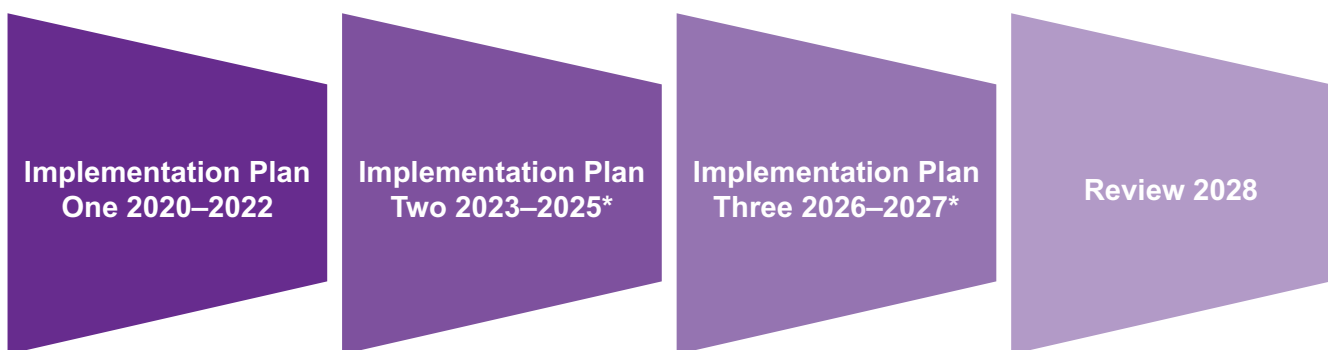
**Vision:** *to improve the lives of all Western Australians through quality end-of-life and palliative care.*

The aim of IP1 is to guide implementation of the Strategy at both a statewide and local level from 2020–2022. The Strategy was developed through extensive consultation with the end-of-life and palliative care community and launched in May 2018.

## Implementation planning cycle

The Strategy is a high-level document providing a ten-year vision to improve the lives of all Western Australians through quality end-of-life and palliative care. Implementing the six priorities of the Strategy and the related building blocks of IP1 requires a tri-phase, long-term approach. This approach allows for flexibility within the changing landscape and contemporary planning across time to meet the needs and expectations of people living with a life-limiting illness and their families/carers. The priorities and building blocks of the Strategy are outlined at Figure 1.

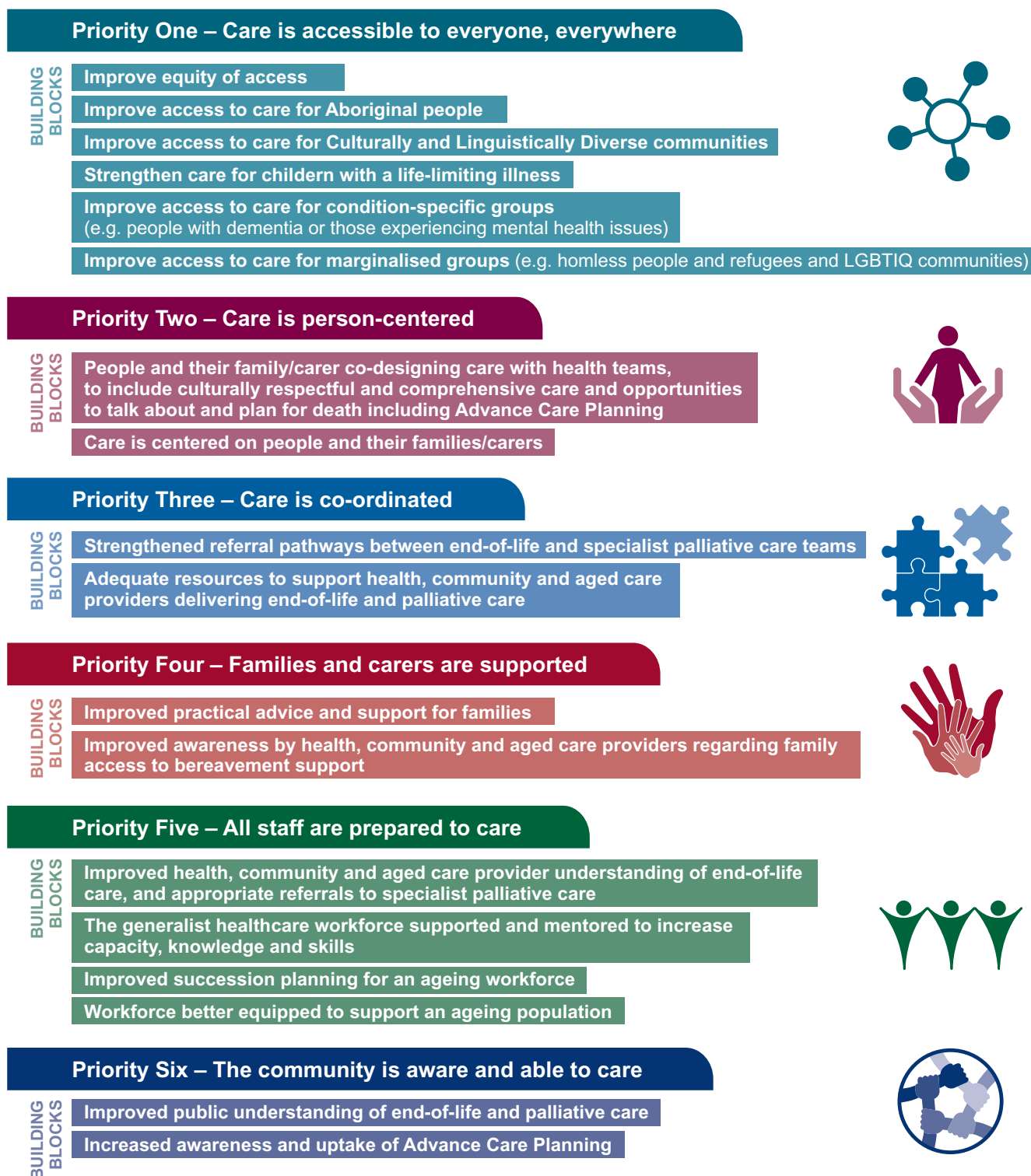
Implementation Plan Two (2023–2025) and Implementation Plan Three (2026–2027) will build upon the progress made in earlier years, and a progress review and focus for the future will take place in 2028. It is recognised that many actions and measures initiated in IP1 will continue into Implementation Plan Two (IP2), Implementation Plan Three (IP3) and beyond.



\* Implementation Plans Two and Three will be subject to consultation with stakeholders to identify priority building blocks, actions and measures for long-term implementation.



**Figure 1**  
Priorities and building blocks



## Strategic alignment

The Strategy and IP1 align to the end-of-life and palliative care recommendations of the *My Life, My Choice Report* of the Joint Select Committee on End of Life Choices (JSC Report). The JSC Report includes 24 recommendations, 12 of which relate to end-of-life and palliative care (see **Appendix 2**). Alignment of the JSC Report's recommendations to the Strategy's priorities is shown at **Appendix 3**.

Figure 2 provides an overview of the Strategy and IP1 alignment with national and state strategies and frameworks.

Figure 2  
**Strategic alignment of the WA End-of-Life and Palliative Care Strategy 2018–2028 and IP1**



*‘A dignified end of life will become part of community conversations, with greater planning and support for people to have more choices and access to appropriate end-of-life care’*

Sustainable Health Review Final Report

Figure 3  
End-of-life and palliative care snapshot

### Living and dying in Australia

More than  
**80%**  
of deaths  
caused by<sup>1</sup>



Cancer



Heart & other  
circulatory  
diseases



Respiratory  
diseases



External  
causes



Stroke

**160,000**  
deaths per annum<sup>2</sup>



**62%**  
predictable<sup>3</sup>



**54%**  
in hospital<sup>4</sup>



**32%**  
lived in residential  
aged care<sup>4</sup>



**Chronic conditions** accounted for  
around **9 in every 10 deaths** in Australia<sup>5</sup>

**75%**  
of **healthy**  
people would  
prefer to die  
at home<sup>6</sup>

Preferences frequently  
change as death  
approaches<sup>6</sup>

For dying patients  
**freedom from distress  
and symptoms** is more  
important than place  
of death<sup>6</sup>

### Definitions



**End-of-  
life care**

Care needed for people  
who are **likely to die** in  
the **next 12 months** due  
to progressive, advanced  
or incurable illness, frailty  
or old age<sup>7</sup>



**Palliative  
care**

Approach that improves the  
**quality of life** of individuals,  
including their families/carers,  
facing problems with life-  
threatening illness/condition,  
through the **prevention and  
relief of suffering**<sup>8</sup>



**Specialist  
palliative  
care**

Undertaken by a  
**professional palliative  
care team or service** with  
recognised qualifications  
or accredited training on  
palliative care<sup>9</sup>



**Palliative  
care for  
children**

An **active and total  
approach to care** from  
the point of diagnosis or  
recognition, throughout  
the child's life death and  
beyond<sup>10</sup>

### Benefits of palliative care



Assists families/carers  
to cope during the  
person's illness and in  
their own bereavement<sup>8</sup>



Addresses the needs  
of the person and  
their families/carers  
via a team approach<sup>8</sup>



Integrates the  
psychological and  
spiritual aspects of  
the person's care<sup>8</sup>



Provides a support  
system to help people  
live as actively as  
possible<sup>8</sup>



Relieves pain and other  
distressing symptoms<sup>8</sup>



Affirms life and  
regards dying as a  
normal process<sup>8</sup>



Enhances  
quality of life<sup>8</sup>



Positively influences  
the course of a  
person's illness<sup>8</sup>

### Access to palliative care

**63%** likelihood of considering palliative  
care after learning its definition<sup>11</sup>

**40%** of people who could benefit  
from palliative care receive it<sup>3</sup>



People who have access to palliative care can live longer, with improved quality of life and mood<sup>12</sup>

See [Appendix 1](#) for infographic references

## Approach to developing IP1

The WA Cancer and Palliative Care Network (WACPCN) at the WA Department of Health (DoH) led and coordinated the development of IP1, under the governance of the End-of-Life and Palliative Care Advisory Committee (EOLPCAC).

In May 2018, the WACPCN hosted the End-of-Life and Palliative Care Strategy Implementation Forum (Forum) to consult the palliative care community on the Strategy's implementation. The outcomes of the Forum are detailed in the *Outcomes Report: End-of-Life and Palliative Care Strategy Implementation Forum 2018* (Outcomes Report). The Forum provided stakeholders with an opportunity to review the building blocks aligned to the priorities of the Strategy and identify potential actions and measures to address these.

Further consultation was held with stakeholders in July 2019 via an online platform regarding the implementation of the building blocks. Feedback from stakeholders was strongly in favour of addressing the implementation of all building blocks in IP1, acknowledging that IP2 and IP3 will build on what is achieved during the IP1 timeframe. Stakeholders also noted that progress to achieve all of the building blocks will evolve over time and that there are significant inter-relationships between each of the building blocks, further supporting the need for an evaluation process over time to develop IP2 and IP3.

Stakeholders within the end-of-life and palliative care community were consulted in the development of IP1 to ensure the actions are achievable and the views of the broader health, community and aged care systems are accurately represented. The WACPCN will consult with the palliative care community annually, via an online consultation process, to enable stakeholders to provide feedback, monitor and build upon progress and identify local and statewide actions and measures to achieve the priorities of the Strategy.

On 24 August 2019, the WA DoH convened the WA Palliative Care Summit, at the request of the Hon Roger Cook MLA, Minister for Health. Members of the WA Country Health Service (WACHS) palliative care teams and services also attended a Palliative Care Summit on Monday 19 August 2019 via videoconference. The Perth metropolitan Summit and the WACHS Summit provided an opportunity to draw on stakeholder and consumer experiences, expertise, perspectives and lessons learnt to strengthen, improve and plan for future end-of-life and palliative care in WA, in light of the Strategy, the JSC Report and the Sustainable Health Review.

# How to use the IP1

## Statewide responsibilities

The WACPCN will provide statewide leadership and stewardship and will monitor performance via systemwide trends and data collection to support more robust measures and trend analysis, in addition to its contribution to the end-of-life and palliative care performance measurement knowledge-base. Mechanisms will be identified to improve existing methods of data collection and develop new methods.

The WA DoH will support stakeholders to connect and collaborate to enable the provision of an integrated, coordinated and strategic approach to influence policy, purchasing, workforce and planning.

The Minister for Health and/or the WA DoH is responsible for addressing the end-of-life and palliative care recommendations of the *My Life, My Choice* Report of the Joint Select Committee on End of Life Choices, incorporated into IP1, IP2 and IP3.

Successful implementation of the Strategy requires the invaluable commitment and collaboration of the WA end-of-life and palliative care community and other key stakeholders across health, community and aged care services.

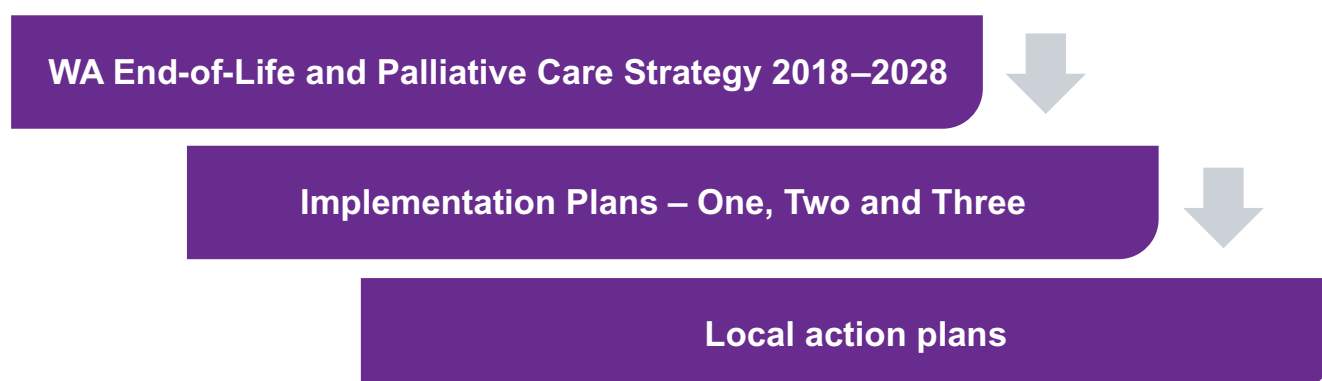
## Local responsibilities

The WA DoH acknowledges that stakeholders are well placed to identify and implement local actions and measures, as well as internal planning and reporting requirements. Stakeholders are therefore encouraged to prioritise building blocks which are relevant to their service.

It is also acknowledged that many systems, services and programs have already progressed local implementation of the building blocks in IP1. For example, services may be participating in the Palliative Care Outcomes Collaboration (PCOC) to improve patient and family/carer outcomes through data collection, structured feedback and benchmarking.

HSPs and stakeholders may use the Action Plan Template in **Appendix Four** to prepare and implement an Action Plan aligned to the Strategy's priorities and the building blocks.

**Appendix Five** summarises the key action areas and measures to address the priorities within the Strategy.

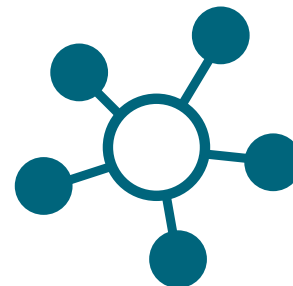


# The implementation plan

## Priority One

Care is accessible to everyone, everywhere

*“If you can’t access the service, it doesn’t matter how good the service is”*



### Consumer experience

I have access to good quality end-of-life and palliative care, regardless of who I am, or how I live my life.

### Building blocks to realise Priority One

1. **Improve equity of access.**
2. **Improve access to care for Aboriginal people.**
3. **Improve access to care for Culturally and Linguistically Diverse communities.**
4. **Strengthen care for children with a life-limiting illness.**
5. **Improve access to care for condition-specific groups** (e.g. people with dementia or those experiencing mental health issues).
6. **Improve access to care for marginalised groups.**

### Outcomes

- People living in WA with life-limiting illness will have access to:
  - timely end-of-life and palliative care if required, regardless of age, illness, location or ethnicity
  - integrated, seamless care in their preferred setting or location: home, residential aged care facility, hospital, inpatient palliative care unit, metropolitan, rural or remote.
- Culturally respectful and appropriate care will be provided to Aboriginal people, culturally and linguistically diverse people, people with condition-specific needs, and people from marginalised groups, and their families/carers, in their place of choice.
- Health (including primary care), community and disability providers will be guided by the Paediatric Addendum to the *WA End-of-Life and Palliative Care Strategy* and the development of a pathway to guide and optimise the care of children with a life-limiting illness and their families, across the spectrum from neonates to adolescents (e.g. the development of an Optimal Paediatric Palliative Care Pathway).
- Health (including primary care), community and aged care providers will have:
  - access to education and resources to enable appropriate assessment and care for people and their families/carers
  - a greater understanding of holistic care needs at end-of-life, including beliefs and values
  - access to culturally appropriate information in relevant formats and languages to enable appropriate assessment and care for people and their families/carers, including access to interpreter services.
- Health (including primary care), community and aged care providers will be able to demonstrate greater capability, understanding and application of end-of-life care principles.
- The specialist palliative care workforce will be able to meet the increase in demand for services.
- The Rural Palliative Care Program will continue to build workforce capacity and improve access to specialist palliative care, including innovative approaches to support access.

## Recommended actions

Care coordination	Stakeholder
<ul style="list-style-type: none"> <li>Integrate palliative care into formal care pathways for those with advancing life-limiting illness, eg Chronic Obstructive Pulmonary Disease, renal disease, end stage cardiac disease.</li> <li>Initiate early referral to Aboriginal Health Liaison Officers to improve access and support culturally respectful and safe care.</li> </ul>	Department of Health / Health Service Providers / Private service providers
Service provision	Stakeholder
<ul style="list-style-type: none"> <li>Define the access needs of the population for end-of-life and specialist palliative care to facilitate timely access to care in place of choice, wherever possible:               <ul style="list-style-type: none"> <li>identify current services provided</li> <li>identify unmet need</li> <li>identify access gaps for:                   <ul style="list-style-type: none"> <li>geographical areas, including rural and remote</li> <li>identified populations, people with specific needs related to their condition and marginalised groups.</li> </ul> </li> </ul> </li> </ul>	Department of Health / Health Service Providers
Service models	Stakeholder
<ul style="list-style-type: none"> <li>Review the current models of care, based on best evidence, and identify gaps.</li> <li>Following a review of the current models of care, identify and develop contemporary models of care, based on best evidence, to most effectively meet the needs of Western Australian adults.</li> <li>Following a review of the current paediatric models of care, identify and develop a contemporary model of care, based on best evidence, to most effectively meet the needs of children across the paediatric spectrum e.g. the development of an Optimal Paediatric Palliative Care Pathway.</li> <li>Collaborate with service providers, stakeholders and consumers to implement appropriate models.</li> </ul>	Department of Health / Health Service Providers / Private service providers
Education	Stakeholder
<ul style="list-style-type: none"> <li>Support roll-out of the Goals of Patient Care Clinical Document across health care services.</li> <li>Build on existing relationships with under-served population groups and organisations to develop culturally respectful and appropriate training and resources (including but not limited to Aboriginal people and organisations, culturally and linguistically diverse communities, condition specific groups and marginalised groups).</li> <li>Inform end-of-life and palliative care practice, including specialist palliative care practice, through collaborative work with health and consumer experts in the comprehensive care of marginalised people and groups.</li> <li>Raise awareness of Advance Care Planning (e.g. Advance Health Directives and substitute decision-makers).</li> </ul>	Department of Health / Health Service Providers / Private service providers

## Recommended actions (continued)

Education (continued)	Stakeholder
<ul style="list-style-type: none"> <li>Engage and work with residential aged care facilities to increase the awareness, preparation and use of Advance Care Plans with a focus on people with dementia.</li> </ul>	Commonwealth Department of Health / Department of Health / Private service providers
<ul style="list-style-type: none"> <li>Engage and work with residential aged care facilities to increase workforce capacity through training, education and mentoring.</li> </ul>	Department of Health / Private service providers
<ul style="list-style-type: none"> <li>Work with Aboriginal Health Worker training organisations to ensure that culturally appropriate palliative care education is included in course curricula.</li> </ul>	Commonwealth Department of Health / Department of Health
Funding	Stakeholder
<ul style="list-style-type: none"> <li>Identify funding sources and models, including alternative models, based on best evidence.</li> <li>Identify current quantum of State and Federal funding.</li> </ul>	Department of Health
Workforce	Stakeholder
<ul style="list-style-type: none"> <li>Build workforce capacity in end-of-life care in metropolitan Perth.</li> <li>Build workforce capacity in end-of-life care within rural and remote regions of WA.</li> <li>Provide support to the end-of-life and palliative care workforce, including opportunities for professional development and strategies to reduce attrition.</li> <li>Build workforce capacity in relation to the specific provision of end-of-life care for people from marginalised groups.</li> </ul>	Department of Health / Health Service Providers / Private service providers



## Recommended measures

What will we have that we don't have now?  
What will it look like?

Service models	Stakeholder
<ul style="list-style-type: none"> <li>• Evaluation of new service models or addendums to current models e.g. the use of TelePalliative care.</li> <li>• Development of formal care pathways for people with advancing, life-limiting illness.</li> </ul>	Department of Health / Health Service Providers / Private service providers
Data	Stakeholder
<ul style="list-style-type: none"> <li>• Documentation of 'current state' end-of-life and palliative care activity (purchased and actual).</li> <li>• Identification of risks and issues with current activity and funding.</li> <li>• Collection and analysis of data related to predictable (expected) and unpredictable (unexpected) deaths, e.g. the number and location of expected deaths, time from referral to death, identification of end-of-life care needs and appropriate referral to specialist palliative care.</li> <li>• Development and collection of measures for those people who die in hospital and locations other than their preferred place of death.</li> </ul>	Department of Health / Health Service Providers / Private service providers
<ul style="list-style-type: none"> <li>• Identification and analysis of gaps in current service provision between State and Federal funding.</li> </ul>	Department of Health
<ul style="list-style-type: none"> <li>• Delivery (number of) Goals of Patient Care Clinical Document training sessions by hospitals and health services.</li> </ul>	Department of Health / Health Service Providers / Private service providers
<ul style="list-style-type: none"> <li>• Analysis of WA Palliative Care Workforce (as part of National count).</li> </ul>	Department of Health / Commonwealth Department of Health
Referrals	Stakeholder
<ul style="list-style-type: none"> <li>• Increase in the number of referrals to Aboriginal Health Liaison Officers for patients who would benefit from palliative care.</li> </ul>	Department of Health / Health Service Providers / Private service providers
Governance	Stakeholder
<ul style="list-style-type: none"> <li>• Development, implementation and evaluation of WACHS Clinical and Program Governance Project.</li> </ul>	WACHS

# Priority Two

## Care is person-centred

*“Where and how you die ... [is] absolutely crucial ... [it] begins in the community”*



### Consumer experience

I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account when care is given.

### Building blocks to realise Priority Two

#### 1. People and their families/carers co-designing care with health teams, to include:

- a. culturally respectful and comprehensive care
- b. opportunities to talk about and plan for death, including Advance Care Planning.

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#### 2. Care is centred on people and their families/carers.

### Outcomes

- People and their families/carers will:
  - transition seamlessly through and between services across all settings
  - have the confidence to be actively involved in the decision-making related to their care, including the importance of Advance Care Planning
  - have sufficient information and be supported to make informed decisions
  - be able to identify their goals of care with the support of their treating team, including their General Practitioner.
- Multiple services will work together beyond organisational, clinical and disciplinary boundaries to support care in the person's preferred location, wherever possible.
- Communication and coordination with people and their families/carers, including primary care, will be improved.
- Clinical decision-making will be a collaborative process and people will be identified for timely care through innovative approaches to assessment.
- Access to patient information across and between services will be enhanced through safe, efficient and effective services, including the use of universal digital solutions, e.g. My Health Record.
- Health (including primary care), community and aged care providers will:
  - have the capacity and ability to anticipate and respond to the changing needs and preferences of people and their families/carers; across advancing disease, increasing decline, last days of life, and in death and bereavement
  - have the knowledge, confidence and skills to initiate open conversations about Advance Care Planning and document goals of care with people and their families/carers.
- Advance Care Planning resources, the Goals of Patient Care Clinical Document, the Paediatric Goals of Patient Care Clinical Document, the Care Plan for the Dying Person and Clinical Indicators to identify the deteriorating person, will be widely used across Western Australia.
- Optimal use of resources, including the uptake of Advance Care Planning, will potentially reduce unnecessary/unwanted hospital admissions.

## Recommended actions

Care coordination	Stakeholder
<ul style="list-style-type: none"> <li>• Engage community service providers and other stakeholders in a collaborative process to inform service planning and consumer/carer engagement.</li> <li>• Promote involvement of General Practitioners, other primary care services and specialist palliative care community providers in the coordinated care of the patient.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Education	Stakeholder
<ul style="list-style-type: none"> <li>• Provide health professional education in all settings, including but not limited to the following content:               <ul style="list-style-type: none"> <li>- death is not a failure</li> <li>- co-designing a person's care</li> <li>- facilitating Advance Care Planning</li> <li>- how to have difficult conversations</li> <li>- identifying when to refer to specialist palliative care</li> <li>- providing culturally-sensitive care</li> <li>- completing holistic assessment.</li> </ul> </li> </ul>	<p>Health Service Providers / Private service providers</p>
<ul style="list-style-type: none"> <li>• Provide a framework for shared decision-making tools such as the Goals of Patient Care Clinical Document, the Paediatric Goals of Patient Care Clinical Document and Advance Care Planning documentation across health services providers.</li> <li>• Utilise digital solutions to share decision-making tools across all care settings and services in real time.</li> <li>• Support and promote the implementation of end-of-life and palliative care policies and resources in all care settings, including:               <ul style="list-style-type: none"> <li>- Advance Care Planning</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document</li> <li>- Care Plan for the Dying Person</li> <li>- Clinical Indicators to identify people with deteriorating health.</li> </ul> </li> <li>• Support and promote Advance Care Planning sessions to consumers.</li> <li>• Provide education to the community on their involvement in care.</li> <li>• Assist the community to share their end-of-life care wishes using digital solutions.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>

## Recommended actions (continued)

<b>Patient records – adults</b>	<b>Stakeholder</b>
<ul style="list-style-type: none"> <li>• Embed Advance Care Planning Guidelines and establish a process to receive and store Advance Health Directives prominently on the medical record, including storing Advance Health Directives on a Register, once developed.</li> </ul>	Health Service Providers / Private service providers
<b>Patient records – paediatrics</b>	<b>Stakeholder</b>
<ul style="list-style-type: none"> <li>• Complete Paediatric Goals of Patient Care Clinical Document and store prominently on the medical record.</li> <li>• Receive and document all discussions with patients/families/carers and store prominently on the medical record.</li> </ul>	Health Service Providers / Private service providers
<b>Clinical assessment tools</b>	<b>Stakeholder</b>
<ul style="list-style-type: none"> <li>• Promote standard Clinical Indicators and assessment tools (e.g. the Supportive and Palliative Indicators Tool [SPiCT™]) to identify people with deteriorating health who would benefit from goals of patient care discussions/end-of-life interventions and access to specialist palliative care.</li> </ul>	Department of Health / Health Service Providers / Private service providers
<b>Funding</b>	<b>Stakeholder</b>
<ul style="list-style-type: none"> <li>• Explore options to re-design funding models to align with co-design of care, for example the use of:               <ul style="list-style-type: none"> <li>- Advance Care Planning</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document</li> <li>- Care Plan for the Dying Person.</li> </ul> </li> </ul>	Department of Health

## Recommended measures

What will we have that we don't have now?

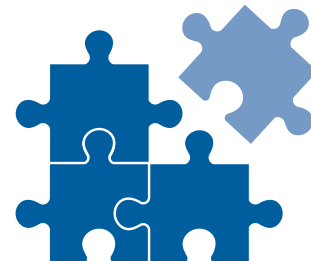
What will it look like?

Care coordination	Stakeholder
<ul style="list-style-type: none"> <li>Statewide implementation of:               <ul style="list-style-type: none"> <li>Goals of Patient Care Clinical Document</li> <li>Paediatric Goals of Patient Care Clinical Document</li> <li>Care Plan for the Dying Person.</li> </ul> </li> </ul>	Department of Health / Health Service Providers / Private service providers
Education	Stakeholder
<ul style="list-style-type: none"> <li>Availability of Advance Care Planning education and training.</li> </ul>	Department of Health / Health Service Providers / Private service providers
<ul style="list-style-type: none"> <li>Development of an evaluation framework for the roll-out of:               <ul style="list-style-type: none"> <li>the Goals of Patient Care Clinical Document</li> <li>the Paediatric Goals of Patient Care Clinical Document.</li> </ul> </li> </ul>	Health Service Providers / Private service providers
Data	Stakeholder
<ul style="list-style-type: none"> <li>Prevalence of Advance Care Planning documentation identified via Advance Care Planning Australia and Palliative Care Australia research.</li> </ul>	Department of Health / Health Service Providers / Commonwealth Department of Health
<ul style="list-style-type: none"> <li>Development and evaluation of:               <ul style="list-style-type: none"> <li>patient experience surveys</li> <li>carer experience surveys.</li> </ul> </li> </ul>	Health Service Providers / Private service providers

# Priority Three

## Care is coordinated

*"I want everyone involved in my end-of-life care to know precisely what I do want and do not want"*



### Consumer experience

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/ collaborative approach, enabling care to be delivered seamlessly.

### Building blocks to realise Priority Three

1. **Strengthened referral pathways between end-of-life and specialist palliative care teams.**
2. **Adequate resources to support health, community and aged care providers delivering end-of-life and palliative care.**

### Outcomes

- People will receive care in their place of choice, wherever possible.
- Quality of life for people and their family/carer will be improved through:
  - an inter-disciplinary approach to care
  - the smooth transition of care, across and between services, including the transition from paediatric to adult care
  - end-of-life care mentoring by specialist teams to support care delivery by general health care teams
  - improved communication and collaboration between health (including primary care), community and aged care providers and specialist palliative care teams
  - timely and appropriate referrals to specialist palliative care from treating teams.
- There will be:
  - increased recognition of the value of allied health professionals providing quality, comprehensive, specialist palliative care
  - an increase in the number of allied health professionals involved in providing palliative care.
- The use of innovative technology, including an increased uptake of digital solutions, will connect people and their families/carers to all teams providing their care.

## Recommended actions

Care coordination	Stakeholder
<ul style="list-style-type: none"> <li>Engage community, service providers and other stakeholders in a collaborative process to better inform service planning and care coordination.</li> <li>Promote involvement of General Practitioners in the planning of collaborative service provision, including collaboration with the WA Primary Health Alliance and the provision of comprehensive care via HealthPathways (Palliative Care).</li> <li>Promote involvement of other primary care services and specialist palliative care community providers in the patient journey.</li> <li>Improve communication via the use of digital platforms.</li> <li>Explore options, including funding, for a Care Navigator role to connect and support people and their families/carers with service providers, including paediatric patients and their families/carers.</li> <li>Advocate and support patient access to the Commonwealth Home Support Program service, in particular for &gt;65 year olds.</li> <li>Improve patient pathways and support for end-of-life care in the aged care sector.</li> <li>Scope requirements for information and communications technology systems to improve continuity of patient care, e.g. via digital platforms and TelePalliative care.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Service provision	Stakeholder
<ul style="list-style-type: none"> <li>Identify resource requirements for palliative care service provision in community settings and inpatient units to meet demand.</li> <li>Scope and fund model/s for specialist palliative care community provider referrals.</li> <li>Explore alternative models of service, including funding requirements.</li> <li>Promote psychosocial care through strengthened funding, governance and quality measures.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Education	Stakeholder
<ul style="list-style-type: none"> <li>Provide health professional education in all settings, including but not limited to the following content: <ul style="list-style-type: none"> <li>death is not a failure</li> <li>co-designing a person's care</li> <li>facilitating Advance Care Planning</li> <li>how to have difficult conversations</li> <li>identifying when to refer to specialist palliative care</li> <li>providing culturally-sensitive care</li> <li>completing holistic assessment.</li> </ul> </li> </ul>	<p>Health Service Providers / Private service providers</p>

## Recommended actions (continued)

Education	Stakeholder
<ul style="list-style-type: none"> <li>• Provide ongoing paediatric palliative care education to health professionals in rural, regional and remote areas (e.g. via the Quality of Care Collaborative Australia project).</li> </ul>	<p>Commonwealth Department of Health / Department of Health / Child and Adolescent Health Service (CAHS) / WACHS</p>
<ul style="list-style-type: none"> <li>• Provide ongoing support for General Practitioners and Nurse Practitioners in end-of-life and palliative care education, including facilitating networks with aged care service providers.</li> <li>• Provide ongoing end-of-life care education in the aged care sector.</li> <li>• Provide a framework for shared decision-making tools across health service providers and enable these to be shared in real time via digital platforms, e.g.               <ul style="list-style-type: none"> <li>- Advance Care Planning documentation</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document</li> <li>- Care Plan for the Dying Person.</li> </ul> </li> <li>• Support and promote the implementation of end-of-life and palliative care policies and resources in all care settings, including:               <ul style="list-style-type: none"> <li>- Advance Care Planning</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document</li> <li>- Care Plan for the Dying Person</li> <li>- Clinical Indicators to identify people with deteriorating health.</li> </ul> </li> <li>• Support and promote Advance Care Planning sessions to consumers.</li> <li>• Provide education to the community on their involvement in care (see Priority Four).</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Clinical assessment tools	Stakeholder
<ul style="list-style-type: none"> <li>• Promote standard clinical assessment tools (e.g. the Supportive and Palliative Indicators Tool [SPICT™]) to identify people with deteriorating health who would benefit from goals of patient care discussions/end-of-life interventions and access to specialist palliative care.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Referrals	Stakeholder
<ul style="list-style-type: none"> <li>• Improve access to centralised referral systems and mechanisms.</li> <li>• Improve timeliness and appropriateness of referrals from treating teams to specialist palliative care teams.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>



## Recommended actions (continued)

Funding	Stakeholder
<ul style="list-style-type: none"> <li>• Explore options to re-design funding models to align with co-design of care, for example the use of:               <ul style="list-style-type: none"> <li>- Advance Care Planning</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document</li> <li>- Care Plan for the Dying Person.</li> </ul> </li> </ul>	<p>Department of Health</p>
<ul style="list-style-type: none"> <li>• Explore funding options to provide paediatric palliative care education for health professionals in rural, regional and remote areas, in the event that Commonwealth funding of the Quality of Care Collaborative Australia project is discontinued.</li> </ul>	<p>Department of Health / CAHS</p>
Workforce	Stakeholder
<ul style="list-style-type: none"> <li>• Define and address gaps in the specialist palliative care workforce, including the paediatric palliative care workforce, social work services and other allied health professionals.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Governance	Stakeholder
<ul style="list-style-type: none"> <li>• Review and align networks and governance structures in end-of-life care and palliative care to promote statewide service integration and improvement.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>

## Recommended measures

What will we have that we don't have now?

What will it look like?

Care coordination	Stakeholder
<ul style="list-style-type: none"> <li>Improvement in the timeliness of commencement of palliative care, available from Palliative Care Outcomes Collaboration (PCOC) data.</li> <li>Improvement in self-reported palliative care outcome and experience measures, available from PCOC data.</li> <li>Development of quality pathways and processes to support partnerships between service providers.</li> </ul>	Department of Health / Health Service Providers / Private service providers
<ul style="list-style-type: none"> <li>Increase in access to billable items related to assistance with preparation of Advance Health Directives.</li> </ul>	Department of Health / Commonwealth Department of Health
Education	Stakeholder
<ul style="list-style-type: none"> <li>Development of a primary care and aged care education plan.</li> </ul>	Commonwealth Department of Health / Department of Health
<ul style="list-style-type: none"> <li>Increase in the number of health professionals participating in education and training, including monitoring of learning outcomes.</li> </ul>	Department of Health / Health Service Providers / Private service providers
Data	Stakeholder
<ul style="list-style-type: none"> <li>Analysis of National Palliative Care Workforce data.</li> </ul>	Department of Health
<ul style="list-style-type: none"> <li>Increase in the uptake of billable items with Medicare, Independent Hospital Pricing Authority and Activity Based Funding.</li> </ul>	Health Service Providers / Private service providers
Workforce	Stakeholder
<ul style="list-style-type: none"> <li>Increase in the specialist palliative care workforce, including allied health professionals.</li> <li>Identification of resource requirements for specialist palliative care community providers and inpatient units.</li> </ul>	Department of Health / Health Service Providers / Private service providers
Governance	Stakeholder
<ul style="list-style-type: none"> <li>Establishment/strengthening of regional palliative care governance committees in all WACHS regions.</li> </ul>	Department of Health / WACHS

# Priority Four

## Families and carers are supported



*“Family should be involved all along to ensure I haven’t missed anything or haven’t been able to make clear decisions due to heavy medication”*

### Consumer experience

Those close to me and/or caring for me are supported and involved in my care.

The contributions made by my family/carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

### Building blocks to realise Priority Four

1. Improved practical advice and support for families.
2. Improved awareness by health, community and aged care providers regarding family access to bereavement support.

### Outcomes

- Health (including primary care), community and aged care providers will:
  - inform, educate and support the family/carer
  - provide support to assist in addressing the financial burden for families who are caring for a person at end-of-life
  - have the skills and resources to identify family needs early in the referral process
  - have access to standardised, evidence-based carer assessment tools, including bereavement assessment
  - understand the potential for complicated family grief in bereavement, and the importance of timely identification of such
  - have access to referral systems for local, community and non-specialist palliative care organisations, if needed.
- Families will:
  - have equitable access to respite and support in setting of choice, wherever possible
  - be able to advocate for the enactment of their loved one’s preferences through Advance Care Planning
  - know how to advocate for access to specialist palliative care, if required
  - have access to innovative models to meet their needs
  - have access to timely and appropriate bereavement support.

## Recommended actions

Advice, support and resources for carers and families	Stakeholder
<ul style="list-style-type: none"> <li>• Involve consumers in identifying the needs of families/carers, to improve the quality and access to practical advice and support, including:               <ul style="list-style-type: none"> <li>- existing resources</li> <li>- culturally appropriate information</li> <li>- service information and coordination</li> <li>- gaps.</li> </ul> </li> <li>• Based on identified gaps, involve consumers in the development and/or redesign of websites to better meet the needs of families/carers, including access to practical information and advice (see Priority Six).</li> <li>• Promote resources that aim to explain the family/carer roles in end-of-life and palliative care.</li> <li>• Develop care pathways to facilitate access to psychosocial, respite and bereavement support for carers, including support from volunteers.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Clinical assessment tools	Stakeholder
<ul style="list-style-type: none"> <li>• Support the implementation of family/carer assessment tools to health professionals, including policy and governance, e.g.:               <ul style="list-style-type: none"> <li>- Carer Support Needs Assessment Tool</li> <li>- PCOC assessment tools (Problem Severity Score)</li> <li>- CarerHelp Toolkit, developed by Palliative Care Australia, to prepare unpaid carers to care for a partner, parent, child or friend at the end-of-life.</li> </ul> </li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>

## Recommended measures

What will we have that we don't have now?  
What will it look like?

Advice, support and resources for families/carers	Stakeholder
<ul style="list-style-type: none"> <li>• Increase in the co-design of resource materials by families/carers.</li> <li>• Increase in the number of families/carers accessing resources.</li> <li>• Development, testing and evaluation of psychosocial, respite and bereavement support mechanisms/tools (e.g. Optimal Care Pathways), in consultation with consumers.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Clinical assessment tools	Stakeholder
<ul style="list-style-type: none"> <li>• Increase in the use of family/carer assessment tools by health professionals.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>

# Priority Five

All staff are prepared to care



*“At first we were shocked by how quickly the referral was made to palliative care after treatment had failed, but with hindsight we saw all the benefits of early referral.”*

## Consumer experience

Wherever and whenever I am cared for, all staff involved in my care have expertise, empathy and compassion. All staff provide confident, sensitive and skillful care before, during and after my death.

## Building blocks to realise Priority Five

1. Improved health, community and aged care provider understanding of end-of-life, and appropriate referrals to specialist palliative care.
2. The generalist workforce supported and mentored to increase capacity, knowledge and skills.
3. Improved succession planning for an ageing workforce.
4. Workforce better equipped to support an ageing population.

## Outcomes

- Health (including primary care), community and aged care providers will be supported and mentored at point of care to increase their knowledge and skills and to build their capacity and capability to:
  - support patients and their family/carer
  - know when to refer to specialist palliative care.
- Palliative care services will be resourced to address identified gaps and challenges.
- The person's treating team will be well supported to provide integrated end-of-life and palliative care through established partnerships between primary, secondary, tertiary and specialist palliative care services.
- The specialist palliative care workforce will grow and be strengthened to meet demand and improve equity of access.
- Specialist palliative care teams will have ongoing access to education and training opportunities.

## Recommended actions

Care coordination	Stakeholder
<ul style="list-style-type: none"> <li>• Improve communication of patient information between services/health settings to assist coordination of care. Documents that may improve understanding include but are not limited to the following:               <ul style="list-style-type: none"> <li>- Discharge summary</li> <li>- Advance Care Planning</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document</li> <li>- Clinical Indicators to identify people with deteriorating health</li> <li>- Outpatient referral.</li> </ul> </li> <li>• Improve communication of patient information between services/health settings via the use of My Health Record.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Education	Stakeholder
<ul style="list-style-type: none"> <li>• Improve access to standardised quality education in all health care settings to support the implementation of:               <ul style="list-style-type: none"> <li>- Advance Care Planning</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document</li> <li>- Care Plan for the Dying Person</li> <li>- How to have difficult conversations.</li> </ul> </li> <li>• Appoint champions, including but not limited to, junior doctors, primary care, community, mental health and disability to:               <ul style="list-style-type: none"> <li>- promote the importance of end-of-life care and palliative care services</li> <li>- support quality end-of-life discussions</li> <li>- embed the use of Advance Care Planning, the Goals of Patient Care Clinical Document, the Paediatric Goals of Patient Care Clinical Document and the Care Plan for the Dying Person.</li> </ul> </li> <li>• Focus on improving consistency of care across the generalist workforce to increase capacity, knowledge and skills.</li> <li>• Promote WA Primary Health Alliance <a href="#">HealthPathways WA</a> (Palliative Care) to increase the primary care sector's knowledge of service models and referral pathways.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
<ul style="list-style-type: none"> <li>• Provide standardised, quality education on planning for the management of anticipated symptoms for people approaching terminal care, by prescribing and providing appropriate medications efficiently and safely.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
<ul style="list-style-type: none"> <li>• Embed end-of-life and palliative care content, including paediatric palliative care, in undergraduate and post graduate medical, nursing and allied health curricula.</li> </ul>	<p>Department of Health / Tertiary educators</p>

## Recommended actions (continued)

Data	Stakeholder
<ul style="list-style-type: none"> <li>Record uptake of Advance Health Directives by:               <ul style="list-style-type: none"> <li>- raising a clinical alert for Advance Health Directives</li> <li>- promoting the use of the Advance Health Directive Register, once developed</li> <li>- uploading to digital platforms, e.g. My Health Record.</li> </ul> </li> <li>Record uptake of Paediatric Goals of Patient Care Clinical Document by raising a clinical alert for this document, once an alert is available.</li> <li>Identify mechanisms to improve data collection for the Goals of Patient Care Clinical Document, the Paediatric Goals of Patient Care Clinical Document and the Care Plan for the Dying Person, pre and post implementation to:               <ul style="list-style-type: none"> <li>- measure efficacy of the tools</li> <li>- measure efficacy of health providers' use of the tools.</li> </ul> </li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Funding	Stakeholder
<ul style="list-style-type: none"> <li>Explore options to re-design funding models to support end-of-life activity (e.g. Advance Care Planning, the Goals of Patient Care Clinical Document, the Paediatric Goals of Patient Care Clinical Document and the Care Plan for the Dying Person).</li> <li>Identify opportunities to partner with the Commonwealth to resource an increase in the availability of end-of-life care education in residential aged care facilities.</li> </ul>	<p>Commonwealth Department of Health / Department of Health / Health Service Providers / Private service providers</p>
Workforce	Stakeholder
<ul style="list-style-type: none"> <li>Conduct an ongoing audit of the end-of-life and palliative care workforce to capture the 'current state' and identify future resourcing.</li> <li>Provide guidance on the future composition and strategic direction of the palliative care workforce, including succession planning for an ageing workforce.</li> </ul>	<p>Commonwealth Department of Health / Department of Health</p>

## Recommended measures

What will we have that we don't have now?  
What will it look like?

Care coordination	Stakeholder
<ul style="list-style-type: none"> <li>Implementation of the following in all health care settings:               <ul style="list-style-type: none"> <li>- Advance Care Planning resources</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document and</li> <li>- Care Plan for the Dying Person.</li> </ul> </li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>

Education	Stakeholder
<ul style="list-style-type: none"> <li>• Availability of standardised, quality clinical education for all staff about end-of-life and specialist palliative care.</li> <li>• Increase in the number of generalist health professionals trained in end-of-life care.</li> </ul>	Department of Health / Health Service Providers / Private service providers
<ul style="list-style-type: none"> <li>• Improvement in workforce capacity to deliver end-of-life care in residential, community, disability and mental health services.</li> </ul>	Department of Health / Private service providers
<ul style="list-style-type: none"> <li>• Identification of, and support for, end-of-life and palliative care champions in identified health settings.</li> </ul>	Health service providers / Private service providers
<ul style="list-style-type: none"> <li>• Inclusion of end-of-life and palliative care content, including paediatric palliative care, in medical, nursing and allied health undergraduate and post-graduate course curricula.</li> </ul>	Department of Health / Tertiary educators

Data	Stakeholder
<ul style="list-style-type: none"> <li>• Auditing of the Goals of Patient Care Clinical Document and the Paediatric Goals of Patient Care Clinical Document, within a quality improvement framework.</li> </ul>	Department of Health / Health Service Providers / Private service providers
<ul style="list-style-type: none"> <li>• Improvement in hospital coding for: <ul style="list-style-type: none"> <li>- Advance Care Planning</li> <li>- Goals of Patient Care Clinical Document</li> <li>- Paediatric Goals of Patient Care Clinical Document and</li> <li>- Care Plan for the Dying Person.</li> </ul> </li> </ul>	Department of Health / Health Service Providers / Private service providers
<ul style="list-style-type: none"> <li>• Increase in the number of Advance Health Directives uploaded to digital platforms.</li> </ul>	Department of Health / Health Service Providers / Private service providers / Consumers

Workforce	Stakeholder
<ul style="list-style-type: none"> <li>• Audit of the end-of-life and palliative care workforce.</li> <li>• Development of a palliative care workforce succession plan.</li> </ul>	Department of Health / Commonwealth Department of Health



# Priority Six

The community is aware and able to care



*“Before my son was in palliative care, it meant death and dying. After understanding it and seeing the first hand difference it made to my son’s life...we saw it as being about living and quality of life.”*

## Consumer experience

I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

## Building blocks to realise Priority Six

1. Increased awareness and uptake of Advance Care Planning.
2. Improved public understanding of end-of-life and palliative care.

## Outcomes

- The general public will have a better understanding of the value of Advance Care Planning, including how to:
  - have conversations about treatment and care preferences
  - access and complete relevant Advance Care Planning documentation, such as Advance Health Directives and Enduring Powers of Guardianship
  - share Advance Care Planning documentation with tertiary, primary, community and aged care providers including via the use of digital platforms, e.g. My Health Record
  - advocate for appropriate treatment and care.
- People and their family/carer will be able to:
  - clearly identify and document their goals of care with the support of health, community and aged care providers
  - identify and request care that is consistent with their goals of care.
- The wider community will have a better understanding of the benefits of timely end-of-life and palliative care, including:
  - normalising death and dying
  - the benefits of Advance Care Planning
  - what is end-of-life care?
  - what is palliative care?
  - common misconceptions
  - accessing palliative care
  - understanding what can be provided.

## Recommended actions

Education	Stakeholder
<ul style="list-style-type: none"> <li>• Develop an end-of-life and palliative care awareness and education campaign, targeting consumers and their families/carers, health professionals and the wider community, to:               <ul style="list-style-type: none"> <li>- provide a better understanding of palliative care and available services, including paediatric palliative care</li> <li>- outline the benefits of palliative care and how to access it</li> <li>- highlight the importance of Advance Care Planning to document future health care priorities and other preferences</li> <li>- normalise death and dying as a part of life, including increased awareness of the stages of advancing illness, increasing decline, last days of life, death and bereavement</li> <li>- dispel common misconceptions regarding end-of-life and palliative care.</li> </ul> </li> </ul>	<p>Department of Health</p>
<ul style="list-style-type: none"> <li>• Facilitate access for patients, families and carers to relevant community awareness and support projects such as 'compassionate communities' models.</li> <li>• Work with the Department of Health Communications team to develop end-of-life and palliative care content with consistent messaging and language.</li> <li>• Facilitate community awareness events (e.g. Palliative Care Week, National Advance Care Planning Week).</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Advance Care Planning	Stakeholder
<ul style="list-style-type: none"> <li>• Develop partnerships with agencies to increase awareness of Advance Care Planning, and improve information and access to Advance Care Planning documentation at point-of-care.</li> <li>• Identify population groups that would benefit from improved access to and uptake of Advance Care Planning discussions and documentation, and deliver targeted support.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>
Partnerships and consultation	Stakeholder
<ul style="list-style-type: none"> <li>• Develop partnerships with agencies to support end-of-life and palliative care across the community (e.g. developing and strengthening partnerships with community palliative care providers and supporting local activities such as Compassionate Communities).</li> <li>• Undertake consultation with the community, including carers, to understand community needs and priorities for end-of-life and palliative care.</li> </ul>	<p>Department of Health / Health Service Providers / Private service providers</p>

## Recommended measures

What will we have that we don't have now?  
What will it look like?

Education	Stakeholder
<ul style="list-style-type: none"> <li>Development of a suite of accessible and coordinated multi-media public health campaign products.</li> </ul>	Department of Health
<ul style="list-style-type: none"> <li>Improvement in public understanding of end-of-life and palliative care, utilising literature search findings (proxy data) as a baseline.</li> </ul>	Department of Health / Health Service Providers / Private service providers
<ul style="list-style-type: none"> <li>Identification of, and support for, end-of-life and palliative care champions in the community.</li> </ul>	Health Service Providers / Private service providers

Data	Stakeholder
<ul style="list-style-type: none"> <li>Prevalence of Advance Care Planning documentation, identified via Advance Care Planning and Palliative Care Australia studies.</li> </ul>	Department of Health
<ul style="list-style-type: none"> <li>Increase in the knowledge and awareness of factors influencing completion of Advance Care Planning documentation.</li> <li>Increase in recorded uptake of Advance Health Directives through:               <ul style="list-style-type: none"> <li>- raising a clinical alert for Advance Health Directives</li> <li>- promoting use of the Advance Health Directive Register, once developed.</li> </ul> </li> <li>Collection and reporting of patient and family/carer outcome and experience measures across all services providing care for people affected by life-limiting illness.</li> </ul>	Department of Health / Health Service Providers / Private service providers

# Acronyms

<b>CAHS</b>	Child and Adolescent Health Service
<b>WA DoH</b>	WA Department of Health
<b>HSP</b>	Health Service Provider
<b>IP</b>	Implementation Plan
<b>JSC</b>	Joint Select Committee on End of Life Choices
<b>LGBTIQ</b>	Lesbian, gay, bisexual, transgender/gender diverse, intersex and queer
<b>PCOC</b>	Palliative Care Outcomes Collaboration
<b>SPICT™</b>	Supportive and Palliative Care Indicators Tool
<b>Strategy</b>	WA End-of-Life and Palliative Care Strategy 2018–2028
<b>WACHS</b>	WA Country Health Service

# Appendices

## Appendix One

### End-of-life and palliative care snapshot references (Figure 3)

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## Appendix Two







### End-of-life and palliative care recommendations of the My Life, My Choice Report of the Joint Select Committee on End of Life Choices

No.	Recommendation
7	The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.
8	The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.
9	WA Health should conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community. The review should examine the benefits and risks of each model and the accessibility of each across the state as well as the admission criteria for hospice care.
10	WA Health should implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services with the aim of making those services available to more Western Australians.
11	To improve understanding of palliative care in Western Australia, WA Health should: <ul style="list-style-type: none"><li>• establish a consistent definition of palliative care to be adopted by all health professionals</li><li>• provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community</li><li>• encourage knowledge sharing by palliative care specialists with their generalist colleagues</li><li>• establish a palliative care information and community hotline.</li></ul>
12	The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.
13	The Minister for Health should ensure regional palliative care be adequately funded to meet demand.
14	Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Health should appoint an independent reviewer to audit: <ul style="list-style-type: none"><li>• the level of palliative care activity actually provided in Western Australia's hospitals and compare it against the level of recorded palliative care activity.</li><li>• the actual spend by WA Health on palliative care on a year by year and like for like basis, across all aspects of palliative care provision, including community service providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care.</li></ul>
15	WA Health should provide ongoing professional development for all health professionals – beyond undergraduate training – about the right of a patient to refuse medical treatment. WA Health should also specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.

No.	Recommendation
16	WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals regarding the absolute right of a competent patient to refuse food and water. Training should also include those working in aged care.
17	WA Health should provide ongoing professional development – beyond undergraduate training – for health professionals about the transition from curative to non curative end-of-life care and effective discussions with patients and families about futile treatments. WA Health should consider how it might effectively educate the community about end-of-life decision making, and implement appropriate health promotion in this area.
18	WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life. These guidelines should include an agreed name and definition of the treatment. As per any other medical treatment, the requirement for informed consent must be clear. The treatment must be specifically noted in the medical record as ‘terminal sedation’.

## Appendix Three

### Strategic alignment of the priorities to the end-of-life and palliative care recommendations of the *My Life, My Choice* Report of the Joint Select Committee on End of Life choices

Priority	Strategic alignment to the <i>My Life, My Choice</i> Report recommendations
 <b>Priority One:</b> Care is accessible to everyone, everywhere	7, 8, 9, 10, 12, 13, 14
 <b>Priority Two:</b> Care is person-centred	9, 11.1, 11.2, 11.3, 11.4, 15, 16, 17.1, 17.2, 18
 <b>Priority Three:</b> Care is coordinated	7, 8, 10, 11.1, 11.2, 11.3, 11.4, 12, 13, 14, 15, 16, 17, 18
 <b>Priority Four:</b> Families and carers are supported	9, 11.1, 11.2, 11.4, 17
 <b>Priority Five:</b> All staff are prepared to care	11.1, 11.2, 11.3, 11.4, 15, 16, 17, 18
 <b>Priority Five:</b> The community is aware and able to care	9, 11.1, 11.2, 11.4, 17

## Appendix Four

### Action plan template

Stakeholders are encouraged to use the Action plan template to prepare and implement an action plan for their health system or service that is aligned to the *WA End-of-Life and Palliative Care Strategy 2018–2028* and Implementation Plan One. Developing an action plan will assist stakeholders to address the Strategy's priorities, and work towards the performance measures and ten-year vision to improve the lives of all Western Australians through quality end-of-life and palliative care.

Stakeholders are encouraged to prioritise the building blocks most relevant to their area and identify the related actions, measures, timelines and areas of accountability.

**Please note examples are shown in italics.**

Priority One – Care is accessible to everyone, everywhere				
Building block	Action	Measure	By when	By whom
Improve equity of access	Please complete what action the area's health system will take to achieve this building block i.e. <i>Roll-out of the Goals of Patient Care Clinical Document in all areas of health service.</i>	<i># Goals of Patient Care Clinical Document training delivered, by ward/clinical area.</i>		

Priority Two – Care is person-centred				
Building block	Action	Measure	By when	By whom
People and their families/ carers co-designing care with health teams, to include: <ul style="list-style-type: none"> <li>• culturally respectful and comprehensive care</li> <li>• opportunities to talk about and plan for death, including Advance Care Planning.</li> </ul>	Please complete what action the area's health system will take to achieve this building block i.e. <i>Provide information about Advance Care Planning/ Advance Health Directives to people and their families/ carers.</i>	<i># of Advance Care Planning/Advance Health Directive resources distributed.</i>		

Priority Three – Care is coordinated				
Building block	Action	Measure	By when	By whom
Strengthening referral pathways between end-of-life and specialist palliative care teams.	Please complete what action the area's health system will take to achieve this building block i.e. <i>Provide training to health professionals re timely and appropriate referrals to specialist palliative care.</i>	<i># of health professionals attending training.</i>		



### Priority Three – Care is coordinated (continued)

Building block	Action	Measure	By when	By whom
Adequate resources to support health, community and aged care providers delivering end-of-life and palliative care.	Please complete what action the area's health system will take to achieve this building block i.e. <i>Establish a Regional Governance Committee.</i>	<i>Regional Governance Committee established.</i>		

### Priority Four – Families and carers are supported

Building block	Action	Measure	By when	By whom
Improved practical advice and support for families.	Please complete what action the area's health system will take to achieve this building block i.e. <i>Support the implementation of the Carer Support Needs Assessment Tool across the health service.</i>	<i># number of wards/clinical areas where Carer Support Needs Assessment Tool has been implemented.</i>		

### Priority Five – All staff are prepared to care

Building block	Action	Measure	By when	By whom
Improved health, community and aged care provider understanding of end-of-life care, and appropriate referrals to specialist palliative care.	Please complete what action the area's health system will take to achieve this building block i.e. <i>Appoint champions to promote the importance of end-of-life and palliative care services, and to support end-of-life discussions.</i>	<i># number of champions appointed in health service.</i>		

### Priority Six – The community is aware and able to care

Building block	Action	Measure	By when	By whom
Improved public understanding of end-of-life and palliative care.	Please complete what action the area's health system will take to achieve this building block i.e. <i>Promotional display in foyer/reception during Palliative Care Week.</i>	<i># of resources/materials distributed.</i>		

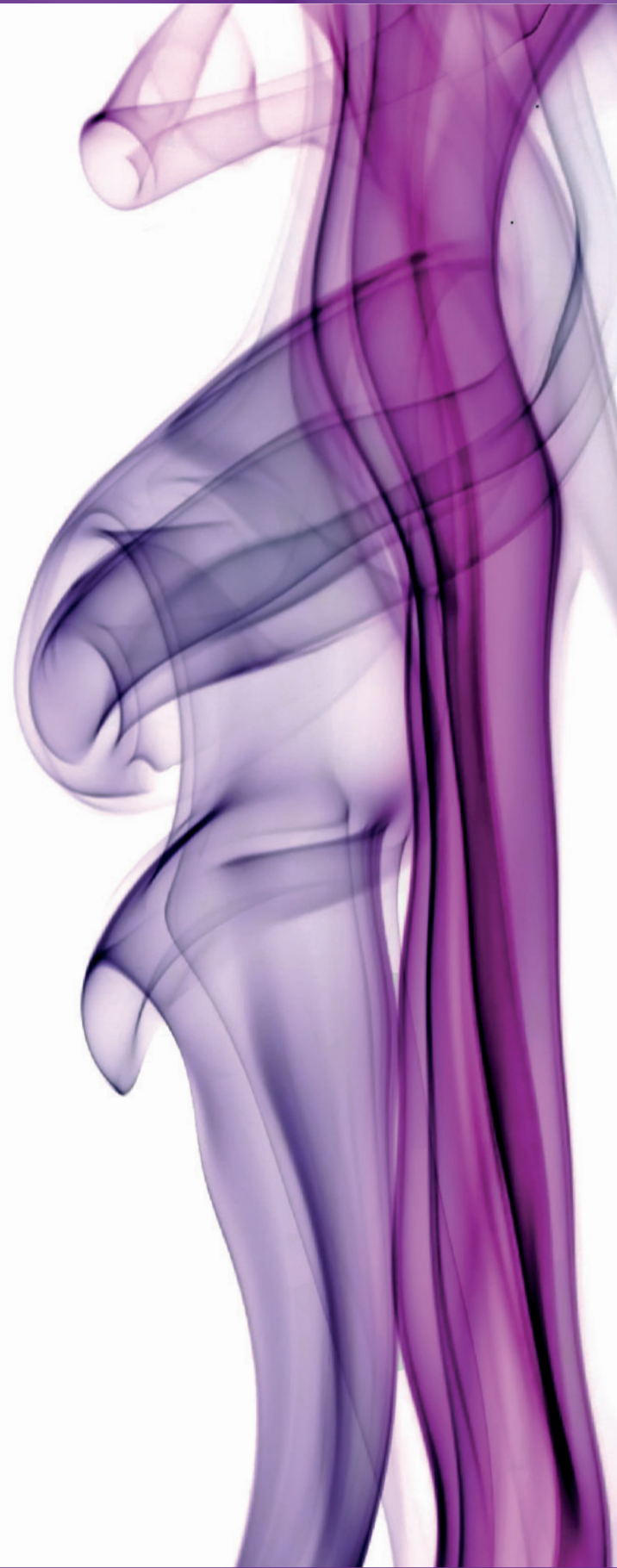
## Appendix Five

### Key IP1 action areas to address priorities within the Strategy

Key action areas	Alignment to Strategy priorities					
	1	2	3	4	5	6
Care coordination	•	•	•		•	
Service provision	•		•			
Service models	•					
Education	•	•	•		•	•
Patient records – adults		•				
Patient records – paediatrics		•				
Advice, support and resources for families/carers				•		
Clinical assessment tools		•	•	•		
Data					•	
Referrals			•			
Funding	•	•	•		•	
Workforce	•		•		•	
Advance Care Planning						•
Partnerships and consultation						•
Governance			•			

### Key IP1 measures to realise the priorities within the Strategy

Key measures	Alignment to Strategy priorities					
	1	2	3	4	5	6
Care coordination		•	•		•	
Service models	•					
Education		•	•		•	•
Advice, support and resources for families/carers				•		
Clinical assessment tools				•		
Data	•	•	•		•	•
Referrals	•					
Workforce			•		•	
Governance	•		•			



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