



# Tailored model of palliative care for people with intellectual disability

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# Acknowledgement of Country

We acknowledge the Traditional Custodians of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present.

We pay our respects to all First Nations people with intellectual disability and acknowledge the higher prevalence of intellectual disability among First Nations peoples and the distinct challenges they face, along with the contributions they make to society.

The model of care and its supporting toolkits were developed on the unceded territory of the Bedegal peoples who are the Traditional Custodians of the lands where the UNSW Sydney Kensington campus is situated.



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# Introduction

The model of care outlined in this document provides a framework for the delivery of tailored, quality palliative care for people with intellectual disability in Australia. The model of care and two supporting toolkits were developed using collective findings from a research project led by the Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney, in consultation with a Project Advisory Group comprising of people with intellectual disability, supporters of people with intellectual disability, and representatives from health, disability and advocacy services. Visit the [project website](#) to find out more about the project and its findings.

All health professionals who support people with life-limiting conditions have an important role in the provision of quality palliative care<sup>[1]</sup>, including for people with intellectual disability. A recent survey of health professionals involved in providing palliative care to people with intellectual disability in New South Wales (NSW)<sup>1</sup> found that 63% of respondents believed that their service is not equipped to meet the needs of people with intellectual disability. In the same survey, the majority of health professionals reported feeling less confident in their ability to provide care to people with intellectual disability compared to people without intellectual disability. This included being less confident in their ability to: recognise the need for palliative care, assess the person's needs, communicate with the person about their end-of-life care, effectively manage symptoms, support the person to be involved in advance care planning and end-of-life decision making, and educate the person about their condition, death and dying.

There are gaps in palliative care for people with intellectual disability; it is imperative that all healthcare professionals act to ensure that quality palliative care is available to every person who needs it.

The tailored model of palliative care outlined in this document offers flexible guidance that can be applied within different services and settings to support an inclusive approach to palliative care that meets the needs of people with intellectual disability. The model has two key components:

1. Building the capacity and capabilities of generalist services to meet the palliative care needs of people with intellectual disability.
2. The development of highly specialised palliative care services for people with intellectual disability.

The model is adaptable to the needs of specific health services. It acknowledges that services across different districts and networks will vary in their current capacity to meet the needs of people with intellectual disability; some districts and networks have well-developed specialist palliative care and/or specialist intellectual disability health services, while others may be looking for opportunities to enhance service delivery in these areas.

The supporting [National Toolkit for health professionals](#) offers detailed strategies to facilitate implementation of the model within both generalist and specialist palliative care services. Strategies in the Toolkit are categorised according to level of specialisation, from fundamental (i.e., everyone's business, Level 1) to specialist palliative care (Level 2) to highly specialised palliative care for people with intellectual disability (Level 3). Findings from consultations around the development of highly specialised palliative care services for people with intellectual disability are provided on the [project website](#). These findings, alongside strategies and resources provided in the [National Toolkit for health professionals](#), offer practical guidance for service development in this area.

<sup>1</sup> The survey was completed as a component of 3DN's research project on Improving palliative care services for people with intellectual disability. Find out more about this study on the [project website](#).



# Summary of the model



## Key audience

This model of care provides guidance to health professionals and health service managers involved in the provision of palliative care to people with intellectual disability in Australia. The model is presented as a framework that can be adapted for use across different service settings, depending on population needs, service resources and personnel capacity.



## Guiding principles and strategies

The model consists of seven guiding principles with associated strategies to support providers to achieve them.



## Target population ('service users')

People with intellectual disability of all ages with life-limiting condition/s, and their supporters.



## Workforce

Delivery of the model requires a skilled and knowledgeable multidisciplinary workforce across different teams and settings that are equipped to meet the palliative care needs of people with intellectual disability.



## Settings

A multi-pronged approach incorporating integration into existing mainstream palliative care services, and where appropriate, the development of a highly specialised palliative care service for people with intellectual disability with more complex health needs.



## Evaluation

Recommendations to evaluate outcomes of the model include measures of service response to needs, as well as patient-, supporter-, and clinician-reported outcome measures. Recommendations for improvement in national data collection are outlined, including the development of disability identifiers and mechanisms for information sharing between services.

# Model and toolkit application considerations

## Age group application

The model and toolkits have been designed for implementation across paediatric and adult services for people with intellectual disability, acknowledging that there are differences in population characteristics and service delivery across these settings <sup>[2]</sup>.

## Geographic application

The model of care and toolkits were developed in NSW, Australia, but have been designed for implementation nationally.

## Service type application

This research is focused on palliative care. The terms 'palliative care' and 'end-of-life care' are primarily used in all outputs based on the definitions on page 22. Supportive care services may still find the information relevant and applicable.

## Identification of palliative care needs for people with intellectual disability

This model is focused on the improvement of palliative care services, which relies on the need for improvements in the identification of palliative care needs of people with intellectual disability. The [Improving palliative care for people with intellectual disability – National Toolkit for health professionals](#) includes links to resources to support identification of the need for palliative care among people with intellectual disability. Additionally, many people with intellectual disability experience barriers to diagnosis of life-limiting conditions which result in delayed access to palliative care and poorer outcomes <sup>[3-5]</sup>. An [ongoing research project at 3DN, UNSW Sydney](#), <sup>[6]</sup> will soon produce findings on ways to improve access to preventative healthcare (including cancer screening) for people with intellectual disability.

## Navigating intersections between health, disability and aged care services

The intersections between health, disability and aged care services are complex and often result in gaps in palliative care service delivery for people with intellectual disability. Known issues include poor coordination and integration of supports and services across sectors, including the interface between palliative care and the National Disability Insurance Scheme (NDIS), and gaps in care for people with disability aged under 65 years <sup>[7-9]</sup>. This model and its associated toolkits provide strategies and resources to assist services to navigate current issues impacting care quality, and propose strategies to promote system-wide change.





# Part 1

## The context

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## Part 1

# The context

### Background

- In Australia, about 1% of the population have a level of intellectual disability which requires the provision of specific supports <sup>[10]</sup>.
- People with intellectual disability are more likely to die prematurely than people without intellectual disability <sup>[11]</sup>.
- While the life expectancy of people with intellectual disability in Australia has improved over time <sup>[12]</sup>, people with intellectual disability are more likely to experience life-limiting conditions as they age with leading underlying causes of death being respiratory diseases, circulatory diseases, cancer and neurological conditions <sup>[11]</sup>.
- People with intellectual disability are recognised in the Australian National Palliative Care Standards <sup>[13]</sup> as a priority population group requiring improvements in care, yet there is currently a lack of guidance for health professionals on how to meet their needs.

### Barriers to meeting palliative care needs of people with intellectual disability

- International research <sup>[14]</sup> has highlighted significant barriers to meeting the palliative care needs of people with intellectual disability including:
  - > Lack of education and training for health professionals about the palliative care needs of people with intellectual disability.
  - > Lack of experience and knowledge of palliative and end-of-life care among professionals within the disability sector.
  - > Communication difficulties between health professionals and people with intellectual disability.
  - > Lack of collaboration within and between health and disability sectors, including engagement and support for supporters of people with intellectual disability, and limited sharing of information.
  - > Factors impacting service delivery, such as staffing levels and funding of health and disability services.
- Research conducted in NSW, Australia<sup>2</sup> has also highlighted that
  - > Gaps within the intersections between health, disability and aged care sectors impact the capacity to provide quality palliative care to people with intellectual disability. This includes a lack of mechanisms to facilitate sharing of information within and between services, access barriers related to service eligibility criteria, and lack of integration between services resulting in gaps in service provision.
  - > People with intellectual disability living in supported accommodation experience inequity of access to community-based palliative care, including barriers to receiving care and dying at home. This includes limited access to community nursing services to administer medicines that cannot not be administered by disability support workers but could otherwise be administered by trained family members in a family home, as well as a need to work collaboratively with supported accommodation providers to facilitate sensitive management of coronial reviews.

2 Findings from components of 3DN's research project Improving palliative care services for people with intellectual disability. Find out more about this study on the [project website here](#).



## Purpose

This model of care and [supporting Toolkit](#) were developed to guide health professionals and service providers in enhancing palliative care service delivery for people with intellectual disability, thereby ensuring equitable access to care. This approach aligns with the [United Nations Convention on the Rights of Persons with Disabilities](#) <sup>[15]</sup> and the [National Roadmap for Improving the Health of People with Intellectual Disability](#) <sup>[16]</sup>.

The model and Toolkit offer guidance and practical resources to support the improvement of the quality of palliative care services for people with intellectual disability by:

- Enhancing expertise in the workforce (capacity and capability) involved in palliative care for people with intellectual disability
- Providing approaches to improve equity of access to quality palliative care for people with intellectual disability.

Additionally, there is a [Toolkit for people with intellectual disability and their supporters](#) with resources to help facilitate the tailoring of palliative care for people with intellectual disability.



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Garden on a Rainy Day 2024





## Part 2

# Guiding principles

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## Part 2

# Guiding principles

The Tailored model of palliative care for people with intellectual disability is based on seven guiding principles. These guiding principles complement existing palliative and end-of-life care guidelines for the general population, including the National Palliative Care Strategy<sup>[17]</sup>. Refer to Appendix 1 for the mapped principles. The emphasis on the protection of human rights, access, and supported decision making align with recommendations arising from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability<sup>[18]</sup>.

Diagram 1: Guiding principles underpinning the Tailored model of palliative care for people with intellectual disability<sup>3</sup>.



Human rights are protected, respected and upheld as per the United Nations Convention on the Rights of Persons with Disabilities



Family, carers and supporters are recognised and valued as partners in providing palliative care, when desired by the person with intellectual disability, and are supported to enact their roles



Palliative care is person-centred and holistic



Access to quality care is equitable



Dying, death and grief are recognised as part of life



Care is well-coordinated and integrated



Care is high quality and evidence-based

For guidance on how to implement the guiding principles, see **Part 3**.

<sup>3</sup> The Guiding principles were determined through an international Delphi study as part of 3DN's research project Improving palliative care services for people with intellectual disability. Find out more about this study on the [project website here](#).





# Part 3

# Model components

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## Part 3

# Model components

### 1. Target population: Who are the intended service users?

People with intellectual disability of all ages, with any diagnosis of a life-limiting condition and their supporters.

### 2. Model settings: In what settings should the model be implemented?

This document proposes a multi-pronged approach for setting implementation, involving the equipping of existing services (generalist and specialist palliative care) and the development of a more highly specialised service:

- a) Tailored care for people with intellectual disability should be integrated within all existing health services and settings in which palliative care is provided for the general population (e.g., primary care, community- and hospital-based support) to promote inclusion. This will require services to develop and implement strategies to enhance the feasibility and acceptability of a universal design approach.
- b) As a complement to existing services, the development of a hub-and-spoke specialised palliative care service for people with intellectual disability with more complex needs. Strategies for service design are provided in the [Toolkit for health professionals](#).

### 3. Approaches to working: How should different services work together?

The model emphasises the need for:

- Communication and coordination between palliative care and other general and specialist health services, according to the needs of the person with intellectual disability.
- Cross-sector collaboration and engagement of the person's chosen supporters.

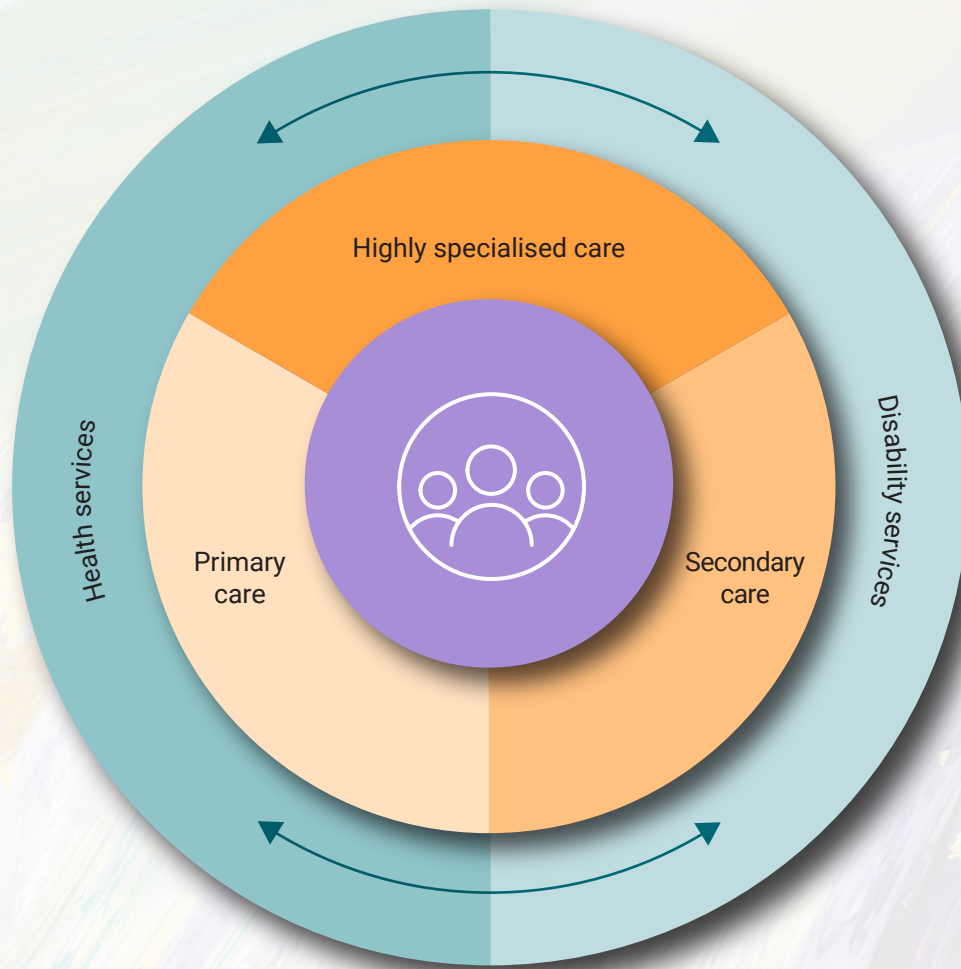
An integrated approach to care encourages collaboration within and between health and social care systems, enabling individuals to access comprehensive, multi-agency care and supports effective transitions between care settings as needed <sup>[19]</sup>.

The strategies outlined in the [Toolkit](#) provide detailed guidance on how to implement these approaches.




# Part 3 - Model components

Diagram 2: Model of care settings and approaches to working



## Key for palliative care settings

 Person with intellectual disability and their supporters

Access to care based on increasing complexity of needs

**Highly specialised palliative care** is recommended as an additional service for people with intellectual disability with complex needs that cannot be met by primary and secondary care services. Scoping work is required to determine the roles and operational requirements of such a service.

**Secondary care** is provided by specialist services generally referred from primary care <sup>[21]</sup>. This might include specialist palliative care teams. Care might be provided by different specialists at once in secondary care. This might be community-based, consultative or hospital based.

**Primary care** is generally the first health service people go to for support and is typically provided in the community <sup>[20]</sup>. Primary care might include palliative care and other health services provided in general practices, allied health services and community health centres.



## Part 3 - Model components

### 4. Model implementation: How can providers achieve the guiding principles of the model of care?

Implementation of the model is supported by a range of strategies and resources presented in the [National Toolkit for Health Professionals](#). The strategies were developed to support achievement of the model's guiding principles<sup>4</sup>. Some strategies are designed for immediate use in clinical practice or at specific points in a patient's palliative care pathway, while others aim for long-term system-level improvements. The strategies have been designed to be flexible so that they can be implemented across different settings and circumstances.

Strategies in the [National Toolkit for Health Professionals](#) are structured by the level of their intended application (i.e., clinical or operational) and by recommended actions.

### The eight themes of action are

#### Part A: Clinical strategies

1. Getting to know the person and supported decision making
2. Delivery of care
3. Preparing for death and bereavement

#### Part B: Organisational strategies

4. Workforce equipping and continuing professional development
5. Collaboration within and across sectors
6. Service design
7. Service planning, quality and improvement activities
8. Advocacy

The recommended actions are aligned with existing guidelines for palliative and end-of-life care for the general population in Australia<sup>[17, 22]</sup> and European consensus norms for the delivery of palliative care for people with intellectual disability<sup>[23]</sup>.

<sup>4</sup> The strategies to achieve the guiding principles of the model of care were determined through an international Delphi study conducted as part of 3DN's research project. Find out more about this study on the [project website here](#).



## Part 3 - Model components

### 5. Workforce: Who should be involved in delivering the integrated model?

Implementation of the integrated model requires access to a multidisciplinary team that involves a diverse range of professionals across different settings. Each member of the multidisciplinary team contributes unique expertise to address the needs of the person with intellectual disability, alongside their supporters. A multidisciplinary approach is essential to address the varied aspects of the person's care.

Table 1: Personnel recommended to be involved in the implementation of the Tailored model of palliative care for people with intellectual disability, as indicated by the needs of the individual<sup>5</sup>.

<b>General practitioner</b>	<b>Psychologist</b>	<b>Occupational therapist</b>
<b>Specialist palliative care physician</b>	<b>Counsellor</b>	<b>Pharmacist</b>
<b>Specialist palliative care nurse</b>	<b>Social worker</b>	<b>Dietician</b>
<b>Registered Nurse</b>	<b>Physiotherapist</b>	
<b>Spiritual care practitioner</b> who is knowledgeable of the individual's spiritual needs, if requested		
<b>Speech therapist</b> for specific needs such as swallowing assessment		
<b>Recreational or diversional therapist</b> to support participation in chosen leisure and recreational activities		
<b>Specialist intellectual disability health teams</b> , including a nurse specialising in intellectual disability		
<b>Service liaison/navigator</b> , if needed, to ensure smooth transition of care (continuity of care) between care settings where these are necessary		
<b>Dentist</b> , as required to address oral problems		
<b>Any other specialist, allied health, or complementary therapist</b> (e.g., art, music, or animal-assisted therapy) as needed		
<b>Trained peer supports</b> (paid and unpaid), where identified and available, to work with people with intellectual disability, family, carers and supporters through periods of dying, death and grief		
<b>Administrative support</b> , acknowledging their role as key contact for services.		

<sup>5</sup> The personnel recommended to be involved in the delivery of a palliative care model, acknowledging that involvement would be dependent on an individual's needs, were determined through an international Delphi study as part of 3DN's research project. Find out more about this study on the [project website here](#).



## Part 3 - Model components

### 6. Evaluation and measurement – How should the integrated model be measured?

The indicators can be used to measure the outcomes of service delivery by providers. Indicators could be utilised by generalist or specialist palliative care providers, and other medical specialists providing palliative care. Some indicators align with those of the [Palliative Care Outcomes Collaboration](#) <sup>[24]</sup> (refer to Appendix 2 for more details).

A 'suitable proxy' should know the person well and should have a good understanding of the different aspects of the person's life, for example a family member or disability support worker <sup>[25]</sup>.

Table 2: Indicators to measure and demonstrate outcomes of the palliative care model<sup>6</sup>.

#### *Measures of service response to needs*

Timeliness of access for patient to palliative care, measured by time from the date that a person is ready to receive palliative care (i.e., the need for palliative care is identified and the person is available to receive care), to the date of actual receipt of palliative care.

Patient time in unstable phase reflected by urgent changes in plan of care or emergency treatment due to i) the person experiencing a problem not anticipated by existing care plan, ii) a rapid increase in severity of an existing problem, or iii) a change in family/carer circumstances impacting the person's care.

#### *Patient (or suitable proxy) reported measures*

Within phase change in patient (or suitable proxy) reported outcome measures for pain.

Within phase change in patient (or suitable proxy) reported outcome measures for distress caused by breathing problems.

Within phase change in patient (or suitable proxy) reported outcome measures for fatigue.

Patient (or suitable proxy) reported outcome measures for psychological wellbeing and quality of life.

Patient (or suitable proxy) measures of sleep quality and duration.

Patient (or suitable proxy) reported measures of appetite and appetite-related distress.

Patient (or suitable proxy) reported experience measures for accessibility and acceptability, e.g., wait time, setting suitability, access to supports including interpreters if needed.

Patient (or suitable proxy) reported overall experience measures for patient-clinician interactions.

Patient (or suitable proxy) experiences of timely screening, detection and management of symptoms and co-occurring health conditions.

Patient (or suitable proxy) reported outcome measures about whether preferences and choices about care were met.

Patient (or suitable proxy) reported measures of quality of palliative care service overall.

<sup>6</sup> Indicators to measure and demonstrate outcomes of the palliative care model were determined through an international Delphi study as part of 3DN's research project. Find out more about this study on the [project website](#).



## Part 3 - Model components

### *Supporter reported measures*

Family, carer and supporter reported measures of quality of service overall, including provision of psychological support and after death bereavement support.

Patient and family/carer awareness of available palliative care services.

Family, carer and supporter reported outcome measures of their psychological wellbeing.

Clinician reported measures.

Clinician reported experience measures of delivering care model.

Clinician and service manager perceptions of sustainability of care model delivery, including requirements for sustainability.

Clinician perceptions of care model scalability and suitability for broader implementation, including requirements for scalability.

Knowledge of the role of palliative care and pathways to palliative care for people with intellectual disability among all key stakeholders.







## Part 4

# Recommendations for national data collection

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## Part 4

# Recommendations for national data collection

A priority goal of the National Palliative Care Strategy<sup>[17]</sup> includes robust data collection, monitoring and reporting. Yet there is currently no mechanism to identify people with intellectual disability in published national reports. Recommendations for improving national data collection related to palliative care service delivery for people with intellectual disability are outlined below<sup>7</sup>.

### Recommendation 1: Creation of state/territory-wide identifiers for people with intellectual disability accessing health services

Limited sharing of information within and across health teams is an identified barrier to accessing palliative care for people with intellectual disability<sup>[14]</sup>. Limited sharing of information can be addressed through the creation of state/territory-wide mechanisms to improve the capacity for identification of people with disability, including intellectual disability, across health systems. An example of an opportunity to include specific digital identifiers by disability type is afforded by advances in digital health record management at a jurisdictional level. For example, one such opportunity is the Single Digital Patient Record<sup>[26]</sup> which is scheduled for roll-out across the NSW health system by 2029/30. The Single Digital Patient Record will facilitate access of real-time patient information from a single source, across all settings within the NSW health system (e.g., ambulance, emergency, inpatient, outpatient, pathology, community health, public health and mental health).

It is recommended that state/territory-wide systems include i) a voluntary identifier of disability by type and ii) capacity for upload documentation about reasonable adjustments in health care for people who indicate the need. The development and implementation of mechanisms to support real-time access to patient information from a single source would address current inefficiencies in care provision related to data duplication, delays due to information requests, and would facilitate delivery of integrated and well-coordinated care. This approach offers a potential disability identifier for use in linkage studies using these administrative data. Other states and territories could follow a similar approach, which is best achieved when digital record systems are due for revision or redevelopment.

<sup>7</sup> Recommendations were determined through 3DN's research project. Find out more about this study on the [project website](#).



## Part 4 - Recommendations

### Recommendation 2: Identification of people with intellectual disability within local health districts and networks

In the absence of a state/territory-wide approach, it is recommended that local health districts and networks implement their own indicators of disability type within health record systems to enable identification of people with intellectual disability. The mechanism for identification should be developed in consultation with people with intellectual disability and their supporters. Local collection of an indicator for intellectual disability would enable services to better understand access to and outcomes of palliative care service delivery to people intellectual disability living within their service districts.

### Recommendation 3: Enhancement of the Australian Palliative Care Outcomes Collaboration (PCOC) program <sup>[24]</sup>

Enhancement of the national PCOC longitudinal database would build the capacity of this program to provide insights related to palliative care access, use and outcomes for people with intellectual disability as a priority population. Specific recommendations include:

- Inclusion of disability data indicators; inclusion of an indicator for intellectual disability in PCOC data collection would facilitate routine reporting, benchmarking and research into palliative care for people with intellectual disability, including the impact of palliative care service delivery on people with intellectual disability and their supporters.
- Planning to enable linkage between the PCOC and forthcoming data assets, including the National Disability Data Asset <sup>[27]</sup>. The National Disability Data Asset is a new data linkage infrastructure which aims to produce insights on outcomes for people with disability in Australia. It is recommended that the PCOC approach the Australian Institute of Health and Welfare and Australian Bureau of Statistics to determine the potential for linkage between the PCOC and National Disability Data Asset.
- Development of a sound understanding of disability indicators by disability type which can be ascertained using administrative data; it is recommended that leaders of the PCOC program keep abreast of developments in this area, e.g., through ongoing consultation with the bodies involved in the National Disability Data Asset.

# Definitions of key terms

<i>Term</i>	<i>Definition</i>
<b>End-of-life care</b>	The care and services given to people and their families as they are reaching the end of their life. End-of-life care is an important part of palliative care <sup>[28]</sup> .
<b>Generalist palliative care</b>	A type of care for people living with a life-limiting health condition provided by health professionals with general knowledge and minimum core competencies in palliative care <sup>[1]</sup> .
<b>Holistic care</b>	Complete or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the person, their response to illness and the effect of the illness on the ability to meet self-care needs <sup>[29]</sup> .
<b>Hub and spoke</b>	A model that is arranged by a network consisting of a central establishment (hub) with full services and secondary establishments in a network (spokes) with a more limited-service offering <sup>[30]</sup> .
<b>Integrated care</b>	The provision of seamless, effective, and efficient care that reflects the whole of a person's health needs from prevention through to end of life, across both physical, psychosocial, and mental health and in partnership with the individual, carers, and family members <sup>[31]</sup> .
<b>Intellectual disability (may also be referred to as learning disability)</b>	A developmental condition affecting a person's cognitive skills (e.g., learning, memory and problem solving) and adaptive behaviour skills (e.g., communication and social skills).
<b>Life-limiting condition</b>	An illness that cannot be cured that the person will likely die from. Life-limiting illnesses can include cancer, motor neurone disease, end-stage kidney disease and dementia <sup>[28]</sup> .



<i>Term</i>	<i>Definition</i>
<b>Multidisciplinary team</b>	A team made up of at least one patient and multiple health professionals from different disciplines working together to address multiple aspects of a person's care <sup>[32]</sup> .
<b>Palliative care</b>	An approach that improves the quality of life of individuals and their families who are facing problems associated with a life-limiting condition. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual <sup>[33]</sup> .
<b>Peer support</b>	Emotional, social, and practical assistance provided by non-professionals to encourage behaviours such as healthy diets or medication adherence <sup>[34]</sup> .
<b>Person-centred care</b>	Care that respects and responds to the needs, values and preferences of a patient <sup>[35]</sup> .
<b>Specialist palliative care</b>	A type of care for people living with a life limiting illness provided by health professionals with specialised skills and training in palliative care. The person living with a life-limiting condition may have more complex needs that are not be met by generalist palliative care <sup>[1]</sup> .
<b>Supporter (may also be referred to as carer, support person, or support network)</b>	Any key person providing support to the person with intellectual disability. This may include existing supports and newly engaged supports, including paid and unpaid disability support, guardians, friends, family, independent advocates and professional mediators.
<b>Supportive care</b>	Multi-disciplinary, holistic and person-centred care of people with chronic or serious health conditions and their supporters, to improve quality of life. Supportive care is available throughout the course of a person's condition alongside diagnosis and treatment <sup>[36]</sup> .

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# Appendix 1

## Mapping of model guiding principles to the National Palliative Care Strategy <sup>[17]</sup> guiding principles

<i>Guiding principles for the Tailored model of palliative care for people with intellectual disability</i>	<i>Guiding principles for the National Palliative Care Strategy</i>
Human rights are protected, respected and upheld, as per the United Nations Convention on the Rights of Persons with Disabilities.	-
Palliative care is person-centred and holistic.	Palliative care is person-centred care.
Dying, death and grief are recognised as part of life.	Death is a part of life.
Family, carers and supporters are recognised and valued as partners in providing palliative care, when desired by the person with intellectual disability, and are supported to enact their roles.	Carers are valued and receive the care they need.
Access to quality care is equitable.	Care is accessible.
Care is well-coordinated and integrated.	Everyone has a role to play in palliative care.
Care is high quality and evidence-based.	Care is high quality and evidence-based.



# Appendix 2

## Model evaluation measures that align with the Palliative Care Outcomes Collaboration (PCOC) measures <sup>[24]</sup>

<i>Model evaluation measures</i>	<i>PCOC measures</i>
<p>Timeliness of access for patient to palliative care, measured by time from the date that a person is ready to receive palliative care (i.e., the need for palliative care is identified and the person is available to receive care), to the date of actual receipt of palliative care.</p>	<p>Time from date ready for care to episode start</p>
<p>Patient time in unstable phase reflected by urgent changes in plan of care or emergency treatment due to i) the person experiencing a problem not anticipated by existing care plan, ii) a rapid increase in severity of an existing problem, or iii) a change in family/carer circumstances impacting the person's care.</p>	<p>Time in the unstable phase</p>
<p>Within phase change in patient (or suitable proxy) reported outcome measures for pain.</p> <p>Within phase change in patient (or suitable proxy) reported outcome measures for distress caused by breathing problems.</p> <p>Within phase change in patient (or suitable proxy) reported outcome measures for fatigue.</p>	<p>Change in symptoms/problems</p>

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## Artwork



The artwork used in this document and all project outputs has been created by people living with disability. Artwork has been provided by Studio ARTES, an independent, not for profit organisation that provides creative programs to adults with disability. All artwork has been individually credited. For more information visit [www.studioartes.org.au](http://www.studioartes.org.au).

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