



Australian College of Nursing

# NATIONAL PALLIATIVE CARE AND END-OF-LIFE CARE INFORMATION PRIORITIES

Australian College of Nursing Response to the Australian  
Institute of Health and Welfare (AIHW) (November 2020)

## General comments

The Australian College of Nursing (ACN) would like to thank the Australian Institute of Health and Welfare (AIHW) for the opportunity to provide feedback on the consultation draft for the **National Palliative Care and End-of-Life Care Information Priorities (November 2020)**. The Australian College of Nursing is the pre-eminent and national leader of the nursing profession and a strong collective voice for nurses in all health care settings. ACN is committed to ensuring those at the end of their lives are treated with the utmost dignity and respect; and are supported in their autonomous choices to explore all available end of life options. Nurses are best placed to provide compassionate, safe and professionally competent care for individuals as they face the end of their lives.

## ACN responses to consultation questions

### Introduction and overarching headings

**Question 1: Please comment on the overarching headings, particularly whether they provide a suitable framework for national palliative care and end-of-life care information development.**

**The overarching headings for the Information Priorities are: People with a life-limiting illness; Families and carers; Workforce; Service and system planning and design; Service delivery and integration; Performance and public reporting; and Understanding.**

ACN has considered these headings and in broad terms believes these are clear, comprehensive, logical, and well-integrated. They provide a suitable framework for national palliative care and end-of-life information development so are likely to facilitate achievement of the various 'vision' statements.

ACN however, also engaged Palliative Care Nurses Australia (PCNA), a member organisation for Australian nurses who are passionate about excellence in palliative care and support their feedback to refine the document title to include the word "data". This may better align with the data strategic priority in the 2018 National Palliative Care Strategy.

**Question 2: Do you support the content in this section?**

☒ Yes ☐ No ☐ Not applicable

If you answered no to this question, please provide a reason.

### People with a life-limiting illness (pp. 26-28)

**The priorities in this section are: Patient-reported experience measures (PREMS); Patient-reported outcome measures (PROMS); Identifying and supporting people without carers; Conversations people are having and how they are planning for their future care. Please see the document above for full explanation of these priorities.**

**Question 3: Please comment on the priorities in this section (People with a life-limiting illness) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.**

ACN welcomes the priorities in this section as they reflect current and probable emerging needs over the next ten years. Likewise, the focus on consulting directly with the groups and people identified are necessary inclusions (as in the National Palliative Care Strategy and the last dot point in the 'vision' statement' on page 27 of the consultation draft).

ACN is supportive of the key areas for development in the national initiative – particularly around patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs). ACN will soon be releasing a White Paper on Value-based Health Care (VBHC) which explores these concepts. Specifically, VBHC is an emerging model of care which looks at the health outcomes that matter to patients relative to the resources or costs required, over a full cycle of care. In this White Paper, ACN argues there is a need to shift the whole system towards models that target core issues in our health and aged care settings; and that the **right incentives** need to be in place to provide the **right care** at the **right time** for the **right price**, in the **right place** by the **right provider**. In this White Paper ACN highlights that patient-reported indicators such as PREMs/PROMs will establish indicators that measure the outcomes and experiences of health care that matter most to people. This is because PREMs/PROMs provide a structured way of helping patients to report information about health outcomes and drive quality improvement in a way that brings patients' voices to the fore.

ACN also engaged the PCNA who note there is significant local and jurisdictional work in relation to use of PREMs / PROMs and other forms of data and it would be useful to collate and leverage from existing data.

ACN's membership indicated the following:

- People living with dementia and their partners are underrepresented as recipients of palliative care. There needs to be a better understanding that dementia is a life-limiting condition which warrants referral to a palliative care service to address this failure.
- Safe and quality health care includes provision of personal-centred care, which is evidenced based, best practice and partnered with consumers, an Australian Health care standard.

**Question 4: Are there additional actions relevant to this section (People with a life-limiting illness) that would advance palliative care and end-of-life care in the next 10 years?**

**The list of actions for this section are provided under the "Our vision is national information should" heading.**

Nurses are the major professional group in all areas of health care, so it is always important to consult with them whenever data systems or other forms of information gathering and analysis are being developed. ACN would like to highlight that "nurses as the largest component of the palliative care workforce". As per our 2019 White Paper titled **"Achieving Quality Palliative Care for All: The Essential Role of Nurses"** (page 9), ACN believes nurses are best placed to provide the compassionate, competent, safe and person-centred care all individuals at the end of their lives deserve. In this white paper, ACN argues nurses are uniquely qualified to address the range of physical, emotional, social and spiritual needs of people with a life-limiting illness and promote

continuity of care across the care trajectory. ACN recommends this White Paper to the AIHW for further details to inform the proposed information development initiatives in this consultation.

Additionally, in a 2020 White Paper, ACN made the case for **“Establishing a nurse-led palliative care service in Australia: implementation toolkit”**, including how to effectively plan, engage stakeholders, develop a business case, implementation and evaluation of nurse-led palliative care. More broadly, this highlights ACN’s belief and recommendation that nurses are essential in health and aged care reform.

SEE CITATION’s HERE:

1. Australian College of Nursing (ACN). 2019, ‘Achieving Quality Palliative Care for All: The Essential Role of Nurses—A White Paper by ACN 2019’, ACN, Canberra. ©ACN 2019 <https://www.acn.edu.au/wp-content/uploads/white-paper-end-of-life-care-achieving-quality-palliative-care-for-all.pdf>
2. Australian College of Nursing (ACN). 2020, ‘Establishing a Nurse-led Palliative Care Service in Australia: An implementation toolkit – A White Paper by ACN 2019’, ACN, Canberra. ©ACN 2020 <https://www.acn.edu.au/wp-content/uploads/white-paper-establishing-nurse-led-palliative-care-service-in-australia-implementation-toolkit.pdf>

ACN’s membership indicated the following:

- For people living with dementia and their partners there needs to be increased awareness made of the importance of referral to a palliative care service. For those working in palliative care there needs to be a better understanding of dementia and how to recognise end of life to avoid unnecessary hospitalizations at this stage. An early diagnosis enables people living with dementia to complete Advance Care Planning (ACP) while they have the capacity to do so. This also enables them to receive treatment of choice at end of life.
- ACP is linked to palliative and end-of-life care in the emergency departments. See Australasian College for Emergency Medicine (ACEM) policy 'End of Life and Palliative Care in the emergency department' <https://acem.org.au/getmedia/d55cb8ce-2d26-49d5-823a-f7f07b5c19cc/P455-PolicyonEoLandPalliativeCareinED-Jul16.aspx> The understanding and differences in patients documented discussions for advance care planning, i.e. an Advanced Care Plan, Statement of choices and the Advance Health Directives, by health professionals varies. This needs to be addressed.

ACN also endorses the submission made by PCNA, in particular their noting there is a need for:

1. “Understanding and articulating the key areas of healthcare experience that are of importance to all patients (with palliative care needs or not) and how to extrapolate data that overlaps all care (which is already collected in most jurisdictions with a hospital setting focus at present) from that which is unique to the population with palliative and end-of-life care needs”;
2. “Co-designing benchmarks to inform national data collection with consumers, health care clinicians, policy makers and data experts – enabling this to lead the data infrastructure design will ensure the outcomes reflect that which matters the most for patients and families/carers”;
3. “Produce data which enables an understanding of whether: the person with a life limiting illness is able to access the particular services they required, for example psychosocial support; the person was provided with services early enough to improve quality of life”;

4. "Collecting data on Advance Care Directives should include information about whether people with a life-limiting illness are receiving the assistance they need to develop an Advance Care Directive";
5. "The carer experience of their needs and the support available to them could have greater focus. This could include a self-assessment of their needs to access grief and bereavement support and assessment of whether they received the assistance needed and the quality of the support programs available. This would inform support programs and information for carers of people receiving palliative care of end-of-life care".
6. "Consider the use of the new ICD-10 code for cachexia to identify inpatients with a progressive chronic illness who did not receive palliative care as a proxy of unmet inpatient palliative care needs. People affected by cancer and other progressive life-limiting illnesses in the final stages of their illness almost always have cachexia, making it a potentially suitable systems level proxy for palliative care need. Utilising the new ICD-10 code for cachexia [R64] in the presence of a known progressive chronic illness could be used to identify inpatients who require palliative care and who received palliative care. This would help to identify the cohort of inpatients with potential palliative care needs who missed out".

**Question 5: Do you support the content in this section?**

☒ Yes ☐ No ☐ Not applicable

**If you answered no to this question, please provide a reason.**

## **Families and carers (pp. 30-32)**

**The priorities in this section are: Identifying who is providing care to Australians at their end of life; Identifying the needs of carers; and Finding opportunities to understand carer experience. Please see the document above for full explanation of these priorities.**

**Question 6: Please comment on the priorities in this section (Families and carers) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.**

ACN supports the priorities as they identify often neglected groups with the broad 'Families and carers' grouping as well as describing challenges nurses frequently encounter. Identification of support for targeted research projects is to be applauded so that nursing care as an essential element of service delivery can be described and expanded.

Relevant to this topic for AIHWs consideration, ACN recently launched a Position Statement (November 2020) titled "**Optimising person- and family-centred end-of-life care during a pandemic**". This can be accessed here: <https://www.acn.edu.au/wp-content/uploads/position-statement-optimising-end-of-life-care-during-pandemic.pdf>. The position statement emphasises a person and family centred solution to address the additional issues the COVID-19 pandemic (also relevant to any future pandemics) has had on those experiencing loneliness at the end of their lives. Specifically, during the COVID-19 pandemic, access to quality end-of-life care has been impacted by enhanced public health and infection prevention and control measures and restrictions associated with COVID-19. Prior to COVID-19, social isolation was already a serious public health concern

amongst older populations, contributing to the cycle of illness, increased healthcare utilisation, increased depressive symptoms in older people and cognitive decline. Restricting visitor access to residential aged care facilities (RACFs) during the pandemic has likely exacerbated these issues, through lost/reduced access to previously established support networks, such as family, as residents are now spending increased time alone. COVID-19 has also placed limitations on treatment and end-of-life care options, emphasising the importance of opportunities for family involvement and collaboration where possible.

As a result, ACN has made the following person- and family centred- recommendations to ensure access to appropriate end-of-life care (ACN 2020 position statement, pg. 1):

- Nursing practice that integrates a person- and family- centred approach to end-of-life care as a core component of a health and aged care service response for managing the COVID-19 pandemic, including effective symptom support, timely communication inclusive of informal carers (including family members, surrogates and informal support persons), and ensuring care aligns with the person's values and preferences;
- Adequate prioritisation of psychosocial and existential support for people at end of life, and their informal carers including access to psychological and social supports for people at end of life and their families;
- Resourcing of flexible and innovative communication mechanisms within all care settings that facilitate meaningful interactions between the person and informal carers at the end of life;
- Initiatives that support nurses providing end-of life care for people during the COVID-19 pandemic across all practice settings, including:

-Specific and targeted opportunities to upskill in providing person- and family-centred care at the end of life, and infection prevention and control where required

-Access to personal protective equipment

-Measures which promote self-care and access to employee support services which acknowledge the stressors experienced by nurses

**Question 7: Are there additional actions relevant to this section (Families and carers) that would advance palliative care and end-of-life care in the next 10 years?**

**The list of actions for this section are provided under the "Our vision is national information should" heading.**

See response to workforce planning question (Q10.)

ACN's membership also considered the following:

- As dementia is a condition which places great strain on carers who are likely to experience anticipatory grief for an extended period of time, it is crucial that they have access to support from a palliative care service during what can be a prolonged period of palliation where difficult decisions need to be made.

- Providing diverse primary multidisciplinary health care centres that assess and connect people and families to responsive services, including assisting with access to 'Services Australia'.

**Question 8: Do you support the content in this section?**

☒ Yes ☐ No ☐ Not applicable

**If you answered no to this question, please provide a reason.**

## **Workforce (pp. 34-35)**

**The priorities in this section are: Complexity and capacity of the workforce supporting end-of-life care; Capacity across the workforce to deliver high-quality and person-centred care; and Planning for future workforce requirements. Please see the document above for full explanation of these priorities.**

**Question 9: Please comment on the priorities in this section (Workforce) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.**

ACN endorses the submission made by PCNA, in particular their noting there is a need for:

- Information on specific aspects of capacity that could be measured, skillsets imperative across the disciplines to manage complex end of life and palliative care.
- Strengthening this section by explicit reference across national and jurisdictional policy platforms.
- Building data and knowledge about what attracts health professionals to work in palliative care.
- Annual AHPRA registration that captures a health practitioner's primary clinical speciality and sub-specialty – currently AHPRA only captures health professionals' primary speciality (i.e. palliative medicine physicians or palliative care nurses). However palliative care is provided in both generally and specialist services available across in-patient, out-patient care, hospices and community services. This means AHPRA misses the opportunity to recognise contributions of other health professionals with primary palliative care capabilities and expertise.

**Question 10: Are there additional actions relevant to this section (Workforce) that would advance palliative care and end-of-life care in the next 10 years?**

**The list of actions for this section are provided under the "Our vision is national information should" heading.**

Nurse led models of care need to be specifically identified for inclusion in any information development systems (refer to ACN's 2019 White Paper "Achieving Quality Palliative Care for All: The Essential Role of Nurses" and ACN's 2020 Position Statement "Optimising person- and family-centred end-of-life care during a pandemic").

Specifically, ACN recommends a focus on the role of nurses in community and domiciliary settings and in the assessment and management of multimorbidity. That data is needed for workforce planning and specialist education, for example, in relation to in-home care for older Australians and those with disability. ACN is soon releasing the “**Diversity and Inclusion Guiding Principles**” for the nursing profession and a position statement on “**The role of the nurse in the assessment and management of multimorbidity**” – these nursing policy documents cover sensitive topics and are relevant to workforce planning into the future.

ACN specifically established the social impact initiative in 2020 titled, the **Diversity and Inclusion Working Party** to provide direction and advice around behavioural expectations, policy and procedural standards for nurses, patients and workplaces to ensure nurses are leading the way and able to work in culturally safe and inclusive environments.

ACN’s membership provided the following feedback:

- Many people living with dementia spend the last part of their lives in residential aged care, which in Australia is predominantly run by for-profit companies. The aged care workforce is poorly educated about dementia and nurses are underrepresented in this workforce. There needs to be increased education of dementia and how to properly palliate people living with this condition to avoid poor symptom management and unnecessary hospitalisations of people living with dementia at the end of their lives.
- The development of National health professional training for palliative and end of life care for all people should include partnering with consumers, from diverse cultures & locations within Australia.

ACN endorses PCNA’s submission, noting recommendations for:

- “A stronger statement about how you would be measuring workforce ability to deliver culturally sensitive care – perhaps this work is a means by which to advise of key elements to support such outcomes and thereby drive improvements. In relation to sensitive care for Australia’s Aboriginal and Torres Strait Islander population it would be useful to consider leadership perhaps around measurement of enabling cultural safety and cultural responsiveness across care settings and to co-design such approaches with key Aboriginal leaders and experts in this work”.

**Question 11: Do you support the content in this section?**

☒ Yes ☐ No ☐ Not applicable

If you answered no to this question, please provide a reason.

## **Service and system planning and design (pp. 38-39)**

The priorities in this section are: **Unmet need for palliative care and end-of-life care to support system and service planning; Vulnerable populations; and People’s preferences and actual place of care and death.** Please see the document above for full explanation of these priorities.



**Question 12: Please comment on the priorities in this section (Service and system planning and design) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.**

ACN supports the priorities as they identify areas where nurses are commonly the interface, for example, transition to and between different care settings such as hospitals and the home. The linkage of data would offer greater context and enhance the quality of this data.

ACN recently responded to the Victorian Government Department of Health and Human Services (DHHS) on the **Health Information Sharing Legislation Reform consultation paper**. In our response, ACN supported clinical information sharing between settings including across the primary (community) and tertiary care (hospital) sectors. ACN sees an opportunity here for the palliative and end-of-life care settings with the collection of this type of data. ACN acknowledges the benefits of clinical information sharing, particularly around "improved patient safety and decreased avoidable patient harm, improved continuity of care, person-centred and place-based care, and better care planning". For the nursing profession this will ensure timely access to patient information which can often be time critical. For nurse leaders this would allow appropriate allocation of resources to improve the quality of palliative and end-of-life care (e.g. data would assist with staff modelling embedded in skill-set and taking into account patient acuity).

ACN also endorses PCNAs views, specifically:

- "As the document is intended to guide planning, investment and action by governments and other stakeholders developing a short, medium and longer term plan of actions will assist with operationalising the vision. Adopting a maturity model which describes the current status of key elements within the data system and articulating what an 'ideal state' would look like and mapping the steps to achieving this will be critical to operationalising this priorities document. It will also ensure that a whole-of-data system approach is adopted, ensuring dedicated resources are assigned, sharing safely and maintaining privacy, data is used to improve health and healthcare, and its purpose is transparent. There are opportunities for this document to challenge existing constraints and map out what how the collection and sharing of relevant and quality information (data) could be enabled, including reference to any infrastructure requirements and legislative enablers".

**Question 13: Are there additional actions relevant to this section (Service and system planning and design) that would advance palliative care and end-of-life care in the next 10 years?**

**The list of actions for this section are provided under the "Our vision is national information should" heading.**

Privacy of personal data is a consideration so any system developed needs to make it clear that existing (and evolving) privacy legislative and ethical frameworks will be adhered to - in a similar fashion to the national statement on ethical conduct in human research.

ACN has consistently reiterated, that when it comes personal data, it is concerned about the potential for other government agencies and departments to access private health records. ACN would like to stress that nurses are patient advocates and must adhere to the Nursing and Midwifery Board of Australia Code of Conduct for Nurses . The Code of Conduct stipulates that nurses abide by patient-centred care and adhere to patient privacy and confidentiality. For some nurses, knowing

that their patients' private health information could be obtained by other parties could cause moral distress. ACN would like the AIHW to address the concerns faced by the nursing profession.

ACN also supports PCNA's views on this:

- “• Greater focus about the temporal nature of preference for location of care and ability to enable changes to be noted and contextual factors also collected
- Increased detail about how 'need' is measured and captured at system and national levels
- Classify proposed solutions into short, medium and longer term priorities that the Commonwealth, jurisdictions and services could work towards addressing; and
- Develop a compendium plan to ensure that the pathway for the establishment of national palliative care data system(s) is more clearly articulated. Gain agreement about the type of data collected, linkage capability of this data and streamlined accessibility by policy makers, clinicians and researchers.”

**Question 14: Do you support the content in this section?**

☒ Yes ☐ No ☐ Not applicable

**If you answered no to this question, please provide a reason.**

## **Service delivery and integration (pp. 42-43)**

**The priorities in this section are: Data capture on care at home and in the community; Ease of access, coordination and transition between services; and Data sharing for appropriate and coherent care across services and care settings. Please see the document above for full explanation of these priorities.**

**Question 15: Please comment on the priorities in this section (Service delivery and integration) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.**

The priorities in this section are appropriate. The COVID-19 pandemic has made it obvious that the use of telehealth is important especially in rural and remote areas; so capturing this type of data is important. In addition, COVID-19 has highlighted that there is also a demand for telehealth services in metropolitan areas – which compliments/corresponds to the increased digitisation of society and the faster pace of life in general.

ACN endorses PCNA's submission, noting:

- “the consideration of adding hospital care within the first data capture priority. At present, data capture for the large number of patients living with advanced life-limiting illness, receiving significant levels of care across Australia's hospital system is often missed, unless the person is specifically coded after receiving a referral to a specialist palliative care clinician. We do not dispute the importance and huge gap in relation to data at home and in

the community but would like to see end-of-life care data from hospital settings included. Data capture from the ambulance service would be another useful addition to consider.”

**Question 16: Are there additional actions relevant to this section (Service delivery and integration) that would advance palliative care and end-of-life care in the next 10 years?**

**The list of actions for this section are provided under the "Our vision is national information should" heading.**

Data sharing is potentially problematic. Privacy of personal data is a consideration so any system developed needs to make it clear that existing (and evolving) privacy legislation and ethical frameworks will be adhered to - in a similar fashion to the national statement on ethical conduct in human research.

ACN would like to mention the current review being undertaken of the Privacy Act 1988 by the Australian Government Attorney-General's Department. The review, which includes a public consultation process, is considering whether the scope of the Privacy Act 1988 and its enforcement mechanisms remain fit for purpose. In relation to this review, a recent Australian Financial Review article pointed out the experience of the Office of the Australian Information Commissioner in relation to data protection. It quotes the Australian Information Commissioner and Privacy Commissioner, Ms Angelene Falk, stating there are four key elements to support effective privacy regulation over the next decade: **“global interoperability** — making sure our laws continue to connect around the world, so our data is protected wherever it flows; **enabling privacy self-management** — so individuals can exercise meaningful choice and control; **organisational accountability** — ensuring there are sufficient obligations built into the system; and **a contemporary approach to regulation** — having the right tools to regulate in line with community expectations.” The review of the Privacy Act 1988 will bring up issues such as consent requirements, additional privacy rights and accountability measures. Digital health records are part of the privacy challenges of the future and how widely and effectively the Privacy Act 1988 applies will potentially have far-reaching implications.

ACN's membership indicated a greater focus and development in integrated care and services across the continuum in all Australian communities is essential.

The PCNA also suggested data mapping in accordance with retrospective Medicare data (pending legislation requirement) after an expected death to inform more immediate review and change prior to longer term prospective data capture – to inform transitions in care and access.

**Question 17: Do you support the content in this section?**

☐ Yes ☐ No ☒ Not applicable

**If you answered no to this question, please provide a reason.**

**Performance and public reporting (pp. 46-47)**

**The priorities in this section are: Improve the quality of existing data; Identify the characteristics of people at the end of life; and Monitor the quality and provision of palliative care in the system overall. Please see the document above for full explanation of these priorities.**

**Question 18: Please comment on the priorities in this section (Performance and public reporting) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.**

Nationally consistent data and coding is likely to improve the provision of care so ACN supports the priorities.

In ACN's 2019 White Paper titled "A National Minimum Dataset for Nursing Workforce Planning and Decision Making" [see here: <https://www.acn.edu.au/wp-content/uploads/white-paper-national-minimum-dataset.pdf> ], ACN argued that there is limited consistency or commonality between current nursing workforce datasets, whether nationally or internationally. The emphasis is often on local utility over state or national standardisation. This inconsistency has a detrimental impact on such central matters as quantifying nursing work, evaluating the impact of current nursing staffing on patient outcomes, and on effective planning for future nursing needs. Many of the existing datasets do not incorporate factors that have been associated with patient outcomes or incorporate them in a limited way that restricts their utility.

The development of tools such as dashboards that can improve service delivery and clinical management are often undertaken at the state or local level, and may not incorporate all relevant data elements, leading to a disparity in how services understand and address their nursing needs. In order to facilitate strong context-relevant decision making, data and support should be made available to dataset users at all levels, who can apply their understanding to ensure the most effective utilisation of these data for positive patient outcomes.

As the pre-eminent professional nursing body, ACN is committed to working with the AIHW and industry to facilitate a strong and sustainable nursing workforce to meet future health care needs of all Australians including in the palliative and end-of-life care settings. An expanded, evidence-based minimum dataset is a fundamental component (this includes a National Minimum Data Sets -NMDS - for palliative care).

The PCNA and Palliative Care Australia (PCA) have also recommended a NMDS for palliative care "to capture service provision by setting; stage and provider; linked with patient outcomes data through PCOC". See report: "Investing to Save: The Economics of Increased Investment in Palliative Care in Australia"; <https://palliativecare.org.au/kpmg-palliativecare-economic-report> (pg. 57).

**Question 19: Are there additional actions relevant to this section (Performance and public reporting) that would advance palliative care and end-of-life care in the next 10 years?**

**The list of actions for this section are provided under the "Our vision is national information should" heading.**

Privacy is once again a consideration including national data about death and causes of death; so indicators need to be developed in consultation with consumers and health professionals, including nurses.

ACN endorses the National Nursing and Midwifery Digital Health Capability Framework as it recognises how this will assist in increasing the effective utilisation of digital health care in Australia. ACN believes digital health has the potential to bring about vast improvements in how healthcare is delivered, where people can access quality care, and health outcomes. This potential can only be realised if there is a workforce ready to adopt digital health tools and services and maximise the

benefits. The Capability Framework will ensure the nursing workforce can confidently utilise digital health technologies.

The PCNA also suggested it would be useful to articulate specific requirements for minority and vulnerable populations in varied settings of care (e.g. paediatric palliative care, care within prisons, the disability sector etc)

**Question 20: Do you support the content in this section?**

☒ Yes ☐ No ☐ Not applicable

If you answered no to this question, please provide a reason.

## Understanding (pp. 50-51)

**The priorities in this section are: Data is easily understood and accessible to improve understanding; Data supports meaningful discussions and informed and shared decision making; and Data is appropriately shared. Please see the document above for full explanation of these priorities.**

**Question 21: Please comment on the priorities in this section (Understanding) for advancing Australia's national palliative care and end-of-life care information needs over the next 10 years.**

Nurses are the major provider of palliative care and end-of-life care. ACN supports the priorities as having the potential to acknowledge this and enhance the provision of nursing care by collecting national data that is reflective of this.

**Question 22: Are there additional actions relevant to this section (Understanding) that would advance palliative care and end-of-life care in the next 10 years?**

**The list of actions for this section are provided under the "Our vision is national information should" heading.**

ACN is actively involved in promoting public awareness of and understanding about palliative care and end-of-life care including discussions about advance care [see reference above to White Papers and Position Statements]. ACN also has a dedicated End-of-Life Care Policy Chapter consisting of nurse experts in the field, who work hard to produce fit for purpose policy documents to advance the nursing profession in this space. From ACN's perspective, it is important to highlight that whatever national information is developed, it needs to take into account health professional regulatory and ethical responsibilities such as codes of ethics and of conduct. See below for nurses:

1. Nursing and Midwifery Board of Australia 2018, *Code of conduct for nurses*, accessed at <http://www.nursingmidwiferyboard.gov.au/documents/default.aspx?record=WD17%2F23850&dbid=AP&checksum=L8j874hp3DTIC1Sj4klHag%3D%3D>

2. Nursing and Midwifery Board of Australia 2012, *Code of ethics for nurses*, accessed at [https://www.icn.ch/sites/default/files/inline-files/2012\\_ICN\\_Codeofethicsfornurses\\_%20eng.pdf](https://www.icn.ch/sites/default/files/inline-files/2012_ICN_Codeofethicsfornurses_%20eng.pdf)

**Question 23: Do you support the content in this section?**

☒ Yes ☐ No ☐ Not applicable

If you answered no to this question, please provide a reason.

## Your overall feedback

**Question 24: Do you support the overall content in this document?**

(Required) ☒ Yes ☐ No ☐ Not applicable

If you answered no to this question, please provide a reason.

**Question 25: What is your overall feedback on the draft National Palliative Care and End-of-Life Care Information Priorities document?**

This is a well written document that is evidence-based and respectful of the many nuances surrounding the provision of palliative and end-of-life care (now and into the future). ACN applauds those involved in its development and release.

ACN suggests it would be prudent to await the final report of the Royal Commission into Aged Care Quality and Safety before finalising this document as there will be critical findings that will inform how best practice in palliative care should look like in Australia, particularly for those living with dementia.

**Question 26: Do you have any other comments about the draft document?**

ACN strongly recommends that however the consultation or development evolves, it must involve the nursing perspective, through the Chief Nursing Officer and through continuing consultation with ACN. ACN is committed to ensuring those at the end of their lives are treated with the utmost dignity and respect; and are supported in their autonomous choices to explore all available end of life options. Nurses are best placed to provide compassionate, safe and professionally competent care for individuals as they face the end of their lives.

We would also like to highlight the work that ACN has been involved in around voluntary assisted dying (VAD) – see below:

- ACN has been actively involved in efforts to enhance end-of-life (EOL) care, regardless of whether individuals opt for advanced care planning or voluntary assisted dying (VAD). ACN represents thousands of nurses working in all health care settings including aged and

palliative care and has strongly advocated for nurse leadership in designing and implementing appropriate and carefully considered VAD frameworks.

- In a 2019 **submission to the QLD Department of Health's Committee on Health, Communities, Disability Services and Domestic and Family Violence Prevention**, ACN argued all health professionals, care workers and volunteers should be supported to work according to their ethical values, while providing safe, quality and compassionate care to people living with a life limiting illness [see here: <https://www.acn.edu.au/wp-content/uploads/20190418-ACN-response-QLD-VAD-parliamentary-inquiry.pdf> ]
- In a 2019 submission to the **Western Australia (WA) Voluntary Assisted Dying Public Consultation**, ACN argued an individual's dignity and choice are vital to ensuring a person's quality of life, comfort and dignity during this vulnerable time [see here: <https://www.acn.edu.au/wp-content/uploads/20190524-ACN-response-WA-voluntary-assisted-dying.pdf> ]
- In a 2018 **submission to the Australian Capital Territory (ACT) Legislative Assembly Inquiry into End of Life Choices**, ACN highlighted the challenges many nurses face in responding to increasing requests for assisted dying in jurisdictions with ill-defined scope of practice or lack of support around EOL care decisions [see here: <https://www.acn.edu.au/wp-content/uploads/2018/03/20180323-ACN-response-ACT-Leg-Assem-End-of-Life-Inq-FINAL.pdf> ].
- In a 2018 Position Statement, ACN argued legislation around **voluntary assisted dying in Victoria** should be based on the assumption that all people with a life-limiting diagnosis deserve to receive high quality, evidence-based health care, and access to appropriate services such as specialist palliative care [see here: <https://www.acn.edu.au/wp-content/uploads/2018/10/Voluntary-Assisted-Dying-in-Victoria.pdf> ].
- ACN has strongly urged greater investment in palliative care nursing in rural and remote areas, to ensure equity of access to high-quality care provision [see here: <https://www.acn.edu.au/wp-content/uploads/white-paper-end-of-life-care-achieving-quality-palliative-care-for-all.pdf> ]
- In the case of discussing and administering VAD care in rural and remote areas, ACN agrees NPs can play a crucial role in ensuring those with life-limiting conditions have the same access and autonomy to make EOL decisions.
- ACN believes in respecting the needs, preferences and beliefs of culturally and linguistically diverse (CALD) people, including the protection of families, children and cultural rights of Aboriginal and Torres Strait Islander peoples. It is likely some members of the Aboriginal and Torres Strait Islander community with life-limiting illnesses will choose to pursue voluntary assisted dying on country, and this should be honoured. Special care should also be taken to support those with a disability to understand and access their different EOL care options, including VAD.

ACN is the pre-eminent and national leader of the nursing profession and a strong collective voice for nurses in all health care settings. Together, we increase the quality of patient care for all Australians. Our mission is advancing nurse leadership to enhance health care.