Paediatric Palliative care

NATIONAL ACTION PLAN PROJECT

Background Literature Review

Paediatric Palliative Care
AUSTRALIA & NEW ZEALAND

PalliativeCare
AUSTRALIA

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Contents

1. Executive summary

The development of a paediatric palliative care workforce, models of care, and research evidence has advanced rapidly in recent decades. This provides a solid foundation for further development of paediatric palliative care in Australia. This project, commissioned by Palliative Care Australia, involved a literature review to inform the development of a National Paediatric Palliative Care Action Plan (hereafter 'National Action Plan'). The National Action Plan will be based on evidence and consultation with key stakeholders. There were three key requirements for this literature review:

1. Synthesise peer-reviewed and 'grey' literature containing information about enhancing paediatric palliative care.
2. Structure the review according to key topics.
3. Use the results of the review to identify key questions that can be used by Palliative Care Australia to develop a discussion paper for consultation with key stakeholders.

A rapid review using thematic synthesis methods was conducted to synthesise information in peer-reviewed and 'grey' literature about improving paediatric palliative care. Systematic searches for peer-reviewed literature were conducted in Medline, CINAHL, and Embase, and a search for 'grey' literature was conducted using Google Advanced Search. These searches were supplemented with additional literature sources identified by members of the project team and steering committee. A total of 2,228 literature sources were screened, with 369 sources deemed to meet criteria for inclusion in the review.

A customised tool was created to facilitate consistent extraction of information from each literature source. Given the aim of the review, only information that clearly identified ways to improve paediatric palliative care was extracted. The extracted information was then synthesised across eight key topics. The synthesis process identified key information about each topic, as well as key questions for future consultation with stakeholders. The literature sources synthesised for each topic spanned perinatal palliative care through to palliative care for adolescents and young adults. Although many literature sources were from and related to the United States of America, sources from Australia typically constituted the second or third highest proportion of the included literature sources for each topic. The literature sources most often contained information obtained from clinicians, sometimes from family members such as parents, but rarely from children with life-threatening or life-limiting conditions or their well siblings. Each key topic, and related key questions are summarised below.

Improving the quality of paediatric palliative care

Information obtained from 137 literature sources indicated that quality of care can be improved by: ensuring care is patient- and family-centred; fostering partnerships across professions and care settings; and setting benchmarks for the delivery of care. Key questions resulting from the synthesis of literature sources relating to this topic are:

1. What are the current priorities in Australia for ensuring patient- and family-centred care for children with life-threatening or life-limiting conditions, within and beyond specialist paediatric palliative care?
2. What are the current priorities in Australia for fostering partnerships across a range of healthcare professions and care settings involved in paediatric palliative care?
3. Should methodologies used to develop guidelines for paediatric palliative care in other countries be considered to update paediatric palliative care guidelines for Australia?

Improving access to paediatric palliative care

Information obtained from 128 literature sources indicated that access to paediatric palliative care can be improved through early integration, providing care in various settings, and considering specific needs of culturally and linguistically diverse populations. Key questions resulting from the synthesis of literature sources relating to this topic are:

4. What are the key requirements for ensuring early integration of paediatric palliative care for children with life-threatening or life-limiting conditions in Australia?
5. What are the key requirements for ensuring provision of paediatric palliative care in a variety of settings in Australia?
6. Should existing approaches for improving access to paediatric palliative care in Australia be evaluated, to determine whether they are meeting the needs of families and promoting equitable access?
7. What initiatives are required to ensure paediatric palliative care is meeting the needs of the culturally and linguistically diverse population of Australia?

Improving uptake of advance care planning

Information obtained from 62 literature sources indicated that uptake of advance care planning can be improved through interventions at the levels of population, systems, clinicians, families, and patients. Key questions resulting from the synthesis of literature sources relating to this topic are:

8. Does the network of specialist paediatric palliative care in Australia have capacity to facilitate or support advance care planning for all children with life-threatening or life-limiting conditions who might benefit? If not, how might this capacity be developed? What alternatives might be possible?
9. What patient- or family-focused advance care planning resources should be priorities for development or implementation in Australia?

Improving skills of the clinical workforce, patients, and families

Information obtained from 133 literature sources did not identify clear priorities for skills development, nor clear evidence about the most effective training and education methods. Key questions resulting from the synthesis of literature sources relating to this topic are:

10. What are priorities for paediatric palliative care skills development for the clinical workforce in Australia?
11. Should a hierarchy of skill levels be used to guide paediatric palliative care training across the Australian clinical workforce?
12. Which approaches to developing clinicians' skills in paediatric palliative care are best suited for use in Australia?
13. What are the priorities for developing the skills of children with life-threatening or life-limiting and their families?

Improving research and data collection

Information obtained from 68 literature sources identified research priorities and advocated for routine data collection. Key questions resulting from the synthesis of literature sources relating to this topic are:

14. What is needed to facilitate routine data collection that supports continuous quality improvement in paediatric palliative care in Australia? How can nationwide data collection be facilitated? Which quality indicators are priorities for paediatric palliative care in Australia?
15. Are international priorities sufficient to guide paediatric palliative care research in Australia, or is there a need to identify priorities for paediatric palliative care research in Australia?

Improving collaboration across jurisdictions

Only nine literature sources were identified as having relevance to collaboration across jurisdictions in Australia (i.e., States, Territories, and the Commonwealth). The Quality of Care Collaborative Australia in Paediatric Palliative Care (QuoCCA) provides the clearest example of government-funded collaboration in paediatric palliative care. Key questions resulting from this section of the literature review are:

16. Does the ‘pop up’ model delivered through QuoCCA provide a basis for further enhancing collaboration between the States, Territories, and the Commonwealth? Is this model scalable to support a whole-of-population approach? Are there other models that might enhance or provide an alternative to this approach?

Improving dissemination of information

The review did not identify additional information that was not synthesised within the first five topics reported above. Based on the findings across these topics, a key question for improving dissemination of information is:

17. What are the optimal ways to comprehensively identify all stakeholders in a child’s care and ensure they have a shared understanding of the needs and care that is necessary for that child and their family?

Improving community knowledge of paediatric palliative care

Only seven literature sources were deemed to have some relevance to improving community knowledge in Australia about paediatric palliative care. This includes, for example, school-based public awareness programs to increase knowledge about dying and palliative care. A key question resulting from the synthesis of literature sources relating to this topic is:

18. How can existing community-based initiatives for improving knowledge of paediatric palliative care be expanded to ensure coverage of the general Australian community?

The findings of this review bring together information from a vast range of literature sources. The information synthesised from these literature sources, along with the key questions that have been identified through the synthesis, provides an evidence base to consult key stakeholders to develop the National Action Plan. Moreover, the action-oriented information identified through the review can be used to target investment and change in paediatric palliative care over the coming decades.

2. Background

Palliative care is an approach that improves the quality of life of people with life-threatening or life-limiting illness and their families. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial or spiritual.[1] It is estimated that as many as 21 million children around the world would benefit from paediatric palliative care.[2] The aim of paediatric palliative care is to help alleviate symptoms and improve the quality of life of a child with a life-threatening or life-limiting condition from the moment of diagnosis, not just at end of life. A 2014 World Health Assembly resolution recognised access to paediatric palliative care as an ethical responsibility of health care systems,[3] and many countries, including Australia, have progressively developed specialist paediatric palliative care over recent decades.[4-8] These decades of work now afford an opportunity to synthesise understanding of effective paediatric palliative care, to inform future policymaking in this area.

Palliative Care Australia (PCA) was commissioned by the Australian Government Department of Health to produce a Paediatric Palliative Care National Action Plan (hereafter 'the National Action Plan'). The aim of the National Action Plan is for all Australian jurisdictions and stakeholders working in paediatric palliative care to align and prioritise and work towards common goals and objectives. This will ensure children with a life-threatening or life-limiting condition and their families receive best-practice care and timely support and information. The National Action Plan will cover perinatal palliative care through to palliative care for young adults.

The National Action Plan will be evidence-based. It will be developed based on a review of evidence and feedback from relevant stakeholders. The current project involved a review of both peer-reviewed and 'grey' (i.e., unpublished and/or not peer-reviewed) literature that addressed one or more of the following topics:

1. Improving quality of services in the community and acute care
2. Improving access to services
3. Improving uptake of advance care planning
4. Improving skills of the workforce, parents, carers, patients, and siblings
5. Improving research and data collection
6. Improving collaboration between States/Territories and the Commonwealth
7. Improving knowledge of paediatric palliative care across the community
8. Improving dissemination of information

Defining paediatric palliative care

The World Health Organization defines paediatric palliative care as:

> *"The active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes."*[9]

Conditions that may require paediatric palliative care can be grouped into four overarching categories, as defined by the United Kingdom (UK) charity Together for Short Lives.[10]

Category 1: Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver, kidney.

Category 2: Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.

Category 3: Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.

Category 4: Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health. Children can have complex health care needs, a high risk of an unpredictable life-threatening event or episode, health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury.

Prevalence of life-threatening and life-limiting conditions

As the number of children with life-theatening or life-limiting conditions continues to rise around the world, so will the need for palliative care.[2,11-18] Extrapolated Queensland prevalence data suggests that as of 2016, there were around 24,386 children (0-18 years old) living with a life-threatening or life-limiting condition in Australia.[16] However, due to the lack or readily available quality data, the actual number is unknown. It is essential that the needs of these children are addressed to ensure their complex needs are met and thus the best quality of life is maintained for them and their families.[17]

Paediatric Palliative Care in Australia

While the concept of palliative care has been around since the 11th century,[19] palliative medicine training has only been delivered as a specialist program in Australia since 1990[18] with paediatric palliative medicine training becoming a ratified speciality training program in 2014.[8] While the provision of specialist palliative care services for children continues to develop globally, in Australia this has been at a much slower pace than other Western countries such as the UK.[20] At present, there are dedicated specialist paediatric palliative care services located in five Australian states (Queensland, New South Wales, Western Australia, South Australia, and Victoria) and one of the two mainland Australian territories (the Australian Capital Territory).[21] There are currently no dedicated specialist paediatric palliative care services in Tasmania and the Northern Territory. There is also a sparsity of dedicated children's hospices across Australia. Very Special kids in Victoria has been in operating since 1996,[22] Bear Cottage in New South Wales since 2001,[23] and Hummingbird House in Queensland since 2016.[24] A project is currently underway to construct Western Australia's first children's hospice, which is anticipated to open in 2023.[25]

Differences between paediatric palliative care and adult palliative care

There are several differences between paediatric palliative care and adult palliative care.[3,26,27] One difference is the types of condition. Children receiving paediatric palliative care may have conditions only seen in childhood. More than half of all life-limiting conditions in children are broadly grouped as neurodegenerative disorders, metabolic disorders, genetic conditions and congenital anomalies, cardiovascular and respiratory diseases and acquired brain injuries. These conditions are often characterised by an unpredictable illness trajectory.[3,5,8,27-29] In contrast, diseases seen in adult palliative care often relate to conditions as a result of lifestyle and aging such as cancers, cardiovascular disease and dementia.[30]

As children are still physically developing and growing,[3,20,27,31] they have different needs according to their developmental stage. The differing age and development of children also affects the pharmacodynamics and pharmacokinetics of medication.[3,32] Children are often referred to palliative care services earlier than adults, so often receive palliative care for longer.[4,27,33] The model of paediatric palliative care is also different to that of adults, with the paediatric model being more family centred and involving the child, family, and a wide variety of support services.[3,27,34]

Challenges for delivering equitable paediatric palliative care in Australia

One of the main challenges in delivering equitable paediatric palliative care is the vast geography of Australia. Currently seven specialist paediatric palliative care services and three dedicated children's hospices cover a total geographical area of 7,688,287 km^2, including 32,160 km^2 of islands off mainland Australia.[35] The majority of Australia is classified as very remote.[36] When compared to people living in major cities, those living in regional, remote and very remote areas of Australia have limited access to health, hospice, and support services.[37,38]

Another challenge is the culturally and linguistically diverse population of Australia.[39] This includes Aboriginal and Torres Strait Islander populations, who are known to have poorer health and health outcomes compared to non-Indigenous peoples.[40] To improve access to and the experience of palliative care, it is vital to address the known barriers such as lack of awareness of palliative care, language and communication difficulties, and racism, discrimination, and cultural stereotyping.[41]

3. Methods

To ensure the National Action Plan is evidence-based, a diverse range of literature was reviewed to address eight key topics. The breadth of this review contrasts with the tight focus typical of systematic review methods. This project instead utilised rapid review methods, which are more suited to synthesising information for policymaking.[28,41,42]

3.1. Search strategy

Searches for peer-reviewed literature were conducted through the Medline, CINAHL, and Embase databases. These were selected to ensure coverage of medical, nursing, and allied health literature. In addition to peer-reviewed literature, a focused search of ‘grey’ literature was undertaken, to identify key policy documents. The search for ‘grey’ literature was conducted using Google Advanced Search, employing similar key terms used for the search of the peer-reviewed literature databases (a copy of the peer-reviewed and ‘grey’ literature search strategies is available in Appendix A). The peer-reviewed and ‘grey’ literature is hereafter collectively referred to as ‘literature sources.’ Additional literature sources were identified through knowledge of the literature by members of the project team and steering group, as well as from the reference lists of included studies.

3.2. Screening

Only literature sources that specifically addressed paediatric palliative care were eligible for inclusion in the review. As discussed in Section 2, such care may be provided to children with life-threatening or life-limiting conditions. Such care may also include patients of diverse ages. This review therefore included perinatal palliative care through to palliative care for young adults. Given the review is designed to inform a National Action Plan, and considering the action-oriented focus of each review topic, only literature sources that incorporated a focus on improvement were eligible for inclusion. Given the National Action Plan is for Australia, information sources were excluded where it was clear that they did not contribute information that was relevant for the Australian context. For example, information sources considering how to develop services in countries that had little to no paediatric palliative care were excluded.

Literature sources were screened using Covidence, a web-based systematic review tool. Each literature source identified through the search strategy was screened by a single reviewer. Where the eligibility of a literature source was unclear, this was referred to a second reviewer for consideration. In the first instance, literature sources were screened by title and, where available, abstract. Where a decision about eligibility could not be made on the basis of title or abstract, the full text of the document was inspected to determine whether the literature source met criteria for inclusion in the review.

3.3. Quality appraisal

Consistent with approaches adopted in other rapid reviews,[28,41,42] no established quality appraisal tool was used. There were two reasons for this. First, this approach was adopted to maximise the amount of improvement-focused information that could be extracted from the existing literature. Second, there are recognised limitations of using existing appraisal systems (such as the NHMRC Levels of Evidence taxonomy[43]) in relation to palliative care.[29,44] An alternative tool was custom developed for this review, based upon common types of evidence used within palliative care literature (see Appendix B).[45] This information was retrieved during the data extraction phase and incorporated into the information synthesis process.

3.4. Information extraction

The customised tool that was created to incorporate information about the type of evidence included in a literature source also incorporated elements designed to facilitate consistent extraction of information from each literature source (see Appendix B). Information extraction was undertaken using Covidence. Information was extracted from each source by a single reviewer. Where the reviewer was uncertain about what to extract from the literature source, this was referred to a second reviewer. The focus of information extraction from each literature source related to the eight key topics underpinning the review. Given the aim of the review, only information that clearly identified ways to improve paediatric palliative care was extracted. In addition to extracting details that could be used to appraise the quality of information from a literature source, this tool also extracted details that could help contextualise the information extracted from it. This included details such as the source of information (e.g., patients, parents, or clinicians).

3.5. Information synthesis

The broad focus of this review necessitated the inclusion of a diverse range of information. To synthesise this diverse information, thematic synthesis methods were used.[46] Thematic synthesis was facilitated using the qualitative analysis software NVivo. A single reviewer synthesised the information and drafted a report for feedback from other reviewers.

4. Results

4.1. Search Results

The peer-reviewed literature search was conducted on 30 October 2020 and the 'grey' literature search on 13 November 2020. As reported in Figure 1, the search strategy, along with additional sources identified by members of the project team or steering committee resulted in 2,228 unique literature sources that were screened for eligibility to be included in the review. Because a broad search strategy was adopted for this review, a large number of sources did not meet inclusion criteria. Common reasons for exclusion included a focus on adults rather than children, not addressing one or more of the focus areas for the review, and not containing information that addressed the action-oriented focus of the review topics.

Following title and abstract screening, 1,060 literature sources were deemed to potentially meet criteria for inclusion in the review. At this preliminary stage, any literature with relevance to paediatric palliative care and one or more of the topics areas that comprise the focus for the review were included. It was not always apparent from the abstract alone if an article was relevant. For this reason, a large number of literature sources were screened by inspecting the full text of the document. Further detailed screening of the full text of these documents excluded an additional 691 literature sources. This left 369 sources that were deemed eligible for inclusion in the literature review.

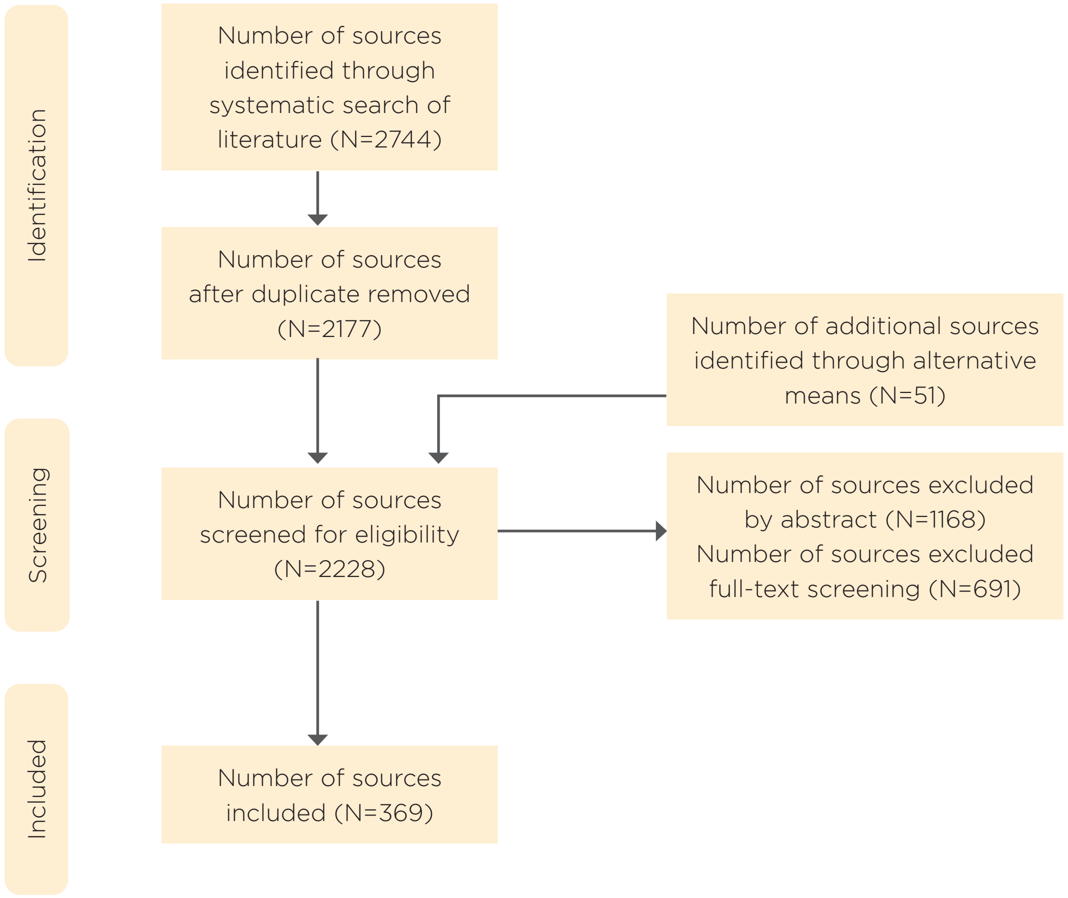

Figure 1: Screening result

4.2. Overview of included studies

The included literature sources address the focal topics for this review to differing extents. As shown in Table 1, there were large numbers of literature sources that provide information about improving quality of services, access to services, and skills of the clinical workforce, patients, and families. There were a moderate number of literature sources about improving uptake of advance care planning and improving research and data collection. Relatively fewer literature sources provided information to inform improving collaboration between the States, Territories, and the Commonwealth and knowledge of palliative care across the community. No unique literature sources were identified in relation to improving dissemination of information that were not already addressed in another topic (see Section 4.2.7 for details).

Table 1: Number of literature sources addressing each topic

Topic	Number of sources
Improving quality of paediatric palliative care services	137
Improving access to services	128
Improving uptake of advance care planning	62
Improving skills of the clinical workforce, patients, and families	133
Improving research and data collection	68
Improving collaboration across jurisdictions	9
Improving dissemination of information	N/A
Improving community knowledge of paediatric palliative care	7

4.2.1. Improving quality of services

Of the 369 literature sources included in this review, 137 provided information that can inform initiatives to improve the quality of paediatric palliative care in acute and community care settings.[3,5,8,26,27,31,47-177] Just under one third of these literature sources were systematic or literature reviews, considering the findings of literature produced across multiple countries and healthcare systems. Approximately one quarter of the sources were from and related to the United States of America (USA). The next equal largest proportions of sources were from and related to Australia[5,8,26,27,59,65,92,109,111,152,172,175] and the UK. A range of evidence were reported across these literature sources, spanning qualitative and quantitative methods. Information was most often obtained from clinicians, but information was often also obtained from parents. Information was rarely obtained from child patients or their well siblings. Across the literature sources, there was information relating to patients with oncological and non-oncological conditions, although this was not clear in all literature sources. The literature sources included information relating to a range of patient ages, spanning perinates to young adults, although this could not always be conclusively determined from the information included in individual literature sources. Compared to literature reviewed in other sections of this report, there was particular emphasis on perinatal populations in relation to improving the quality of paediatric palliative care.

Once synthesised, the information contained in these literature sources provide evidence to improve the quality of paediatric palliative care by promoting patient- and family-centred care, fostering partnerships across a range of healthcare professions and care settings, and through the use of benchmarks for care. These are considered in turn. Evidence supporting other means to improve the quality of paediatric palliative care were also identified and are considered in other sections of this report. These include early integration of paediatric palliative care (see Section 4.2.2), using advance care planning to enhance quality of care (see Section 4.2.3), ensuring provision of care across diverse settings (see Section 4.2.2), promoting quality of care through the education for the clinical workforce (see Section 4.2.4), and using data to inform continuous quality improvement (see Section 4.2.5).

Patient- and Family-Centred Care

There is a sizable body of literature that supports improving quality of paediatric palliative care services by promoting patient- and family-centred care.[26,54,59-61,64,103,106,118-158,173] This is an objective that is recommended by the World Health Organization,[173] the Australian Commission for Quality and Safety in Healthcare,[59] Palliative Care Australia,[26,27] and Paediatric Palliative Care Australia & New Zealand.[27] Family-centred care extends beyond a child patient's parents or guardians, to include other family members, such as a patient's well siblings.[123,127,130] Depending on their individual circumstances, there is scope for even very young patients to participate in their own care.[64] Beyond child patients, parents are typically the most expert about their children,[130] and thus their involvement through family-centred care is essential to maximise quality of services. This care should continue as death approaches, and beyond death into bereavement.[60,135,137,149,151,153,154]

A review published in 2013 argues there is a lack of evidence about whether current services are meeting the needs of patients and families.[141] Nevertheless, there are sources that identify tangible ways to promote patient- and family-centred care. For example, ensuring continuity of care by a clinician who is known and trusted by a child and their family is one way to deliver patient- and family-centred care.[120,129,130,133,136] It is also important to consider diverse ways services can promote patient- and family-centred care. For example music therapy can be tailored to suit the needs of individual patients and their families,[118] creating opportunities to empower patients.[119]

Advance care planning provides opportunities to promote patient and family centred care by facilitating conversations where patients and family members can express their preferences and discuss these with clinicians.[123,131,132,143] Improving uptake of advance care planning is considered in detail in Section 4.2.3. Similarly, Queensland Health promotes the development and use of patient and family charters as means to encourage patients and families to expect to be actively involved in making decisions about a child's care.[152]

The transition of adolescents with life-threatening or life-limiting conditions from paediatric to adult services is a period when patient- and family-centred care can be particularly important.[54,155-158] Documented ways of managing this include transition programs.[157,158] Support for transitioning paediatric palliative care to adult services is recommended by the World Health Organization,[173] the Australian Commission for Quality and Safety in Healthcare,[59] and Palliative Care Australia.[26]

Key Question:

What are the current priorities in Australia for ensuring patient- and family-centred care for children with life-threatening or life-limiting conditions, within and beyond specialist paediatric palliative care?

Fostering partnerships across a range of healthcare professions and care settings

In addition to the central importance of ensuring patients and families are partners in planning and providing care, there is a sizable body of literature describing the importance of multidisciplinary care for improving the quality of paediatric palliative care.[3,5,26,27,47-117] In addition to peer-reviewed literature, a multidisciplinary approach to paediatric palliative care is recommended by the World Health Organization,[3] the Australian Commission for Quality and Safety in Healthcare,[59] Palliative Care Australia,[26,27] and Paediatric Palliative Care Australia & New Zealand.[27] There are a range of advantages of multiple healthcare disciplines contributing to paediatric palliative care,[47,54,56,68,70,71,76,78,80,82,91] especially in relation to ensuring effective psychological, social, and spiritual care.[47,54,56,68,70,71,76,80,82,91] Evidence-based guidelines from the UK suggest the composition of a multidisciplinary paediatric palliative care team should depend on the needs of an individual child and their family.[60]

Beyond specialist paediatric palliative care services, there are recognised benefits from fostering partnerships between specialist paediatric palliative care services and other acute care specialities.[3,27,48,50,51,57,59,61,72,73,75,83-106,108,168,171,174] This need was identified particularly in perinatal care.[3,48,51,72,83-85,90,92,95,96,98-100,103,105,168,174] A multidisciplinary approach across acute care settings is recommended by the World Health Organization,[3] the Australian Commission for Quality and Safety in Healthcare,[59] Palliative Care Australia,[26,27] and Paediatric Palliative Care Australia & New Zealand.[27] There are a range of models for engaging specialist paediatric care with other specialities (e.g., the consultative model[87,97,171]), but no literature could be identified in this review suggesting one model is superior to others.

In addition to acute care settings, there are recognised benefits from fostering partnerships between specialist paediatric palliative care services and a diverse range of community healthcare services, including but not limited to community palliative care.[27,60,81,107,109-117,172] In addition to peer-reviewed literature, this multidisciplinary approach spanning acute and community care is recommended by the Australian Commission for Quality and Safety in Healthcare,[59] Palliative Care Australia,[26,27] and Paediatric Palliative Care Australia & New Zealand,[27] including across sectors such as education and disability services.[26,59] One strategy used in Australia to enhance quality of paediatric palliative care across acute and community settings is the 'pop up' model, where specialist paediatric palliative care services provide responsive support to local acute- and community-based care services. This can be especially useful for ensuring quality of care beyond the major cities of Australia, where specialist paediatric palliative care services are located.[26,172]

Notwithstanding the recognised benefits of multidisciplinary care, the involvement of different healthcare professions, often working across different acute and community care settings, can create challenges for integrating care.[49] A common strategy for managing integration that is reported in the literature is through care coordinators (sometimes referred to with alternative terms, such as 'key workers').[5,26,49,52,53,55,57,58,62,64,65,67,79,99] The World Health Organization,[3] the Australian

Commission for Quality and Safety in Healthcare,[59] and Palliative Care Australia[26] advocate for ensuring processes are in place to support care coordination and continuity. In Australia, this can be especially important for families living outside major cities.[55,65] Another approach involves making electronic medical records accessible to a patient's care teams in both hospital and community settings.[81]

Key Question:

What are the current priorities in Australia for fostering partnerships across a range of healthcare professions and care settings involved in paediatric palliative care?

Settings benchmarks for quality of paediatric palliative care

Many sources identify documents such as guidelines, frameworks, and policies as means for setting benchmarks for high-quality paediatric palliative care.[8,31,50,75,83,90,143,159-170] There is recognition that guidelines will require adaptation to suit particular populations, such as neonates[160] and adolescents,[50] and specific aspects of care, such as symptom management.[143,163,164]

A practical guide to paediatric palliative care was published in Australia in 2014[175] and service development guidelines in 2018.[26] Future iterations of these guidelines could be informed by guideline development methodologies that have been used in other countries. For example, there are clinical practice guidelines in the USA. These were developed by the National Coalition for Hospice and Palliative Care by conducting reviews of published systematic reviews,[176] the results of which were translated into guidelines by an expert committee.[177] The most recent version of these guidelines, published in 2018, cover both paediatric and adult palliative care. However, most evidence in these guidelines relates to adult palliative care, with some aspects of the guidelines informed by little to no evidence relevant to paediatric palliative care. An alternative approach has been adopted in the UK. In 2016, the National Institute for Clinical Excellence (NICE) published guidelines specifically addressing end of life care for infants, children, and young people.[60] These were developed on the basis of systematic reviews that were conducted specifically to develop the guidelines. Where there were gaps in available evidence, such as in relation to the perspective of child patients, these were addressed through commissioned focus group research or by the expert opinion of the guideline committee. Existing methodologies for developing guidelines could be considered for the development of future paediatric palliative care guidelines in Australia.

Key Question:

Should methodologies used to develop guidelines for paediatric palliative care in other countries (e.g., the NICE guidelines in the UK) be considered to update paediatric palliative care guidelines for Australia?

In addition to the initiatives considered in this section of the report, quality indicators can also be used to set and evaluate benchmarks. This is considered in Section 4.2.5.

4.2.2. Improving access to services

Of the 369 literature sources included in this review, 128 provided information that can inform initiatives to improve access to paediatric palliative care.[3,26,27,50,51,55,59-61,64,65,72,75,80,82,88,90,91,95,97,103,104,107,111,113,122,130,132,135,137,138,140,146,154,157,167,172,178-268] Approximately two fifths of the literature sources reported systematic or literature reviews, considering the findings of literature produced across multiple countries and healthcare systems. Approximately another two fifths of the literature sources were from and related to the USA. The next equal largest proportions of literature sources were from and related to Australia[26,59,65,111,118,119,172,240,246-250,267,268] and the UK. A range of evidence was reported across these literature sources, spanning qualitative and quantitative methods. Information was most often obtained from clinicians, but information was often also obtained from parents. Information was only occasionally obtained from child patients and rarely from their well siblings. Across the literature sources, there was information relating to patients with oncological and non-oncological conditions, although this was not clear in all literature sources. These literature sources included information relating to a range of patient ages, spanning perinates to young adults, although this could not always be conclusively determined from the information included in individual literature sources.

Once synthesised, the information contained in these literature sources identify early integration of paediatric palliative care services and supporting the provision of care in a variety of settings as ways to improve access to paediatric palliative care. The synthesis also identified the importance of considering the specific needs of culturally and linguistically diverse populations. These three ways to improve access to paediatric palliative care are each considered in turn.

Early integration of paediatric palliative care

A large proportion of literature sources highlight the importance of early integration of paediatric palliative care as means to increase access to this type of care for those who are likely to benefit from it.[3,26,27,50,51,59,61,72,75,80,88,90,95,97,103,104,113,122,130,132,140,146,154,157,167,178-220,245,261-266] Early integration is most commonly defined as the concurrent provision of treatment offered with curative and palliative intent.[3,27,50,95,97,130,180,184,192,193,199,201,205,262] Early integration of paediatric palliative care is recommended by the World Health Organization,[3] the Australian Commission for Quality and Safety in Healthcare,[59] Palliative Care Australia,[26,27] and Paediatric Palliative Care Australia & New Zealand.[27] The integration of paediatric palliative care can occur as early as during the provision of antenatal care.[27,72,90,103,130,186,189]

The most common strategy for supporting early integration of paediatric palliative care is through the adoption of one or more 'triggers' that indicate referral to specialist paediatric palliative care should be made.[61,65,75,97,167,178,179,182,183,191,194,198,206,220,245,260] Many different triggers are discussed in the literature. These range from relatively more objective triggers, such as diagnosis of a life-threatening condition,[51,95,193,203,216] to relatively more subjective triggers, such as a clinician's judgement that a patient's death is possible within the next year.[178] In addition to single triggers, attempts have been made to combine multiple triggers into referral tools, such as the Paediatric Palliative Screening Scale (PaPaS).[178,220] Within the scope of the current review, no evidence was identified suggesting the superiority of any particular trigger, or triggers, over possible alternatives. Reflecting the absence of evidence, there is recognised need for better referral tools.[196] Embedding routine data collection, as described in Section 4.2.5, may integrate additional triggers for referral to specialist paediatric palliative care.

Key Question:

What are the key requirements for ensuring early integration of paediatric palliative care for children with life-threatening or life-limiting conditions in Australia?

Supporting the provision of care in a variety of settings

Many literature sources highlight the importance of improving access to paediatric palliative care by supporting the provision of care in a variety of settings, including at the end of a child's life.[3,27,60,64,91,107,130,135,137,188,204,221-237] Supporting the provision of care in a variety of settings is recommended by the World Health Organization,[3] the Australian Commission for Quality and Safety in Healthcare,[59] Palliative Care Australia,[26,27] and Paediatric Palliative Care Australia & New Zealand.[27] This can include settings such as a child's home, a hospital, or a hospice, and can accommodate shifting the location of care in response to changes in circumstances or preferences. Ensuring access to respite care is crucial for supporting the provision of paediatric palliative care in diverse settings, by ensuring families have opportunities to manage the needs of their child with a life-threatening or life-limiting condition alongside the needs of other family members.[60,107,111,138,204,238-243] Planning policies should incorporate ways to provide such care across challenging circumstances that are beyond the control of families and clinicians, such as during pandemics.[244]

Key Question:

What are the key requirements for ensuring provision of paediatric palliative care in a variety of settings in Australia?

In Australia, a population dispersed across vast geographical space creates challenges for ensuring equitable access to specialist services, including paediatric palliative care. Support for families living in regional, rural, and remote parts of Australia can be improved through use of a 'pop-up' model of care, which involves a specialist paediatric palliative care service working with a child's family and local health services to develop a network that supports the needs of an individual child.[172,245] This pop-up model underpins the Quality of Care Collaborative Australia in Paediatric Palliative Care (QuoCCA), which is further considered in Sections 4.2.4, 4.2.6, and 4.2.8. One review calls for additional research to develop further evidence about the utility of the pop-up model.[245] An alternative approach, adopted in places such as Victoria, involves the use of regional offices for services such as a children's hospice.[55]

In addition to inpatient and outpatient consultations, telehealth technologies increasingly provide opportunities to deliver a variety of care from a distance.[27,65,172,214,246-254] Access to care can also be enhanced through an after-hours phone service that connects families with specialist paediatric palliative care.[60,65,82,107,204,228,242,243,245,255,256]

Key Question:

Should existing approaches for improving access to paediatric palliative care in Australia be evaluated, to determine whether they are meeting the needs of families and promoting equitable access?

Culturally and linguistically diverse populations

A small body of literature highlights the importance of considering the specific needs of culturally and linguistically diverse populations.[3,26,59,181,226,257-259] The World Health Organization,[3] the Australian Commission for Quality and Safety in Healthcare[59] and Palliative Care Australia[26] advocate for ensuring capacity in the clinical workforce to accommodate the unique needs of culturally and linguistically diverse populations. In Australia, particular emphasis is placed on the provision of culturally responsive end-of-life care to Aboriginal and Torres Strait Islander people.[26,59]

Key Question:

What initiatives are required to ensure paediatric palliative care is meeting the needs of the culturally and linguistically diverse population of Australia?

4.2.3. Improving uptake of advance care planning

Advance care planning is "...a process of discussions between families and health care providers about preferences for care, treatments and goals in the context of the patient's current and anticipated future health".[269] The benefits of advance care planning include promoting consensus about the best possible way to care for a child, including maximising the quality of their life and avoiding unnecessary suffering.[270] Advance care planning is recommended by the World Health Organization,[3] the Australian Commission for Quality and Safety in Healthcare,[59] Palliative Care Australia,[26,27] and Paediatric Palliative Care Australia & New Zealand.[27] In spite of the recognised benefits of advance care planning, evidence suggests that many children with life-threatening or life-limiting conditions who are likely to benefit from advance care planning either do not receive this at all or receive it close to the end of their life, when its usefulness can be limited.[271]

Of the 369 literature sources included in this review, 62 provided information about improving uptake of advance care planning.[3,26,27,59-61,79,84,85,94,112,132,152,165,166,170,195,204,208,210,237,262-266,271-307] Most literature sources were from and related to the USA, with the second greatest number coming from and relating to Australia.[26,27,59,152,263,272,273,275,281,306] A range of types of evidence were used across these literature sources, spanning qualitative and quantitative methods. There were literature sources that include information obtained from clinicians, parents, and patients. Across the literature sources, there was information relating to patients with oncological and non-oncological conditions, although this could not always be conclusively determined from information included in individual literature sources. These literature sources included information relating to a range of patient ages, spanning neonates to young adults, although this could not always be conclusively determined from information included in individual literature sources.

Once synthesised, the information contained in these literature sources provide evidence to enhance uptake of advance care planning through systems and population level interventions, patient- or family-focused interventions, and training for clinicians. These are considered in turn.

Systems and population level interventions

At the level of healthcare systems, literature sources contained information suggesting uptake of advance care planning will be improved by early integration of specialist paediatric palliative care (see also Section 4.2.2).[60,61,94,112,170,195,208,210,237,262-266,271,284,285,288,289,294,295,297-305] For example, a study in Queensland found patients receiving specialist paediatric palliative care are more likely to have advance care plans documented.[263] Support for increasing uptake of advance care planning through early integration of paediatric palliative care was found across a range of patient ages and conditions.

At a population level, there is some research evidence that uptake of advance care planning can be improved by developing policies and procedures that support proactive planning,[204,274] which is also recommended by the Australian Commission on Safety and Quality in Healthcare.[59]

> **Key Question:**
>
> Does the network of specialist paediatric palliative care in Australia have capacity to facilitate or support advance care planning for all children with life-threatening or life-limiting conditions who might benefit from this? If not, how might this capacity be developed? What alternatives might be possible?

Patient and family-focused interventions

There were literature sources that indicate uptake of advance care planning can be improved through interventions that are focused on patients or their families (e.g., resources that empower patients and families to discuss their preferences for care with clinicians).[79,132,166,273,277-280,282,292,293] For example, research conducted in Victoria suggests improvements to advance care planning through the use of resources written specifically for parents and carers.[306] Research also emphasises the importance of ensuring these interventions are targeted or adaptable to the needs of particular groups, such as adolescents and young adults[132,278,280,281,292] and culturally and linguistically diverse populations.[132] The provision of patient and family focused interventions to support advance care planning is recommended by the World Health Organization,[3] the Australian Commission for Quality and Safety in Healthcare,[59] Palliative Care Australia,[26,27] and Paediatric Palliative Care Australia & New Zealand.[27]

> **Key Question:**
>
> What patient- or family-focused advance care planning resources should be priorities for development or implementation in Australia?

Clinician training

There were literature sources included in the review highlighting the role of clinician training for improving uptake of advance care planning.[272,273,275,276,279,285,296,307] There is evidence suggesting simulation training increases clinicians' confidence in advance care planning.[275,276] There is also scope to use resources created for patients or families to increase clinicians' knowledge, understanding, and skills related to paediatric palliative care.[272,273] Many initiatives for increasing the skills of the clinical workforce in relation to paediatric palliative care more generally are applicable to clinician training that is designed to specifically improve uptake of advance care planning. Improving skills is considered in further detail in the next section.

4.2.4. Improving skills of the clinical workforce, patients, and families

Of the 369 literature sources included in this review, 133 provided information that can inform initiatives to improve the skills of the clinical workforce, patients, and families.[3,6,26,48,54,56,57,59,63,65,66,72,87,95,98-100,109,110,116,117,123,128,130,132,166,167,169,171,172,187,192,207,214,216,219,242,253,260,272,273,275,276,284,292,296,308-387] Beyond literature sources with an international scope, the largest proportion of literature sources were from and related to the USA. The third largest proportion of literature were from and related to Australia.[26,59,65,109,130,172,272,273,275,352,353,358] A range of types of evidence were used across these literature sources, spanning qualitative and quantitative methods. Information was overwhelmingly obtained from clinicians, but there were also literature sources that reported information obtained from patients and their families.[66,123,167,169,272,292,383-385] Across the literature sources, there was information relating to patients with oncological and non-oncological conditions, although this was not clear in all literature sources. These literature sources included information relating to a range of patient ages, spanning perinates to young adults, although this could not always be conclusively determined from the information included in individual literature sources.

Once synthesised, the information contained in these literature sources identified some limitations of this existing literature, as well as providing indicative information about the range of ways paediatric palliative care skills might be enhanced. These matters are considered in turn.

There are some important limitations to the literature sources reviewed below. First, most literature sources consider ways to improve the skills of the clinical workforce. The literature tended to focus on the skills of doctors and nurses, although there was also a sizable portion of literature sources that considered allied health professionals. Only a small proportion of the literature considered ways to improve the skills of patients and parents or guardians. No literature sources considering the skills of patients' well siblings were identified. Second, although many sources recommended skills training in specific areas (e.g., communication, symptom management, etc.), determining priorities for skills development was rarely the focus of this literature. This made it difficult to generalise this information to a broader population. Only two literature sources that specifically identify the range of training needs among clinicians were located through the review. One was a large study of oncologists in North America and the UK, which was published 20 years ago,[308] and the other was a more recent smaller study conducted via the Asia Pacific Hospice Network.[309] Due to the absence of evidenced-based information, the current review does not include a list of priority areas for skill development among the contemporary clinical workforce in Australia. Some information is available, however, through priority areas that have been identified by Palliative Care Australia.[26] Third, as considered below in further detail, there is an absence of robust evidence about optimal approaches to education for the different groups that would benefit from enhancing their skills in paediatric palliative care.[260]

Key Question:

What are the priorities for paediatric palliative care skills development for the clinical workforce in Australia?

Levels of clinician competence in adopting a palliative approach within paediatrics

There are calls across a range of literature sources for a general level of competence in palliative care across a range of specialties in paediatrics, in recognition that these clinicians are likely to encounter instances where a palliative approach to care will be appropriate.[3,26,48,56,57,59,63,65,72,87,98-100,116,128,130,132,166,192,207,242,260,296,308,310-345,386,387] This recognition of foundational competence in palliative care among all clinicians is recommended by the World Health Organization,[3] the Australian Commission for Quality and Safety in Healthcare[59] and Palliative Care Australia.[26] There are also calls for equipping adult palliative care clinicians with the skills they need to provide paediatric palliative care, particularly in areas where specialist paediatric palliative care is not available.[216,253,346-348] A hierarchy of skill levels may be useful for guiding investment in skills training.[3,87,310,320] For instance, core competencies in a palliative approach could be required for undergraduates and qualified paediatric professionals,[3,128,166,296,310,311,313,320,327,328,330,331,335,345] general palliative care training for those more frequently involved in caring for children with life-threatening or life-limiting conditions,[3,87,310,320] and specialist paediatric palliative care training for those whose core activity is caring for children with life-threatening or life-limiting conditions.[3,310,320] Understanding unique aspects of care, such as for adolescent and young adult populations,[54,325] should be incorporated across these levels.

Key Question:

Should a hierarchy of skill levels be used to guide paediatric palliative care training across the Australian clinical workforce?

Centralising educational resources and curricula

A recent call has been made for developing central repositories of educational resources and curricula that suit the different contexts where paediatric palliative care is provided.[110] To achieve this, there may be scope to expand upon existing international initiatives. These include Education in Palliative and End-of-Life Care (EPEC-Pediatrics)[284,310,349-351] and the International Children's Palliative Care Network (ICPCN) eLearning programmes.[187,310] In addition to these curricula, there is an additional resource in Australia through the Quality of Care Collaborative Australia in Paediatric Palliative Care (QuoCCA), which is funded by the Australian Government. QuoCCA facilitates scheduled, pop-up, or incidental training, which is provided by tertiary paediatric palliative care services across Australia.[109,172,352,353]

Educational methods

The literature sources included in the current review contained a range of different educational methods for enhancing paediatric palliative care skills across the clinical workforce. Most of these are endorsed by the Australian Commission for Safety and Quality in Healthcare.[59] They include:

- Diverse approaches to identifying and accommodating learners' needs[172,192,315,353-356]
- Employing simulation-based learning[214,275,276,357-360]
- Facilitating experiential learning[6,132,192,308,323,334,353,356,361] (e.g., in Australia, clinical placements organised through the Program of Experience in the Palliative Approach [PEPA][353])
- Diverse approaches to promoting collaborative learning[95,117,171,216,219,346,362-367] (e.g., through morbidity and mortality meetings[365,366])
- Diverse approaches to incorporating family perspectives[214,272,273,323,350,356,368-371] (e.g., families as co-facilitators of education sessions[214,350,368,371])
- Delivering learning content via eLearning[132,187,192,311,372-374]
- Train-the-trainer approaches to education[284,350]
- Reflective learning[375]
- Problem-Based Learning (PBL)[376]
- Conferences[192]

There are different approaches reported across the included literature sources about the timing of attempts to improve skills amongst the clinical workforce. Some literature sources report that a single day-long period of training can be sufficient,[367,377,378] while other sources report the success of delivering training over time.[192,337,379-382]

Limitations of existing literature on developing skills of the clinical workforce

A limitation of the information synthesised above is that there is an absence of robust evidence about optimal timing and methods for delivering educational opportunities that will develop paediatric palliative care skills amongst the clinical workforce. This view is supported by a review conducted in 2016, which determined insufficient evidence was available to recommend optimal methods for skills training.[260] Although that review was limited to neonatal intensive care, the literature sources considered for the current review are consistent with this finding. That is, there is no clear evidence about which educational methods and the timing of their delivery are best suited for increasing skills in paediatric palliative care. There is thus considerable scope to better understand optimal education approaches to different groups that would benefit from enhancing their skills in paediatric palliative care.

Key Question:

Which approaches to developing clinicians' skills in paediatric palliative care are best suited for use in Australia?

Developing the skills of patients and families

Compared to the literature on the clinical workforce, there are considerably fewer literature sources that identify ways to improve skills amongst patients and their families. There are some literature sources that address the usefulness of resources that can empower families.[66,167,169,272,292,383,384] There is also information about initiatives that help foster resilience amongst patients[123] and families.[66,123,385] There remains considerable scope to understand optimal initiatives to enhance the skills of patients, their parents or guardians, and their well siblings.

Key Question:

What are priorities for developing the skills of children with life-threatening or life-limiting conditions and their families?

Overall, the literature sources included in this part of the review indicate the range of ways paediatric palliative care skills might be enhanced. Nevertheless, in the absence of clear understanding about optimal ways of enhancing skills, the development of this aspect of the National Action Plan should be informed by close consultation with key stakeholders.

4.2.5. Improving research and data collection

Of the 369 literature sources included in this review, 68 provided information that can inform initiatives to improve research and data collection in paediatric palliative care.[26,27,31,47,50,59,66,92,95,107,110,112,123,137,157,163,173,187,188,220,226,252,254,257,283,291,316,324,365,371,384,388-423] Although literature sources were produced in a range of countries, almost half were from and related to the USA. The next largest proportion of literature sources were from and related to Australia.[26,27,59,92,423] A range of types of evidence were used across these literature sources, spanning qualitative and quantitative methods. Information was most often obtained from clinicians, but there were also literature sources that reported information obtained from patients and their parents. Across the literature, there was information relating to patients with oncological and non-oncological conditions, although this this was not clear in all literature sources. These literature sources included information relating to a range of patient ages, spanning neonates to young adults, although this this was not clear in all literature sources.

Once synthesised, the information contained in these literature sources describe challenges for research, and advocate for enhancing routine data collection, promoting research in recognised areas of importance, and ensuring representation of key stakeholders. These are considered in turn.

Challenges for research in paediatric palliative care

There are recognised challenges for conducting research in paediatric palliative care.[50,107,163,388,393,397,404,407,417,422,423] Randomised controlled trials (RCTs) are often considered to be the 'gold standard' for research,[424] but the small and heterogenous population of children with life-threatening or life-limiting conditions makes this approach challenging. This has led some to argue that there is no 'gold standard' method to evaluate paediatric palliative care,[107] while others have advocated strategies to make RCTs viable.[397,404] There is recognition that the challenges confronting research in paediatric palliative care necessitate methodological innovation, including the use of multiple quantitative and qualitative methods, which may ultimately benefit paediatric palliative care and research more broadly.[397] For example, pharmacological research often involves RCTs, but this can be particularly challenging in paediatric palliative care.[163,417] Alternative approaches, such as the Rapid Paediatric Program in Australia, offer innovative alternatives, but there were no outcomes from this new approach at the time of writing this report.[425]

Enhancing routine data collection

More than half the studies related to this topic advocate for enhancing routine data collection. Most often, this routine data collection was recommended for informing continuous quality improvement, but there were also recognised benefits for using these data in research. There have been calls to develop national data collection systems for paediatric palliative care.[226,254,291,324,394,397-400] Most of the literature sources advocating for such a system have been produced in the USA. No literature source from Australia advocating for such a system was identified, so the applicability of this recommendation to the Australian context is unclear. The Australian Government funds the Palliative Care Outcomes Collaboration (PCOC), which undertakes routine data collection in adult palliative care.[426] The most recent PCOC report includes some data that relates to children, adolescents, and young adults.[426]

In addition to calls to enhance routine data collection through a national data collection system, there are also calls to develop and implement quality indicators that are relevant for the specific needs and characteristics of paediatric palliative care. These calls come from the World Health Organization,[173] the Australian Commission on Safety and Quality in Healthcare,[59] Palliative Care Australia,[26] and in peer-reviewed publications.[31,47,92,95,110,112,137,188,220,226,254,365,384,389,392,395-398,401,403,405,406,409,411-413,415,416,418-421] The review did not identify specific quality indicators that have been developed or adapted for the Australian context. It may be that new indicators need to be designed for this context. Alternatively, it might be possible to adapt existing indicators, such as the Children's Palliative Outcome Scale (C-POS).[403]

Key Question:

What is needed to facilitate routine data collection that supports continuous quality improvement in paediatric palliative care in Australia? How can nationwide data collection be facilitated? Which quality indicators are priorities for paediatric palliative care in Australia?

Promoting research priorities

There have been many projects undertaken that identify priorities for research in paediatric palliative care.[31,123,157,187,252,283,391,402,408,410] Most often these have identified clinicians' priorities, but there have also been attempts to understand priorities of children and their families.[391] Some of these projects are international in scope, while others are specific to particular countries. No literature source could be identified identifying priorities in the Australian context, although investment in research is recommended by Palliative Care Australia[27] and Paediatric Palliative Care Australia & New Zealand.[27]

Key Question:

Are international priorities sufficient to guide paediatric palliative care research in Australia, or is there a need to identify priorities for paediatric palliative care research in Australia?

Ensuring representation of key stakeholders

Almost one third of the literature sources included for this topic advocate for representation of key stakeholders across the research process.[66,107,112,257,316,371,390,391,397] Most of these call for direct engagement with patients and families,[66,107,112,371,390,391] although there are also calls to ensure representation of diversity[257] and to ensure the involvement of clinicians in research.[316,397] The latter are considered important not only to ensure the clinical relevance of research, but also to support clinicians to develop skills as practitioner-researchers.

4.2.6. Improving collaboration across jurisdictions

Both federal and state or territory governments have a role in the development, funding, and provision of paediatric palliative care in Australia.[353] Service development guidelines produced by Palliative Care Australia advocate for planning across jurisdictions to ensure every child with a life-threatening or life-limiting condition and their family will have access to at least one specialist paediatric palliative care service, even if that child lives in a state or territory that does not have a specialist service.[26] Collaborations across jurisdictions are already facilitated through Paediatric Palliative Care Australia & New Zealand[27] (formerly known as the Australian and New Zealand Paediatric Palliative Care Reference Group[353]) and the Quality of Care Collaborative Australia in Paediatric Palliative Care (QuoCCA), which is funded by the Australian Government.[109,352] The literature review identified a small body of literature, from both Australia and internationally, that can inform improving collaboration between the States, Territories, and the Commonwealth.

Of the 369 literature sources included in this review, nine provided information that have some relevance to the Australian context and may be useful for improving collaboration between the States, Territories, and the Commonwealth.[26,59,109,352,353,355,398,399,427] There were five literature sources that were produced in and related to Australia,[26,27,109,352,353] with the remainder from other countries that are also comprised of multiple government jurisdictions. Most literature sources report descriptive studies using quantitative or qualitative methodologies. The literature sources typically covered both oncological and non-oncological conditions. Although a variety of age groups were covered, no specific focus on neonates was identified. Given the large proportion of neonatal deaths relative to other age groups within the paediatric population,[3,428] this may constitute an important gap in information.

The Australian literature highlights the importance of enhancing collaboration by ensuring that state-based services are developed and delivered in line with best-practice guidelines, including those developed at the national level.[353] Since the publication of this recommendation in 2014, additional national guidelines have been made available. These include a national consensus statement on paediatric end-of-life care, produced by the Australian Commission on Safety and Quality in Health Care,[59] and a paediatric addendum to palliative care service guidelines, produced by Palliative Care Australia.[26] There have been similar calls in other countries, such as the UK, to scope current policies and practices to ensure a shared vision for paediatric palliative care and consistency across jurisdictions in working to achieve this vision.[355]

QuoCCA provides the clearest example of government-funded collaboration in paediatric palliative care that has been subject to evaluation.[109,352] The educational arm of QuoCCA involves formal educational sessions in central locations, such as major cities, and a 'pop-up' model that can bring specialist paediatric palliative care services and support to regional locations. The 'pop-up' approach establishes a tailored network to help facilitate the 'right care in the right place at the right time'.[172] Evidence suggests this approach has enabled QuoCCA to operate successfully across jurisdictional boundaries to improve quality of care, access to care, skills within the clinical workforce, and knowledge within the community.[109] A coordinated and networked approach to care is also reported in a literature source published in England in 2016, which suggests managed clinical networks may help families make choices about the place of care and death, and increase access to professionals with the skills and expertise needed to care for their child.[427] It is unclear from the literature whether the 'pop up' model has scope to meet current and future levels of need with current funding arrangements and human resources.

Key Question:

Does the 'pop up' model delivered through the Quality of Care Collaborative Australia in Paediatric Palliative Care (QuoCCA) provide a basis for further enhancing collaboration between the States, Territories, and the Commonwealth? Is this model scalable to support a whole-of-population approach? Are there other models that might enhance or provide an alternative to this approach?

Literature sources from Germany and the USA suggest that national governments can facilitate collaboration across national jurisdictions by supporting national-level data collection on children with life-threatening or life-limiting conditions and paediatric palliative care services.[398,399] Improving research and data collection was considered in detail in Section 4.2.5.

4.2.7. Improving dissemination of information

The syntheses reported in Sections 4.2.1 (improving quality), 4.2.2 (improving access), 4.2.3 (improving uptake of advance care planning), 4.2.4 (improving skills), and 4.2.5 (improving research) contained information about improving dissemination of information between families and clinicians, among clinicians, and across care settings. The review did not identify additional information that was not already synthesised within these topics. The key findings of these syntheses that are relevant for improving dissemination of information are:

- Promoting patient- and family-centred care care, to ensure the expertise and preferences of patients and families inform the provision of care (Section 4.2.1)
- Fostering partnerships across a range of healthcare professions and care settings (Section 4.2.1)
- Managing dissemination of information through care coordination (Section 4.2.1)
- Using routine data collection and 'triggers' to support early integration of paediatric palliative care and the effective concurrent provision of care with curative and palliative intent (Sections 4.2.5 and 4.2.2)
- Ensuring a general level of competence in adopting a palliative approach across the clinical workforce, including to support early integration of paediatric palliative care (Section 4.2.4)
- Improved documentation of information through advance care planning (Section 4.2.3), which can be enhanced through early integration of specialist paediatric palliative care (Sections 4.2.2 and 4.2.3).

Key Question:

What are the optimal ways to comprehensively identify all stakeholders in a child's care and ensure they have a shared understanding of the needs and care that is necessary for that child and their family?

4.2.8. Improving community knowledge

Improving knowledge of palliative care within the community is likely to enhance other focal areas for improvement that are considered in this literature review. For example, there is research evidence indicating that members of the general community were more likely to approve of paediatric palliative care once they understood that it focuses on alleviating symptoms and enhancing quality of life.[429] At a general level, improving community knowledge of paediatric palliative care shares foundational objectives with improving knowledge of adult palliative care. This includes attempts to address reluctance in society to discuss dying and death and correcting misunderstandings of the focus of palliative care, especially how it can be delivered alongside care that is provided with curative intent.[50]

Although improving community knowledge is known to be critical, few literature sources were identified through the review that inform improving community understanding of paediatric palliative care. Of the 369 literature sources included in this review, seven provided information that have some relevance to the Australian context.[79,109,352,353,430-432] There were three literature sources from Australia,[109,352,353] with the next largest proportion from Italy[430,431] and the USA.[79] The sources report information obtained through a range of quantitative and qualitative research methods. The literature sources typically covered both oncological and non-oncological conditions and a variety of age groups.

Education initiatives of the Quality of Care Collaborative Australia in Paediatric Palliative Care (QuoCCA) demonstrate that community knowledge of paediatric palliative care can be improved by delivering education sessions for community groups.[109,352] This initiative builds on community-level support provided by specialist paediatric palliative care to individuals and community groups connected to children with life-threatening or life-limiting conditions.[353] These literature sources indicate there is existing knowledge and strategy within Australia for improving knowledge of paediatric palliative care across the community, however this approach relies on specialist paediatric palliative care services. No literature sources identified from Australia addressed a whole-of-community approach to improving knowledge of paediatric palliative care.

In Italy, there has been recognition of the need to promote death literacy within schools.[432] Community knowledge of palliative care was improved through a high school-based intervention about severe illness and palliative care. The intervention involved screening a movie, an interactive debate with experts, classroom meetings chaired by a psychologist and hospice nurse, and a class-based multimedia production about coping with severe illness.[430,431] Following this intervention, high school students demonstrated an improved understanding of the focus of palliative care on improving quality of life.

There is limited evidence suggesting benefits from working with communications specialists and pursuing publicity opportunities as means to promote community understanding of paediatric palliative care.[79] There is scope for further work in this area. There is also scope to consider how existing initiatives that involve community engagement in relation to paediatric palliative care, such as fundraising undertaken by paediatric hospices,[433] provides opportunities to improve community knowledge.

Key Question:

How can existing community-based initiatives for improving knowledge of paediatric palliative care be expanded to ensure coverage of the general Australian community?

Appendix A: Search strategy

CINAHL: 30.10.2020		
Search #	Search terms	Results
1	(MH"Models, Theoretical"=/OG") OR "model of care" OR model	**578,147**
2	model OR "model of care" OR "Integrative model" OR "Liaison model" OR "Pop-up model" OR "Shared care model" OR "Team-based model" OR "Multidisciplinary team model" OR "Trajectory model" OR "capacity building" OR "building capacity" OR quality OR improve* OR education OR training OR skill* OR access OR knowledge	**2,229,195**
3	S1 OR S2	**2,229,195**
4	Paediatric OR pediatric OR child* OR adolescent* OR teen* OR infant OR neonat* OR young	**1,271,895**
5	Evaluat* OR assessm* OR compar* OR apprais* OR review OR descri* OR account OR report OR narrative	**3,212,079**
6	(MM "Palliative Care")	**25,346**
7	S3 AND S4 AND S5 AND S6	**1,000**
8	Expanders - Apply equivalent subjects Narrow by Subject Age: - fetus, conception to birth Narrow by Subject Age: - infant, newborn: birth-1 month Narrow by Subject Age: - infant: 1-23 months Narrow by Subject Age: - child, preschool: 2-5 years Narrow by Subject Age: - all infant Narrow by Subject Age: - adolescent: 13-18 years Narrow by Subject Age: - child: 6-12 years Narrow by Subject Age: - all child Narrow by Language: - English Search modes - Boolean/Phrase	
Medline 30.10.2020		
1	(MH"Models, Theoretical"=/OG") OR "model of care" OR model	**3,718,029**
2	model OR "model of care" OR "Integrative model" OR "Liaison model" OR "Pop-up model" OR "Shared care model" OR "Team-based model" OR "Multidisciplinary team model" OR "Trajectory model" OR "capacity building" OR "building capacity" OR quality OR improve* OR education OR training OR skill* OR access OR knowledge	**8,060,323**
3	S1 OR S2	**8,060,323**
4	Evaluat* OR assessm* OR compar* OR apprais* OR review OR descri* OR account OR report OR narrative	**12,548,745**
5	Paediatric OR pediatric OR child* OR adolescent* OR teen* OR infant OR neonat* OR young	**5,174,738**
6	(MM "Palliative Care")	**31,139**
7	S3 AND S4 AND S5 AND S6	**1,568**

8	Expanders - Apply equivalent subjects Narrow by SubjectAge: - infant: 1-23 months Narrow by SubjectAge: - infant, newborn: birth-1 month Narrow by SubjectAge: - child, preschool: 2-5 years Narrow by SubjectAge: - all infant: birth-23 months Narrow by SubjectAge: - child: 6-12 years Narrow by SubjectAge: - young adult: 19-24 years Narrow by SubjectAge: - adolescent: 13-18 years Narrow by SubjectAge: - all child: 0-18 years Narrow by Language: - english Search modes - Boolean/Phrase	**1,211**
Embase 30.10.2020		
1	'model'/exp	**3,077,843**
2	evaluat* OR assessm* OR compar* OR apprais* OR review OR descri* OR account OR report OR 'narrative'/exp	**20,339,127**
3	'paediatric'/exp OR 'pediatric'/exp OR child* OR adolescent* OR teen* OR 'infant'/exp OR neonat* OR young	**5,716,453**
4	S1 AND S2 AND S3	**227,263**
5	'palliative therapy'/exp/mj OR 'palliative therapy'	**115,296**
6	model OR 'model of care' OR 'integrative model' OR 'liaison model' OR 'pop-up model' OR 'shared care model' OR 'team-based model' OR 'multidisciplinary team model' OR 'trajectory model' OR 'capacity building' OR 'building capacity' OR quality OR improve* OR education OR training OR skill* OR access OR knowledge	**10,779,631**
7	S4 AND S5 AND S6	**552**
Google Advanced Search 13.11.2020		
"palliative care" AND (Paediatric OR pediatric OR child* OR adolescent* OR teen* OR infant OR neonat* OR young) AND (model OR "capacity building" OR "building capacity" OR quality OR improve* OR education OR training OR skill* OR access OR knowledge)		**379**

Appendix B: Information extraction tool

Source	Author (date) Select one: Journal article / Website / Report
Location	*Specify as much of the following as possible:* Country / State / Territory
Level of evidence	**Level of evidence:** *Select one of the following:* • Expert opinion • Consensus guidelines • Descriptive study (qualitative) • Descriptive study (quantitative) • Descriptive study (mixed-methods) • Intervention study (non-RCT) • Intervention study (RCT) • Systematic review • Evidence-based guidelines • Delphi Study • Literature review • Other (please specify) **Information source:** Select those that apply: • Clinicians • Parents • Patients • Siblings • Other (please specify)
Sample / Population Characteristics	*Where information is available, specify the following categories. Where specific information is not available, describe setting (e.g., paediatric hospice)* • Perinatal • Neonatal • Child • Adolescent • Young Adult • Oncological • Non-Oncological • Doctors • Nurses • Allied Health Professionals • Healthcare Students • School Teachers • Other (please specify)
Major findings	*Where information is available, write a paragraph (>300 words) on each of the following domains for the review, using the below sentence stems where possible. Where relevant, briefly comment on transferability of findings to the Australian context.* • Quality of services in the community and acute care can be improved by… • Access to services can be improved by… • Skills of the clinical workforce / parents / carers / patients / siblings can be improved by… • Knowledge of palliative care across the community can be improved by… • Collaboration between jurisdictions can be improved by… • Research and data collection can be improved by… • Uptake of advanced care planning can be improved by… • Dissemination of information can be improved by…

Appendix C: Literature sources addressing improving quality

Please note the following list only includes literature sources relating to the topic of improving quality of services. The full list of references cited in the literature review is located at the end of this report.

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Appendix D: Literature sources addressing improving access

Please note the following list only includes literature sources relating to the topic of improving access to services. The full list of references cited in the literature review is located at the end of this report.

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Appendix E: Literature sources addressing improving uptake of advance care planning

Please note the following list only includes literature sources relating to the topic of improving uptake of advance care planning. The full list of references cited in the literature review is located at the end of this report.

3. World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course. Resolution WHA6719. Sixty-seventh World Health Assembly, Geneva, 19–24 May 2014.

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Appendix F: Literature sources addressing improving skills

Please note the following list only includes literature sources relating to the topic of improving skills of the clinical workforce, patients, and families. The full list of references cited in the literature review is located at the end of this report.

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Appendix G: Literature sources addressing improving research and data collection

Please note the following list only includes literature sources relating to the topic of improving research and data collection in paediatric palliative care. The full list of references cited in the literature review is located at the end of this report.

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Appendix H: Literature sources addressing improving collaboration

Please note the following list only includes literature sources relating to the topic of improving collaborations across the States/Territories and the Commonwealth. The full list of references cited in the literature review is located at the end of this report.

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Appendix I: Literature sources addressing improving dissemination of information

The review did not identify additional information that was not synthesised within other topics, which were reported in Sections 4.2.1 (improving quality), 4.2.2 (improving access), 4.2.3 (improving uptake of advance care planning), 4.2.4 (improving skills), and 4.2.5 (improving research). The reference lists for these topics include literature sources that contain information about improving dissemination of information between families and clinicians, amongst clinicians, and across care settings.

Appendix J: Literature sources addressing improving community knowledge

Please note the following list only includes literature sources relating to the topic of improving community knowledge of paediatric palliative care. The full list of references cited in the literature review is located at the end of this report.

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