



**Paediatric  
Palliative care**  
NATIONAL ACTION PLAN PROJECT

# Paediatric Palliative Care National Action Plan Thematic Summary

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**Paediatric  
Palliative Care**  
AUSTRALIA & NEW ZEALAND



**PalliativeCare**  
AUSTRALIA

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## List of abbreviations

<b>AHPRA</b>	Australian Health Practitioner Regulation Agency
<b>ACCHO</b>	Aboriginal Community Controlled Health Organisation
<b>CALD</b>	Culturally and Linguistically Diverse
<b>GP</b>	General Practitioner
<b>LHD</b>	Local Health District
<b>NGO</b>	Non-Government Organisation
<b>PCA</b>	Palliative Care Australia
<b>PCC4U</b>	Palliative Care Curriculum for Undergraduates
<b>PCOC</b>	Palliative Care Outcomes Collaboration
<b>QuoCCA</b>	Quality of Care Collaborative Australia
<b>SCV</b>	Safer Care Victoria

## Acknowledgement of Country

Palliative Care Australia (PCA) is in Canberra on the land of the Ngunnawal People. PCA wishes to acknowledge the traditional owners of this land, the Ngunnawal People and their elders past and present. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region.

## Disclaimer

Please note that, in accordance with our Company's policy, we are obliged to advise that neither the Company nor any employee nor sub-contractor undertakes responsibility in any way whatsoever to any person or organisation (other than Palliative Care Australia) in respect of information set out in this report, including any errors or omissions therein, arising through negligence or otherwise however caused.

# Introduction



## CONTEXT AND PURPOSE

Palliative Care Australia (PCA) has been funded by the Australian Department of Health to undertake the *Paediatric Palliative Care – National Action Plan project*. The project has received Ethics Committee approval.

The overall objective of the National Action Plan is that all Australian jurisdictions and stakeholders working in paediatric palliative care align to prioritise and work towards common goals and objectives to ensure that children with high medical needs and life limiting conditions and their families are supported and receive the information and the care they need.

A separate consultancy project has been undertaken to develop a Literature Review for the project. Based on the Literature Review, a Discussion Paper has been prepared. A comprehensive consultation process has been undertaken across all jurisdictions to canvass feedback on key areas of inquiry for the National Action Plan.

Together with the findings from the Literature Review, stakeholder feedback from the consultation process will inform the development of the National Action Plan for Paediatric Palliative Care. PCA is working closely with Paediatric Palliative Care Australia and New Zealand (PaPCANZ) and other key stakeholders in undertaking this project.

## CONSULTATIONS

### Process for inviting participation

PCA invited a broad range of stakeholders to participate in the consultations based on its extensive knowledge of the service provider network and the range of organisations expected to be relevant and interested in participation. This involved sending out invitations by email with a brief description of the context and purpose of the project. PCA used the online platform Events Air to manage registrations for the consultations.

In the case of consumers, PCA sought expressions of interest from service provider networks. A similarly process was used for registration by consumers via Events Air for workshops, with email invitations for individual consultations. All individual meetings and workshops were conducted online via Microsoft Teams.

### Stakeholders

The following groups of stakeholders were consulted:

- » Consumers and carers;
- » Paediatric palliative care services and hospices;
- » Health Professionals;
- » Member Organisations and Non-Clinical;
- » Government; and
- » Other individual service providers.

### Ethics Approval

Given the consultation process involved healthcare consumers, human research ethics approval was sought and approved by the Bellberry Human Research Ethics Committee. For each consumer interview and workshop, consistent with the requirements of Bellberry HREC approval, the consultation process involved verbally confirming the following information that was included in the Information sheet and consent form as well as the consultation slide-pack:

- » **Support available** – We understand that you may experience distress by sharing your experience. If you become upset or distressed because of your participation in the research project, we have organised for the Australian Centre for Grief and Bereavement to provide support at no cost to you. The phone number for the Australian Centre for Grief and Bereavement is 1800 642 066. Don't forget to say that you have been participating in a consultation for Palliative Care Australia
- » **Ethics Committee approval and complaints procedure** – The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the National Statement on Ethical Conduct in Human Research (2007) – incorporating all updates. This Statement has been developed to protect the interests of people who agree to participate in human research studies. Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information, or complaints about the conduct of the study or your rights as a participant, you may contact the Operations Manager, Bellberry Limited on 08 8361 3222.

## Workshops and interviews

As summarised in Table 1, there were a total of ten workshops undertaken with 68 individual stakeholders. Additionally, there were seven interviews conducted with individuals who expressed an interest in participating in the consultations. These interviews included two healthcare providers, one researcher and four consumers. Overall, there were 75 individuals who participated in consultations for this review, which took place in the period July to September 2021. Aspex wishes to acknowledge the rich contribution by all who contributed.

*Table 1: Summary of consultations*

Consultation type	Stakeholder group	No. of meetings	No. of participants
Workshop	Consumer	3	10
	Government	1	15
	Healthcare provider/Associations	6	43
	<b>SUB-TOTAL</b>	<b>10</b>	<b>68</b>
Interview	Consumer	4	4
	Healthcare provider	2	2
	Researcher	1	1
	<b>SUB-TOTAL</b>	<b>7</b>	<b>7</b>
<b>TOTAL</b>		<b>17</b>	<b>75</b>

A discussion paper, prepared by PCA with input from Aspex, was made available online to all participants. In the case of workshops, a slide-pack was sent to participants in advance of the workshop.

## Online feedback

In addition to workshops, stakeholders could also elect to provide online feedback to discussion questions in the online discussion paper. There were 30 respondents to the online discussion paper; 5 from consumers, 25 from healthcare providers/peak groups. Appendix 1 lists the discussion questions.

*Table 2: Summary of online responses to discussion paper*

Stakeholder group	No. of responses
Consumers	5
Healthcare providers/peak groups	25
<b>TOTAL</b>	<b>30</b>

## Focus of discussions

The focus of discussions was on the following topics:

- » Improving quality of services;
- » Improving access to services;
- » Improving skills of the workforce, parents, and carers;
- » Advance care planning;
- » Dissemination of information;
- » Community awareness of paediatric palliative care;
- » Research and data collection; and
- » Collaboration between all levels of government.

The key themes identified and direct quotes from participants (de-identified and in blue text) are summarised in the sections that follow.

# Improving quality of services



This section summarises feedback from stakeholders about improving the quality of paediatric palliative care services in the community and acute care. This broad topic launched the consultations and also links to subsequent areas of discussion including service access, information and communication strategies, and enhancing data and research capabilities.

Specific topics covered in this section are:

- » Capability;
- » Parent involvement;
- » Coordination;
- » Terminology;
- » Resourcing;
- » Communication;
- » Adolescent and young adult considerations;
- » Bereavement support; and
- » Sibling support

## CAPABILITY

The capability of paediatric palliative care services was identified as an essential element of quality. Most specialist paediatric palliative care services considered that the strengths of their service models were based on the expertise and experience of the multi-disciplinary team. In some jurisdictions that lacked a multi-disciplinary team with specialist paediatric palliative care physicians or other key clinical service modalities, this was considered a limiting factor in their service capability and effectiveness.

*Multidisciplinary teams are required so that all aspects of care are met.*

**Specialist clinician**

*Prioritise greater multidisciplinary and interdisciplinary service provision (nursing/medical and allied health).*

**Healthcare provider**

Ensuring that the competencies of specialist palliative care providers were systematically networked with the broader health system was advocated as a way of enhancing capability.

*Networking the specialist and primary paediatric palliative care workforce to build capability and capacity across the system.*

**Government organisation**

## PARENT INVOLVEMENT IN CARE

Many consumers commented that a challenge for healthcare practitioners is to recognise that parents of children with a life limiting condition gain high levels of capability in the care of their children. In effect, the parents become experts in their own children's care. Consumers felt that their caring role should be recognised, validated and appreciated by paediatric palliative care teams. Equally, when parents perceived that their role was not acknowledged, this created significant anguish and disempowerment.

*One of the things I feel is so important to "quality of life care" and any form of health care and holistic care is ensuring that alongside recognising the parent as "their child's expert" is to ensure that the care and support a child and their family receive is individualised and centred around what they need in that moment. To have a focus on individual and person-centred care, hearing what the parents are saying and hearing what the child is (whether verbally or through another way) saying. To hear what is important to that child and that family and centre care around that. I think some of the most confronting moments for me were when I was disregarded as an expert in my child and when I felt that people were not seeing what he needed and what we needed. That he wasn't being heard.*

**Bereaved parent**

*Asking the consumers is important. What would have helped them? Instead of us trying to do it as professionals. Rather, go to the experts, those who have had a child in need.*

**Paediatric palliative care provider/organisation**

*Too many times I hear that health professionals try to influence families to choose options that suits them instead of the patient and the family unit.*

**Healthcare provider**

*Having your thoughts and feelings validated is important. No-one goes out to not hear. But often people are busy. So the overarching feeling of being heard and the expert of their child really matters - we know our child better than anyone else. Being part of practice is so important.*

**Bereaved parent**

## COORDINATION

Coordination is identified as a key role played by effective specialist paediatric palliative care providers. This was highlighted as a particular strength of paediatric palliative care and was emphasised by consumers as essential to team-based planning for children who may have several specialists involved in their care.

Families appreciated the advocacy role played by the paediatric palliative care team, which enabled the child and family's decisions around care planning to be acknowledged and enacted.

*Often the paediatric palliative care providers were the mediators. I used to call up [name of paediatric palliative care clinician] and she would make it happen. They're the best advocates - they don't sit within a [medical] specialty. I wished I'd done this earlier. Things went more smoothly. For example, I'm having this issue, can you help? They'd fill gaps that other specialities couldn't address. They [other specialities] are isolated in their own specialities. You need to look at the whole person, with the lungs and the digestive system...They [paediatric palliative care providers] were the biggest role models of how effective communication can be.*

**Bereaved parent**

*Families often report that palliative care teams provide person-centred, holistic care. Many report that the palliative care team can assist young people and their family to have their voices heard amongst the multiple medical specialists.*

**Bereaved parent**

Conversely, when services are not well coordinated, families identified the additional burden of having to repeat their stories when there are multiple service providers involved.

*Communication between services is an issue. Families are having to repeat themselves on many occasions about various issues, adding to the already overloaded family.*

**Bereaved parent**

*Navigation is a major issue - it's completely ad hoc.*

**Bereaved parent**

There is a key role identified for coordination between specialist palliative care providers and other specialists, such as neurologists or paediatricians. There were challenges identified in ensuring the balanced involvement of medical specialists as part of an integrated palliative care team. Respondents identified difficulties for specialists who are perceived in some instances to be reluctant to work collaboratively with palliative care specialists. Others perceived that some specialists were needing support from specialist palliative care teams to improve their confidence in integrating palliative care principles into their own practice approach.

*Strive for collaboration and ensuring that the child is not seen as being "owned" by any particular service.*

**Healthcare provider**

*Where to start on this... as a regional allied health professional who works day in and day out with children with complex disabilities, my first hurdle is advocating the family's voice to their local paediatrician, who varies in their handling of "hearing" parent preferences. My life would be a bit easier if I could contact colleagues in our respective palliative care centres to present a "United Front" on the potential benefits of involving palliative care services to support quality of life. In my experience, the local Paediatrician need SO MUCH MORE SUPPORT to feel confident about having P-word conversations, and not feel guilty about "giving up" on that patient. Please, please, please TARGET your regional paediatricians to dissolve this mentality and make them feel more confident about asking specialist palliative care services for more support, help and guidance!*

**Healthcare provider**

*They (specialists) see their role as diagnostics only (for rare disorders) - they make a diagnosis and pat themselves on the head and refer the family to the GP without follow up.*

**Bereaved parent**

Many highlighted that one of the valuable roles played by specialist palliative care teams was their coordination role. Several advocated that this role should be further augmented and that nurse navigator roles should be defined - others advocated for case manager roles.

*The importance of that delivery of care cannot be understated, and would best be coordinated through a 'case manager', someone who can:*

- advocate for the family/patient;
- ensure access to all available and relevant services;
- centralise, collaborate and disseminate all information in regards to the family/patient's care;
- either be available personally or have the knowledge of where/who is the best alternative when issues, problems, or questions arise; and
- provide valuable feedback to all teams, clinicians, health professionals, and services involved.

*Only then can ALL items as discussed in the review, be guaranteed to be delivered in efforts to optimise patient- and family-centred care.*

**Bereaved parent**

## TERMINOLOGY

There was a widespread view that the term palliative care was off-putting to many consumers and to health professionals as well. Many felt that it implied end-of-life care and imminence of death. As one participant put it “If it were a business, you’d rebrand.”

Consumers’ initial response to the concept of palliative care tended to be negative, given its association for them with death and dying.

*My parents heard the word palliative and were just... no. We are not there yet.*

**Bereaved sibling**

*It’s overwhelming – the rhetoric around palliative care is grim. It’s about dying. That can be changed. There should be more awareness of what it means to be involved in palliative care. A focus on quality of life. The gap can be narrowed.*

**Bereaved parent**

*A better explanation of what the service entails and what the service can provide for a family would have been great. I believed it was end of life for the last few days not an ongoing, collaborative, supported team that would be an advocate for our family and guide us in decision-making.*

**Bereaved parent**

Many healthcare providers and consumers recommended that the term palliative care should be replaced with one that is less confronting, such as quality of life care.

*It’s (paediatric palliative care) not about death and dying - it’s about life and living. We should call it Quality of Life care.*

**Bereaved parent**

Palliative care providers identified the challenges they frequently face from many families – and sometimes the treatment team – when palliative care is raised as an option alongside curative treatment for a child with a diagnosed life limiting condition.

*Even though you’re trying to use (the term palliative care) in the “right” way, you’re using it in a different way to the dominant use of language... you’re pushing it up hill. There’s the dominant use of the word “palliative care” as end-of-life care... [Over my decades of work in the area] there are more people you don’t have to convince of the ‘technically correct’ use of the term, but in general use it’s not changed. It’s been decades... there’s not enough change.*

**Specialist clinician**

Others agreed that the term ‘palliative care’ is widely misinterpreted as end-of-life care, rather than complementing curative treatment and enhancing quality of life.

*Definitions vary, even in the healthcare system, and that is problematic in itself.*

**Specialist clinician**

*We understand but the general public don’t... anyone who works in paediatric palliative care [understands the definition as being from diagnosis and caring for the whole child and their family], but if you go regionally, do GPs know? Regionally in tertiary hospitals? There’s a public perception that palliative care is ‘towards the pointy end’, towards death... if you’re not associated in some way [you don’t know that it’s more than end-of-life care]... My organisation has 300 people, all of whom work with children in hospital. Whenever I talk about [our palliative care program] with a group of ten people I’ll have three people who put up their hand and say “Is that what palliative care is?”*

**Community professional**

Several healthcare professionals echoed this sentiment, and the impact it has on introducing palliative care to families who would benefit from its use.

*When you mention the word “palliative” to a family who have a child with a life-limiting condition, it’s quite an overwhelming phrase... it would be great to develop some softer language and differentiate between different stages.*

**Specialist clinician**

*Especially in the perinatal palliative care space, there is a fear from families to allow palliative care to be involved as they associate this with loss of hope and end-of-life. Also, we’ve been asked to stop using the words ‘palliative care’... the education of what we do is exhausting and ties up our time which could be used clinically.*

**Specialist clinician**

*Sometimes I wish we weren’t called the palliative care team, we were called the quality of life team... would it make a difference?*

**Specialist clinician**

*Some services we get good referrals from, the feedback we get from other services- they don’t like our name.*

**Specialist clinician**

There were multiple conversations around different language options, including conversation around the terminology “Quality of Life and Palliative Care” team which is used in some places in the UK. Some felt that this better captured what paediatric palliative care truly does, while some thought that a change of name was too ambitious a goal.

There was also conversation around promoting better understanding of paediatric palliative care using the current language, with a number of proponents for use of consumer storytelling to this end, outlined in section seven, *Improving knowledge of paediatric palliative care across the community*.



## COMMUNICATION

Consumers identified person-centred communication to be a pivotal area for quality improvement. The importance of empathetic communication was emphasised as crucial in the initial discussions with children and families about a child's condition and the considerations around the involvement of palliative care.

*Communication is always the top of the list. It can always be improved. The way things are conveyed.*

**Bereaved parent**

*Communication and information is key. As a parent, you don't know what to ask for when, you don't understand what the service entails or what is actually involved.*

**Bereaved parent**

A number of consumers related experiences in which they felt that their child's needs for general medical care were overlooked or discounted as a direct result of the stigma healthcare practitioners displayed towards children with life-limiting conditions.

*As soon as there is the palliative care label, the ED and ICU feel like you're wasting your time. They have such an attitude. Rather than recognising that children with life limiting conditions have a shorter timeframe and that we need to keep them comfortable – that should be the focus rather than all about saving lives.*

**Bereaved parent**

There was a further dimension to communication in which consumers emphasised the underlying importance of healthcare professionals communicating with children and families with compassion and a focus beyond the clinical aspect of care – to recognise the human dimension of people's care needs.

*Our kids aren't just sick kids with life limiting conditions, they're kids who want to know the people they rely on and to trust them. To feel they are important little people that are more than just their diagnosis.*

**Bereaved parent**

*Get to know your child/patient learn who they are outside of the medical condition and treat them as a person - the rest will fall into place.*

**Bereaved parent**

Ensuring that family's views and preferences are understood was emphasised to ensure there is appropriate communication with family/carers.

*Who a family would like to include in the communication, be guided by family wishes. Establish preferred communication with family/carers.*

**Healthcare provider**

*Sometimes as a parent you don't know what you'll need. Or that you could scream from the rooftops and feel that you're not being heard. I think there are many families that are not being heard. Sometimes as a parent, you just need people to say, hey let's have a chat. What's your gut feeling?*

**Bereaved parent**

## PEER SUPPORT

Some consumers considered that more focused attention be given to facilitating peer support to families whose children have a life limiting condition. Those who share common experiences are considered to provide a level of empathy qualitatively different to the support that healthcare providers can offer.

*There was no peer support group. It's all very well having a health professional telling you. But when you're in that position it's different. If someone who has been through it can be available, then that can be powerful. It's like oxygenating the family. And you're helping yourself.*

**Bereaved parent**

*(Offering peer support) keeps our children alive. Helps us feel that their lives mattered. That's a resource that the clinical world doesn't see. It can potentially be life changing.*

**Bereaved parent**

*Connection with other families or bereaved families can be more beneficial than what health professionals can sometimes provide. As it is the most confusing, heart breaking, emotional roller- coaster you can ride.*

**Bereaved parent**



## RESOURCING

There was positive regard for the quality of paediatric palliative care specialist services that are provided. That said, many expressed the view that more services and more reliable funding are required to ensure adequate service coverage.

*People feel well supported by the specialist paediatric palliative care services across the country... it's important for adult palliative care [who take on paediatric patients in community where paediatric services are unavailable] to have access to that paediatric palliative care service to liaise with.*

**Health professional**

There was a view that due to resource constraints, there was often a requirement for the inclusion of community-based adult palliative care teams to meet the needs of children. Many considered that this was not appropriate given the complexity and specific considerations relevant to paediatric palliative care.

*From a community perspective within adult, the expectation of adult services to be able to turn their hand to paediatrics surprised me when I was working in the community. People saying it's the same- it's not the same. Community adult services will have the resources to deal with a child at end-of-life... [we say all the time that paediatrics is different, adult services can't suffice, but] when it's required to have end-of-life care at home suddenly it's ok to have adult services... [the issue is] the expectation that adult services can do the care. There's the expectation that we are specialist at paediatrics but at end-of-life, it's end-of-life and adult services [can do the same job].*

**Health professional**

Others highlighted that paediatric palliative care differed from adult palliative care given the potential for extended duration of care with greater longevity of many children with life limiting conditions.

*Longevity is very different for children. Children can be palliative for years and years.*

**Healthcare professional**

Some commented that resource constraints limited the ability of paediatric palliative care providers to be able to provide 24/7 service access.

*We are so poorly resourced that we cannot provide the 24hr care that some of the adult services can provide.*

**Healthcare professional**

Others took a pragmatic view that given there are finite resources, it is important to strengthen the capability of the broader healthcare system in meeting paediatric palliative care needs.

*There's a limited workforce and a limited ability for services to address the needs of paediatric palliative care. All healthcare professionals need to be aware of the needs of children with palliative care needs. It's a basic thing that needs to be embraced regardless of specialty. There's no way the workforce are going to be able to encompass all children... palliative care should be a concept we provide to everybody.*

**Specialist clinician**

## ADOLESCENT AND YOUNG ADULT CONSIDERATIONS

Healthcare professionals emphasised that adolescents and young adults have distinct developmental needs. These needs are relevant when delivering responsive service models, including approaches to advance care planning and access to services. Additionally, the transition from paediatric to adult services was raised as a crucial requirement for responsive service planning and delivery. Many commented that there was a lack of specialist knowledge in adult services when working with young adults, and that transitions from paediatric to adult care needed to be given high priority to support young adults and their families through this transition.

Young adult consumers identified specifics of ill-tailored care such as ignoring the young person in decision making and instead speaking with their parent, and physical palliative care spaces which are designed for elderly patients or their visiting small grandchildren. The suitability of tailored spaces in oncology, such as the You-Can centres, was acknowledged.

## BEREAVEMENT

*The other transition which is missing is the bereavement issue... it's a period where families even more than the transition to community see [supports disappear] ... I think that should be integral.*

**Community clinician**

Healthcare professionals reported benefits for families able to access suitable bereavement support. These included improved mental health outcomes and families' ability to contribute to their community.

*The other (aspect) that goes unnoticed is the families mental health during and more so after the child/patient has died. This is an area that also impacts mental health.*

**Bereaved parent**

They see the positive impact of appropriate bereavement support on family members' engagement in education and employment, as well as direct use of their experience in supporting others.

Difficulties in resourcing bereavement support was a major challenge identified from a hospital and health service perspective.

*More funding is needed for training for specialist bereavement services not your generic psychologist/counselling but more specific palliative care counselling*

**Bereaved parent**

## SIBLING SUPPORT

One health provider described sibling support as if it were 'under the water line'. Many consumers commented that there is a substantial challenge faced by families in meeting the support needs of siblings. Comments included ensuing their needs are not overlooked in care planning discussions and that they are included in information sharing processes. At a psychological, and compassionate level, many considered that sibling support needed to be an integral part of the services provided.

The support and information needs of siblings was emphasised by many.

*(Sibling) watched the whole process. We were transparent. That's what felt right to us. Would have been nice to know about options. Some mentorship would have been appreciated. Even a flyer to say this is where you go for sibling support. These are the things that would be expected at this stage.*

**Bereaved parent**

## FAMILY SUPPORT

There was a recognition that families take on the caring role willingly and with great commitment. Bereaved parents spoke of the extraordinary energy they expend and the overwhelming focus they have given to caring for their child with a life-limiting condition. Inevitably this brings tremendous strain on family relationships.

*More support (is needed) of whole families with mental health and relationship issues. As caring for a child takes its toll and a parent can be much more effective as a carer if they are supported emotionally, therefore keeping a child safe.*

**Bereaved parent**

*Carers are underfunded and under-supported.*

**Bereaved parent**

## RESPIRE CARE

Caring for carers was a point raised by several consumers and health professionals. This included consideration of respite care opportunities to provide families with a break from the physical demands of caring for their children. However, the availability of respite care is not consistent.

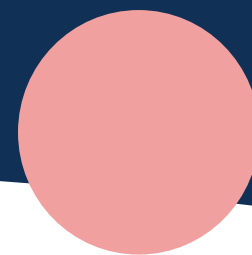
*Support services provision for respite are needed.*

**Bereaved parent**

*If it's a long palliative care journey then sometimes respite care is very useful. It's entirely dependent on where you live and who funds it. It's ad hoc and inconsistent.*

**Consumer**

# Improving access to services



This section summarises feedback on issues of access to paediatric palliative care from a range of dimensions including timeliness of referral, geographic access, coordination of transitions of care and enabling responsiveness of palliative care services to different cultural and vulnerable populations.

## TIMELINESS OF REFERRAL

### Consumer perspectives

Consumers expressed mixed feelings about timeliness of referral. Many highlighted that they had major reservations about palliative care, given its negative associations with end-of-life. For those who had accessed specialist palliative care, almost all wished they had accepted a referral earlier; some noted the barrier was their own concept of what palliative care is and its connotation with imminent end-of-life. For others, they felt let down that they had not been offered palliative care earlier in their child's condition.

*Everyone needs more awareness. We need a culture change. It's so valuable. Once we were with the service it was amazing. I nearly kicked myself for not getting referred earlier. It's a lack of understanding of what paediatric palliative care involves. Took a lot before the specialists referred us. Possibly because there's more uncertainty by the treating team about the prognosis. There was a lot of umming and ahing in those initial 12 months. It's scary – you feel like you're drowning. You can't get a grip. Can't cope. Palliative care are the people who can support. Then they can refer. Better to over refer than under.*

**Bereaved parent**

One young person who has recovered from a life-threatening condition stated a wish for palliative care to have been introduced during treatment. This was considered to offer 'a sense of control' by knowing there was a plan if it all went well and being able to contribute to 'plan B' if their disease progressed to being terminal.

Consumers spoke of the need for the conversation introducing palliative care specialists to be done by a team they are familiar with or by an intermediary team. This was contrasted with the confronting prospect of having a palliative care team introducing themselves.

*A discussion about palliative care should be initiated by someone in the middle, such as a social worker or a liaison person. Not from paediatric palliative care – because if they'd approached me I'd have been guarded.*

**Bereaved parent**

Some spoke negatively of the way palliative care was introduced to them, where explanatory literature was given to the family with no surrounding conversation that their child's life was likely to be shortened by their condition, or support offered.

*There was a lag between me accepting a referral and not feeling like giving up on my child. I could have received help in the decision making. I was in a room and it felt like a bomb went off. I was left in a room.*

**Bereaved parent**

Storytelling – hearing from families who had accessed palliative care through educational materials – was proposed as one solution to the issue of helping families to understand what is meant by palliative care. Benefits of engaging with specialist palliative care teams were reported as care coordination and additional services the palliative care team provided, such as arts-based therapies, specialist advice in navigating various health and disability systems, advice on supporting siblings, and bereavement support.

*There was no follow-up (from the primary team after referral to palliative care) – they did not make it clear that they're not letting go. That it's a supplementary service. Even if (they) had told (us) a story of another family that would have helped."*

**Bereaved parent**

## Specialist Palliative Care Perspectives

The term 'referral' was considered problematic by some. It implies a 'handover to' another service, as opposed to the goal of palliative care services 'working alongside' curative care and community teams. For this reason, the preference for some was to use the language 'inclusion of palliative care' in care planning discussions. It was noted that this mindset is a barrier to timely referrals, and often it is only after a particular team has worked with the specialist paediatric palliative care service that they understand fully what can be offered, and then are more likely to include the specialist service in the future.

It was noted that often the process of initiating referrals is individual-dependent, rather than systems-based. Providers considered that this led to clinical variation in referrals for palliative care and compromised equitable access to specialist paediatric palliative care.

*We're a hard sell. The ones we engage with, we are preaching to the converted. How do we capture those who will potentially engage with a family with a palliative care need? You don't know what you don't know.*

**Specialist palliative care clinician**

*I'd be a millionaire for all the families who have said 'Oh my goodness I wish I'd known about you guys earlier' ... They need the information to make informed decisions [otherwise they] miss out on counselling, sibling support...*

**Specialist palliative care clinician**

*I think it's fear - a lot of people just hear death and dying. And that comes back to knowledge of what we do if people have knowledge and resources that would help with referrals. For timely and equitable access, we need networking... When we know what they offer and they know what we do on the ground, then we can work together.*

**Specialist palliative care clinician**

*... I think you're right - if there's an issue with kidneys... it's presented to the families 'I need to refer you'... but [with paediatric palliative care] it's said 'they're not ready to meet you yet' - well probably no one is ever ready to meet us... It is interesting because we wouldn't normally say to someone 'Would you like to see the surgeon because of your appendicitis?'*

**Specialist palliative care clinician**

*I can identify children who are "missing out" on aspects of care that I've previously seen similar children be able to access because they "made it" to the tertiary centre. It takes up so much energy in patient advocacy currently to help families "fight" their medical team to get referrals to where they deserve.*

**Healthcare provider**

There was a sense that having a conversation introducing palliative care requires specialised communication and empathic skills, which should be a core training component for all healthcare professionals. Others emphasised the distinction they felt should be made between being 'referred to' and 'connected with' a service – the latter (connected with) is preferred because it emphasises the importance of a warm hand-over that allows for the family to meet the palliative care team in person together with the treatment team.

*I've heard of families who have received a diagnosis in [name of jurisdiction] and connected to a service - and I mean connected to, as in the family met the team [and that was supported through the referring team] ... [in contrast to] a family in [name of jurisdiction] with two children who have been referred to palliative care, as in they have a letter to go and connect to the team, and that letter has been around for a year, they haven't acted on it... because they don't understand what they can access.*

**Community service professional**

The timing of the referral was also an important factor for specialist teams, who noted 'we get ours late and it doesn't give you time to build up the rapport'. A similar concern was evident in the context of neonatal palliative care.

*Gatekeeping occurs because of fear. There is concern pregnant women will cease to engage in their obstetric care if referred to palliative care ... then we have to scramble after the baby is born rather than having time to build up that rapport.*

**Specialist palliative care clinician**

Specialist clinicians also commented that a lack of timely referral has flow-on effects for the patient's pain, and subsequently the family's processing of grief.

*I've had quite a few deaths that have been unnecessarily painful for the patient and therefore their families, and we get the flow on effect into their bereavement... even when we have families who are proactive in looking for the palliative care service... we still hear stories of 'we wish we'd known about you earlier'... Palliative in some instances feels like fear mongering. [It's as if] "oh you've been given a diagnosis, we're not going to talk about palliative because you've already been given a diagnosis" and you get push back from the consultants... you wonder how much it's about this sense of 'well we have to do what we have to do, and you have to come along for the ride whether you want or not', with no true consultation with what the parents think is right for the child.*

**Specialist palliative care clinician**

*I think sometimes palliative care is not discussed until late. When treatment options are completely exhausted. This can lead to a great deal of suffering. If conversations could be had earlier it would maybe improve the outcomes in terms of a 'good death'*

**Healthcare provider**

A further challenge that specialist providers identified is that delayed referrals to palliative care can be particularly problematic if there has not been an opportunity for dialogue with families to align expectations.

*The other thing that can happen is teams trying to push that connection because the family don't want to meet the palliative care team then they end up over-promising... it really is about normalising (the referral to palliative care) and these things being part of every-day practice.*

**Paediatric palliative care provider/organisation**

There was also comment regarding obstacles faced when a condition is rare and its trajectory difficult to predict.

*Many of our families have undiagnosed or rare genetic conditions so they don't know the trajectory of the disease... [I hear stories like] "we've just been accepted into a hospice house, I'm surprised, I didn't think my child was bad enough"... that process hadn't been explained to her.*

**Specialist palliative care clinician**

## LOCATION OF SERVICES

It was noted that the availability of services varies state by state. Stakeholders commented that not all states have a children's hospice, and jurisdictions such as ACT and Tasmania rely on other states' specialist paediatric palliative care teams. It was also noted that specialist services are 'city-centric', the impacts of which were not just practical but also emotional.

*We just wanted to go home – we were so far away from family and friends*

**Bereaved parent, rural location**

*Reflecting that we are all state-wide services, we have these mandates across a very big state. It's even difficult to map where the families are in our state... [even just] knowing where children live, what services exist in their local regions [is relevant]. It's a moving feast and that's a challenge. We are very reliant on our generalist colleagues in those communities to provide that support. Then we have programs such as QuoCCA<sup>1</sup> which is a national program, it's a project though. But the need never ends- you never go 'job done'. We have to continue to provide support to these regional areas [so why does the funding come to an end?]*

**Specialist palliative care clinician**

*Please actively encourage specialist teams in those CAPITAL CITIES that you've listed to Google Maps where these rural and regional places are and actually SPEAK to health professionals from those areas. In regional areas, we all go above and beyond to ensure "our people" aren't disadvantaged, but when specialist centres just send someone home without first understanding that the health centre that is geographically closest to their home only have 24hr nursing coverage and the nearest equipment supplies come from 100kms away (meaning they take days to arrive), just helps to maintain perspective with specialist teams are providing remote or virtual advice and support.*

**Healthcare provider**

One family who experienced community palliative care provided by an adult service in a rural area deemed this to be delivered very well and were satisfied with the support provided. They noted that they had experience as health providers and organised this care largely by themselves and lamented that if families did not know what to ask for, they may have been left without services. They had knowledge of another bereaved family's experience in rural community care and noted that they were sorely lacking in support, with notable impacts on the family's experience of grief.

*A friend of mine who has also lost a child, puts on a brave face. She had had very little support. [When her child was at home dying] she was lucky to see a service every other week. They're classified as [rural but not remote]... She's angry about the lack of support. Compared to her, we were well known within the community... Every second day we had home-based palliative care visits... That support was around us [and] the impact is for years. I came to terms with it more quickly... There's not a single thing that we would have changed... It's heartbreaking that my friend had so little support - that was heart-breaking. [And I know] she won't advocate for herself - it's devastating.*

**Bereaved parent**

Whilst there was notable support for the suitability of adult community palliative services caring for children, there was also significant comment to the contrary.

*We were being treated by a palliative care service for adults. Our child was 15. Everything they brought to us was adult. Even to get a pain killer it took a couple of hours sometimes... The palliative care team were beautiful and caring, but they didn't have the expertise. We were doing all this work for ourselves because the team were adult focused. We were carers - we had to advocate for everything. We didn't get to spend the time with our daughter that would've been treasured.*

**Bereaved parent**

In addition to adult community palliative care teams and QuoCCA's outreach programs, telehealth was frequently raised as a solution to some issues of service availability in regional and remote areas and more broadly, to optimise care and collaboration between service providers.

*Covid has made us up our game for telehealth and online options. Our play clinic is online at the moment so regional families can join in as well as metro. Doing multidisciplinary team case conferences in that way, so regional colleagues can join in that way. [Indigenous health workers are embedded in this also] [Some barriers include] reception - some families don't have internet. To get around that we've been able to provide them with data. This approach works best if our families have met us face to face at some point, as there's already a relationship there to build on.*

**Specialist palliative care clinician**

*Digital enablement and solutions to support integration of care and collaboration*

**Healthcare provider**

A further point was made that engagement of regional services in care planning strategies requires respectful communication by city-based specialist palliative care teams, to acknowledge that whilst regional and rural service providers may have a relatively narrower resource base and less specialisation, the value of their role ought to be acknowledged and supported.

1. QuoCCA stands for the Quality of Care Collaborative Australia project run by the Children's Health Queensland Hospital and Health Service and was funded by the Commonwealth Department of Health for two cycles - (2014-2017) and (2017-2020).



*Don't talk down to them - you don't know their history or their experience and trust me, they will WANT your support and regionally, we spend most of our time holding the fort and covering all caseloads. So, even having someone at the end of the phone to clinically reason with or listen to what you had to do the previous week that wasn't in your role description helps us refill our cups so we can continue to optimise the quality of life of our patients. And ensuring the resource stocks, everything from oxygen cylinders and compressors to wheelchairs with head rests, are robust enough to be able to support states as geographically diverse as Queensland and Western Australia.*

**Healthcare provider**

## EQUITY OF SERVICES

Several stakeholders commented that equity of access to services differed according to different life limiting conditions. Consumers identified that children with rare diseases with unknown prognosis felt that they were less likely to have access to palliative care services and that the quality of services was also less than for children with a cancer diagnosis. There were several reasons identified for these differences in access including the lack of a clear prognosis, healthcare professionals differing views on the relevance of referring to paediatric palliative care and different resourcing levels. Charities were more established and of a larger scale for children with cancer and this has a direct impact on the amenity of services and range of support services available for children with cancer compared to children with rarer life limiting conditions.

*About only 10% of chronic illness patients use palliative care. There's a huge imbalance in who should get access to palliative care. The palliative care system doesn't know how to enable access for chronic illness patients.*

**Bereaved parent**

*It hurt to walk past the kids ward - the oncology ward was beautiful - it had working bubblers and immaculate bed pans. Should be equitable care.*

**Bereaved parent**

*My child had a non-oncology diagnosis. It feels like we're left off the diagram - because there's not enough of us, maybe we don't matter. Oncology has a lot of support.*

**Bereaved parent**

## CULTURAL RESPONSIVENESS

Cultural elements were considered key components of access to care. This was emphasised as relevant for culturally and linguistically diverse (CALD) populations and Aboriginal and Torres Strait Islander populations. The point was made by several stakeholders that even when a service is available if it is not culturally responsive and culturally safe it will not be accessed to its full extent. It was noted that the Northern Territory has developed a palliative care model for Aboriginal and Torres Strait Islander populations and that Aboriginal Community Controlled Health Organisations (ACCHOs)

have culturally responsive resources to support families through their palliative care needs.

*...When we acknowledge the cultural and spiritual needs of a child... [I hear things like] 'everyone gets treated the same'. Well I'm sorry but not everyone should be treated the same way. An Aboriginal child needs an Aboriginal health worker. The cultural awareness needs to be done upfront, and then you will recognise the importance of an Aboriginal health worker.*

**Aboriginal Health Worker**

*[Medical teams] need to use their strengths - it's not just the clinical team. [ACHHOS] have social workers, Aboriginal workers... We often hear "I didn't understand what your job was." The Aboriginal health workers are really key. They understand the context and cultural meanings that are most important to consider when a child is going to spirit.*

**Healthcare provider**

*There is the past trauma of children being taken that goes through those families. If you have a child that needs to be taken out of community, some community members just look at it like you're taking that child again, even if it's palliative... it's the whole leaving community, leaving family behind and all the supports. It really does take a village to raise a child in an Aboriginal community, so it doesn't just affect the family, it affects the whole community.*

**Healthcare provider**

*Tailor the optimal care pathway for paediatric palliative care for Aboriginal and Torres Strait Islander children and families, and children and families from culturally and linguistically diverse backgrounds in need of paediatric palliative care.*

**Government**

Refugees and other CALD communities were also noted as important to consider in the development of the national action plan, although there was little comment around the specific needs of these groups.

## ACUTE TO COMMUNITY CARE TRANSITION

Stakeholders identified the common practice of adult community nursing services stepping in to provide home palliation and end-of-life care, as no such paediatric equivalent exists. Within the issue of transitioning between acute and community care it was acknowledged that both systems are filled with capable individuals, and that QuoCCA provides an exceptional model for upskilling community supports where that is required.

*It works beautifully in the tertiary and in the community, but the transition going from one to the other, there's a massive gap between those two... A lot of our palliative children are acutely ill to start with so they're within a tertiary setting... [but then] going home to palliate they don't have a rapport, they don't have a network, they're thrust home to palliate with a team they don't know, that they've never met before.*

**Specialist palliative care clinician**

*We are there to work with other services that provide primary palliative care... we want to work with them in consultation, not saying they are not capable, but we want to equip them to ensure they can work safely*  
**Specialist palliative care clinician with QuOCCA experience**

The challenge for adult specialist palliative care service providers in providing paediatric palliative care is the lack of training and awareness of the paediatric context. Whilst for some consumers, the arrangements worked well, for others there was a sense that the home-based care team were ill at ease.

*Specialist palliative care nurses were adult nurses, so paediatrics was unusual. Some emotionally went to water because they were around a child.*  
**Bereaved parent**

## PAEDIATRIC TO ADULT SPECIALIST PALLIATIVE CARE TRANSITION

The stakeholder engagement process included a small number of participants with lived experience of transitioning from paediatric to adult palliative care settings. Similar to the transition between acute and community care, consumers noted that paediatric and adult palliative care specialists individually have considerable expertise, but that the transition between the two was often problematic. As one bereaved parent stated:

*(The experience of transition from paediatric to adult palliative care was) horrific. Traumatic. Just extraordinarily difficult.*  
**Bereaved parent**

There was a sense that when adolescents transition to adult services, they are left with gaps because the definition of palliative care is different between paediatric and adult settings. Families are used to a model with a focus on quality of life, with wraparound care for the family and no timeframes on death.

*Children with life-limiting conditions are living longer - and then they're transitioning. [The adult palliative care team] are not used to parents knowing their children more than they do. They're not used to patients having a voice.*  
**Bereaved parent**

The need for the adult setting to have a more definitive prognosis to be eligible for palliative care was difficult for families with complex conditions to navigate.

*With my son's life-limiting condition, every year we had circumstances where we thought it was the end. [He] was significantly unwell over many periods. He would constantly dip and recover. You never knew when the dip would be the last time - it was hard to predict the trajectory.*  
**Bereaved parent**

Families relayed stories of feeling resistance from the adult team to the transition. The experience for some parents was that once through that initial 'barrier', they felt they had a team of advocates on their side. Others felt that they never reached that sense of a common goal with their adult palliative care team.

*Some staff said, 'Why are we still doing this?' They were questioning her existence - but they were in the minority. Some doctors would just not turn up to appointments. But the team came together over time.*  
**Bereaved parent**

Parents were at a place of acceptance that their child would die, but some felt that they were treated as if they were being unreasonable in expecting care for often unrelated or novel health issues which arose, such as broken bones and urinary tract infections.

*I said 'I'm not asking anyone to cure him, I just want to manage his symptoms'...it felt like you were a bother.*  
**Bereaved parent**

The availability of a transitional service for 18-25-year-olds was noted as a positive, though this is only available for some health conditions and in some locations. Highlighting the need for a more systematically applied model for this age group, one family experienced refusal of treatment in the paediatric hospital three weeks after their child's 18<sup>th</sup> birthday, and difficulty engaging with the adult palliative care team whom they had connected with in preparation for their child's 'aging out' of paediatric services. This admission eventually transpired in the adult setting, but the delays meant that their child had been in unmanageable pain for a prolonged period, in what ended up being their final health demise. This experience of unnecessary suffering was noted by several consumers and health professionals as impacting on the family's subsequent processing of grief. Consumers underscored the importance of getting end-of-life care right, due to the implications for the family's grief in addition to the important consideration of the child's experience as they die.

## AVAILABILITY AND AWARENESS OF COMMUNITY SERVICES

Stakeholders highlighted the importance of access to community services, such as emotional support for parents, siblings, and grandparents during the child's life and in bereavement, financial support, and social and recreational services which offer opportunities for memory-making, joy and connecting families with others in a similar situation.

A lack of awareness of the breadth and eligibility requirements for community services was identified as a major impediment, with constant education in health services needed. Too often this was expected to be undertaken by hospital social workers who were said to be too thinly stretched to effectively address this role.



*Social workers are the gate way. In theory access is there but it's dependent on the skill level of individual - and they're overworked - but we rarely ever saw them. Doesn't need a social work role to do navigation.*

**Bereaved parent**

Specialist health services and consumers reported a desire for all children receiving paediatric palliative care to be able to access the same services, with the main example being that oncology supportive services are much more common than those for families whose child has a rare condition. This situation was highlighted by a family whose child had a life-limiting condition and was then diagnosed with cancer.

*[My daughter has a life-limiting condition...but] when she then got lymphoma... all of a sudden there were people in the room offering services. The cancer is treatable, but the [life limiting condition] is not. You don't see any support systems with [life limiting condition].*

**Parent consumer**

The importance of creating equitable paediatric palliative care supportive services irrespective of the child's life-limiting condition, was emphasised.

*Enhancing equity. There seems families who are able to access a lot and others that seem to have little. This extends to NDIS as well as hospital supports.*

**Healthcare provider**

Others emphasised that better integration required *multiple strategies* for developing enhanced links between the specialist palliative care service and other parts of the health and social care system were needed.

*Integrate specialist and primary care to facilitate equity of access to specialist multidisciplinary teams (MDTs) through in-reach and outreach, care navigators, and innovative models of care, eg: telehealth.*

**Government**

Others highlighted the challenges when the capability levels of community-based services were not adequate to support discharge of children from specialist services.

*A barrier is the transfer of care when you're going to be relying on the GP to provide the care at home... that can be a barrier of the specialist service being able to hand over to a GP safely. This is problematic for families who rely on a part-time GP or who don't have a designated GP within a large GP practice.*

**Paediatric palliative care provider/organisation**

*An issue is seeing families left without that support network they've built across many years in the acute setting, [going] to a community team who are very good but who they haven't built that relationship with.*

**Specialist palliative care clinician**

## VULNERABLE GROUPS

Notably, families in vulnerable groups such as refugees, families with underlying mental health conditions, and children in the child protection system were not identified in the consumer consultations. There was a call from both professionals and consumers who were consulted to ensure that the National Action Plan take into account the specific needs of these complex groups.

## NEED FOR ADVOCACY

The consumers involved in this project were all either themselves health professionals, had significant experience and training as consumer advocates, or both. It is important to note that the nature of this project has likely biased the sample of consumers towards those with the capacity and inclination to advocate strongly, and this has also been part of their healthcare journey. The consumers often highlighted this in identifying components of their care that they 'fought for' and expressed concern for those without the knowledge, communication capacity, or resilience to advocate for themselves.

*There are families who tried to get access [to hospice respite] with similar conditions but couldn't... They have been knocked back and don't have the energy to fight.*

**Parent**

Consumers also highlighted that whilst they are glad they fought for their child to have access to the services and supports they required, that they should not have to. They reported that the additional load of constantly 'fighting' for their child was mentally taxing and took away from the experience of making memories with their child in the time that was available to them. They advocated for a system that removes the variability of services provided to families navigating a palliative care journey based on how much 'fight' their family has capacity for. As a bereaved parent phrased it:

*The fight was hard - and we shouldn't have to have that fight.*

**Bereaved parent**

# Improving skills of the workforce, parents, and carers



This section describes themes raised about skills development both for the workforce and for consumers.

## MODES OF SKILL DEVELOPMENT

It was recognised across categories of stakeholders that there are differing levels of skill needs for specialist, generalist health, and community services such as schools. Some methods for ensuring adequate education in health include incorporation of paediatric palliative care across medical, nursing, and allied health undergraduate degrees, which is advocated for and supported by PCC4U (Palliative Care Curriculum for Undergraduates), broadly across all areas of palliative care. Other specific methods of skill development mentioned in consultations include telehealth training models such as *Project Echo*, and community education through in-person or virtual summits such as *Good Grief this Hurts*, a symposium on childhood bereavement available to health, education, and community organisation professionals as well as general community members, facilitated by Quality of Care Collaborative Australia (QuoCCA).

QuoCCA was mentioned in most professional stakeholder consultations. QuoCCA provides 'just in time' education through its 'pop-up' model of education. This sees specialist palliative care clinicians across medical, nursing, and allied health, travelling to communities to educate the support network around children with a life-limiting condition, including local hospitals, GPs, schools, family, and other organisations or individuals identified as relevant to that family.

QuoCCA was identified as an exceptionally well-suited model by QuoCCA healthcare practitioners as well as other health professionals in the field, government representatives, and consumers. A number of regional GPs and community adult palliative care clinicians who also support children receiving paediatric palliative care in the community were unaware of this program, which may indicate a gap in awareness of people who are not linked with a tertiary health facility. This 'just in time' education was considered highly suitable in the paediatric context, where communities or GPs might only interact with a child with palliative care needs once or twice in their career, and where one person's needs can differ hugely to the next.

*QuoCCA has been doing pop-up which is central to a family and their needs, but it's one of a myriad of approaches that's needed. You need to have the embedding of paediatric palliative care in the undergraduate, that's cemented in post-graduate... then the 'just in time' where you target the GP, the schools... they want to know, because they're scared to death. The strain on paediatric palliative care services is not going to go away so we have to ensure that the generalists are going to be able to do their job suitably... it's building that community approach to palliative care.... The more we impact and influence along the way the more likely we are going to get that good outcome for the family.*

**Clinician with QuoCCA experience**

An awareness of paediatric palliative care within generalist standards was identified as a model for upskilling health professionals outside of the specialist team. Centralised and reliable online information was also deemed important for all categories beyond specialist palliative care providers.

*We also need a central hub where people have that access to the information. The first place people go is google which is not the right place, people need to know [for example] 'Oh I can go to Palliative Care Australia...' We need easy access of information designed for generalist and not just people working within palliative care.*

**Clinician**

Enhancing the role of generalist providers of community nursing was identified as a priority to support children and families.

*Give priority to collaborative training with outside providers like Silver Chain [home palliative care provider] in paediatric palliative care*

**Bereaved parent**

Extending the role of nurse practitioners to paediatric palliative care was identified as a strategy to broaden access to a clinically skilled workforce.

*Nurse Practitioners in adult palliative care prove to be an excellent model of care. This role could be grown to ensure all families have access to a Nurse Practitioner service.*

**Healthcare provider**

Another perspective for enhancing workforce capability was to develop specialisations within training pathways, including the option of a palliative care regional generalists pathway. This was considered to be applicable for GP rural generalists as well as for nurse practitioners and allied health practitioners.

*A generalist specialisation pathway is amazing.. it acknowledges there are specific nontechnical and technical skills in working regionally /remotely and it takes a life span approach. These clinicians' study is subsidised and their pay level reflects their specialisation and the improved retention and distribution of the workforce is sustainable. A pall care regional generalist pathway would be great for GPs, nurse practitioners, OTs, physio, and social work.*

**Healthcare provider**

## REQUIRED SKILL AREAS

Once again, the importance of communication was highlighted as an area for improvement. In this case, both consumers and health professionals recognised the need to improve the communication skills of clinicians.

### Consumer Perspectives

Consumers relayed stories which identified communication as an often-lacking clinical skill, especially around the introduction to palliative care. A number of consumer stories also focussed on a need for clinician empathy and respect of the parents as the experts in their child, and what 'quality of life' looks like for that family.

*I'd advocate for a Quality of Life that means something for that person. It's unique. And clinicians should respect what the family wants, and then do it. [You should be able to] look at the top 5 wants or needs for that child, and not say it's too hard.*

**Bereaved parent**

*As soon as there is the palliative care label, the ED and ICU feel like you're wasting your time. They have such an attitude. Rather than recognising that children with life-limiting conditions have a shorter timeframe and that we need to keep them comfortable – that should be the focus rather than all about saving lives. I remember a client who was in the outpatient clinic. He had breathing difficulties. The doctor couldn't hear what I was saying. I said, you don't need to do the whole battery of respiratory tests - this is his normal baseline for respiratory. There should be some level of understanding of the palliative care context.*

**Bereaved parent and clinician**

Consumers also advocated for a care coordination role, articulating that when they have to step into that role, they are learning everything about multiple health, disability, and funding systems from the ground up. This is an ineffective use of time, particularly in the context of paediatric palliative care where the time and stress involved impacts on their ability to make the most of the time they have while their child is alive.

### Professional Perspectives

Areas for skill development identified by professional stakeholders included communication with children and families, self-care, symptom management, dietetic considerations for the child and for the family in bereavement, cultural competency, after-death care and ethical dilemmas.

*It would be lovely to see ethical decision making seen as a skill... involving consumers, unpacking clinical incidents all together... In palliative care we do it better than some teams, but when you think about the number of teams that are required to support a child with a life-limiting condition... communication is incredibly important.*

**Clinician**

*Neonatal discomfort/pain tool for symptom management. Increased training with difficult conversations and provision of palliative care*

**Healthcare provider**

*Education across the disciplines to ensure sensitivity and understanding. Skills around how to support the family at the point of death and after death care. Care of the child's body is an important element and supporting the family with opportunities to create meaning and hold rituals in a place of choice.*

**Healthcare provider**

*Skill development should address ethics and differing points of view and collaborating between teams.*

**Healthcare provider**

*As a child gets close to end of life, there is a challenge for dietitians. They (the treating team and family) may stop feeds to make the child comfortable. There is a need for guidelines to ensure when it's applicable.*

**Healthcare provider**

Ensuring skill development was available for regional and remote service providers was highlighted.

*Improved education and support for rural/regional professionals working in this area.*

**Healthcare provider**

Awareness of the needs of Aboriginal communities was highlighted as an area of specific skill required for Australian clinicians, bringing in both cultural and practical components of some remote areas.

*Especially for children it's a taboo subject and not spoken about. Depending where and what mob you come from it effects how taboo it is.... I can speak for my [mob], it becomes devastating for the whole community... We only have [Aboriginal Controlled Community Health Organisation] clinics in some communities and communities are spread [from highway to desert]- so we don't have the specialists. Telehealth is unheard of because the internet is so crap and the electricity goes off for three weeks at a time... talking about a child who is going to die is absolutely taboo, and they'll look for someone to blame.*

**Aboriginal Health Worker**

*Everyone's focused on doing right by the child in front of them, and sometimes forget to zoom out and look at the bigger picture.*

**Clinician**

## CONSUMER SKILLS

This section considers skills of consumers as members of formalised advisory, advocacy, and supporting services. Consumer skills relating to the child's care and family's psychological coping are considered aspects of the *Quality of care* section.

### Advocacy and Service Development

The majority of consumers who took part in the stakeholder engagement for this project were previously trained as consumer advocates, with vast experience in formal advocacy and support of other consumers, such as running condition-specific helplines, advocacy at the service and political level, and informal social support of other bereaved families. The significant role consumers have played in these consultations, as well as the continued role they play in the co-design of the National Action Plan, is testament to the important role of consumers. These trained consumers brought not just their own lived experience but advocated on behalf of other consumers whom they had consulted with formally and informally to ensure they brought as broad a range as possible of relevant experience to the conversation.

Importantly, these perspectives highlighted the real impact of the current state of paediatric palliative care in Australia, as opposed to the intended impact which is the predominant perspective that service providers bring. Consumer interviews provided both advocacy for and testimony to the importance of ensuring consumers can access skill development to continue to inform the sector.

Health professionals reported the positive role of having consumers share their stories as part of staff and community training, and that this is often also perceived as positive for the bereaved families who feel that they can give back and have something positive come from their experience. It was unclear from the stakeholder engagement how widely consumers are involved in staff training.

### Peer Support

Consumers are less involved in formalised peer support in the health sector, which was raised by health professionals as a potential avenue for both expanding the reach of services and improving the quality. Storytelling, where families who have lived experience of palliative care share their experience, was seen as an avenue for improving community awareness of paediatric palliative care and of helping families who are being referred to palliative care for the first time to understand what palliative care is.

Formal and social peer support was more commonly used in bereavement and often in non- government organisations, such as Canteen and Redkite, which are both cancer support organisations. Peer support was seen as valuable and irreplaceable by both consumers and professionals.

# Improving the uptake of advance care planning



Stakeholder feedback on advance care planning is presented in this section.

## IMPROVING UPTAKE

### Understanding of Advance Care Planning

The phrase ‘advance care planning’ in the stakeholder consultations was predominantly interpreted as planning for decisions around life-sustaining medical treatment options. This contrasts with the literature which supports a broader definition of advance care planning about plans for a child’s life and death, for example through documents such as ‘Five Wishes’ and ‘Voicing my choices’ (for adolescents and young adults) which incorporate planning for personal, spiritual, medical, and legal wishes.

### Clinician-level barriers- Fear, Recognition, Skill

From a clinical perspective, the most reported barrier to implementing advance care planning was at an individual clinician level, such as fear and avoidance of being vulnerable with patients. It was also noted that making the call that a child is eligible for palliative care and having the training and skill to have advance care planning conversations are factors which impact this fear.

*The problem is fear- often it's done late because primary teams or the physician hadn't recognised it's a likely event that the child might die, they might not have the skills to have the conversation, [and] there's no formal training for doctors on how to break bad news or how to have these conversations.*

**Clinician**

*As a community we aren't comfortable talking about end-of-life care, about death and dying. Then if you think of the worldview that children don't die, getting that into a paediatric palliative care context is even more [difficult]... it's little wonder people have this difficulty when we ourselves have trouble having these conversations with our loved ones... to be then able to enter into those conversations with the families we walk alongside.*

**Clinician**

It was also noted that paediatric advance care planning occurs in a different context to that of adults and that these conversations matter as part of a deeper process of understanding the family’s goals.

*Advance care planning in adults carries the weight of 'who's the decision maker?', and in paediatrics there's that sense of well, the parents are around, so it's less pressured. Well one of the important parts of advance care planning are advance care discussions... [If we miss the advance care planning then] there's a whole pile of deeper discussions that don't happen.*

**Clinician**

## CAPACITY

It was noted that whilst specialist palliative care services have the skill to have advance care planning conversations, this may not always be suitable due to particular circumstances of the family or capacity of the specialist service.

*Generalist and primary care- everyone would rely on specialists to be able to have these conversations.*

**Clinician**

*We're not going to be able to cover all those advance care planning conversations, and empowering other health care professionals to understand the steps involved and the progression families have around that- building rapport then discussing goals of care, that's going to evolve into having advance care planning conversations. It's important to build capacity [across more than just the specialist services].*

**Clinician**

Enabling the expertise of the multi-disciplinary team to be included in advance care plans was a further issue raised by an allied health practitioner.

*It would be helpful to have the dietitian to be involved in the advance care planning. They're not involved typically.*

**Healthcare provider**

## ADVANCE CARE PLANNING TOOLS

There was little mention of specific tools being used for advance care planning conversations. A handful of clinicians and one consumer were familiar with the 'Five wishes' suite of advance care planning tools, although this was not always specifically brought up, and a 'cue sheet' used in Queensland was noted. It was noted that tools are often not suitable for families where the trajectory is unknown, and that work could be done to adapt tools that are designed for families with a child with cancer.

## POSITIVE CONSUMER PERSPECTIVES

In contrast to the fear predominantly discussed around advance care planning and clinician experience, consumers who had experienced advance care planning were appreciative of the process.

*[Once the advance care planning was completed, it] gave us permission to breathe again, to live... [The process] was cathartic... [I could stop thinking about] making these tough calls. Now I can be present as his Mum... I know what we've talked about. My husband knows. It was empowering, and it meant it was done... we can live now.*

**Bereaved parent**

Consumers who had not received access to advance care planning expressed regret at this missed opportunity. A young person, who is in remission from a life-limiting condition and was never classified as 'terminal', expressed that they wished they had access to advance care planning.

*Once you've received a diagnosis it tends to take control out of your own hands. It's beneficial to have a plan. It wasn't a clear plan that I had, [just] "see how it goes". It's always helpful to have clear steps - "if this happens, we go down this path. [If it goes that way, we've got a plan]." It's valuable to have it in the patients' hands. I'm a planner and it's hard to go through it on the unknown things.*

**Young person in remission from a life-threatening condition**



# Improving dissemination of information



The need for information sharing was highlighted as important, including sharing information with consumers, between members of the healthcare team and between organisations.

## INFORMATION SHARING WITH CONSUMERS

Consumers identified the importance of having information shared with children with a life-limiting condition and their families. There were many aspects of information sharing that were identified as relevant.

### Responsiveness

The approach used by healthcare providers to share information with children with a life-limiting condition and families was highly variable. Many instances were identified where children with a life-limiting condition and families felt emotionally distressed by the lack of responsiveness of the treating team when initially having a conversation and being given information about a transition towards the inclusion of palliative care.

For some consumers, there was a view that there was a lack of empathy and compassion shown towards children with a life-limiting condition and families when conversations were had.

*It's palliative care, not just medical information. Palliative care is the whole skill of translation of medical knowledge into something that someone understands. It's much more complex but rewarding if you're walking someone through what's happening. In a kind way but not obfuscating - making sure that someone knows what they're going through and what it means.*

**Bereaved parent**

*People were talking to us as if our agenda was to extend life rather than provide comfort. Those judgement calls are so upsetting. They've never had a sick child. Just because of their clinical expertise they're calling the shots.*

**Bereaved parent**

Children with life-limiting conditions and their families described situations in which they felt unsupported and lacking an understanding of information about planning and expectations for the next stages of their child's life. There was also a view that they had unfulfilled information needs on the range of support services across health and other social, education, financial and general wellbeing concerns.

*Navigating the system can be so hard. Don't know where to search - it falls to the overworked social workers to do this. This is not always great.*

**Bereaved parent**

*A National palliative care website - a one place go to for families - that would be amazing. A one stop interactive tool. It would even be relevant for grandparents and cousins. That would be really helpful.*

**Bereaved parent**

Many consumers identified that they had proactively sought information themselves. For these consumers, many of whom had high levels of health literacy and high education levels, they reflected that their experiences in seeking open and direct communication with health professionals were nonetheless more difficult than they would have anticipated or preferred. The concern they expressed was that rather than consumers having to be exceedingly confident and proactive in seeking out information from the treatment team, this situation should be reversed. The treatment team should be seeking to identify consumers' information needs and tailoring communication to their needs. This includes being responsive to the type of information required at different stages of the child's condition; the types of information required by different members of the family; the range of care and support options; the communication format including verbal, written and online materials; and the cultural context.

Healthcare providers highlighted the importance of empowering families who are required to communicate with multiple services and team members.

*Identification of the team - listed somewhere in their records - I have found empowering the families to create a list or giving the family a list to take to OPD's so that letters/information can get sent to their teams- Primary care/local hospital and specialist teams even schools/NDIS providers where appropriate. MDT's/handover meetings/email updates. it is tricky as many of our families have so many teams involved.*

**Healthcare provider**



*Families need access to a network that will support them through a journey that they've got to go on, what services are available etc. A big thing I hear from families is they don't know what they don't know... when they're diagnosed they are overwhelmed with information - but they don't know what they need, they haven't [navigated that] access- they need that early support and it needs to be lead by the parents... one parent was told they can get an access to a chair, just google it- they didn't know what to google. Parents learn best from other parents, how to access information like a catalogue. Same with NDIS they need to know what they'll need, and they don't know that without that specialist advice.*

**Healthcare provider**

Consumers considered that there would be a high risk that those families with less confidence, lower health literacy and lower social support would confront barriers to gaining information relevant to the palliative care needs of their child and that this would adversely affect their ability to cope.

*Looking back there wasn't the choice (we just did it). But other families won't have the resources to do that. It shouldn't be dependent on certain carers having the skills to advocate and organise.*

**Bereaved parent**

One consumer felt that some parents may deliberately avoid seeking information or providing feedback on the care they were receiving for fear that this may jeopardise the care their child was receiving.

*A lot of education and attitudinal change is needed. Any way of providing educational material is important. Many of the families are scared that any feedback will work against the care they receive.*

**Bereaved parent**

## Age-appropriateness

Consumers identified that they felt there were often shortcomings in the age-appropriateness of communication by the treatment team. This included perceptions that the treatment team sometimes communicated in a way that downplayed the capacity of children, adolescents, and young adults to comprehend clinical information and to be active participants in their own care.

*After I finished the medical part, the communication side is next. It's too broad to say we should just increase communication. Especially with teenagers - it's not just about communication. It's about ensuring the patient feels like the communication is on their terms. There's already so much control taken away. We're dealing with a lot of things. Control is so key - especially regarding advance care planning. It's the feeling of not just being communicated to but with.*

**Bereaved parent**

*Particularly around language - treating paediatrics, teenagers, young adults. We need to treat them as young adults - don't simplify language as if you would for a young child. Sometimes some of the doctors wouldn't tell you something if they don't think you're ready to hear it.*

**Bereaved parent**

Ongoing consequences for consumers were reported. Those who perceived they had been excluded from information-sharing and inclusive, age-appropriate conversations at an earlier stage in their treatment, reported subsequent concerns and anxiety over the course of their treatment about the information deficits.

*I'm still finding out about things to do with treatment that happened years ago. It feels like I have to email the hospital - and then I have to read through the clinical notes to try to understand. I don't want to have to go through a drawer. Everything is opaque and hard to get through.*

**Bereaved parent**

## INFORMATION SHARING BETWEEN HEALTHCARE PROVIDERS

Information sharing between healthcare providers is considered essential to effective palliative care. Many commented that communication between clinicians across a broad range of specialties is a key role played by paediatric palliative care and that there are high competency requirements for teamwork.

*In palliative care service at our children's hospital, interprofessional practice competencies are key. There are so many teams involved, particularly for those with complex conditions. The aim is to improve efficiency and decision making, how to manage conflict. These are foundational skills.*

**Paediatric palliative care provider/organisation**

*It should not be reliant just on enlightened individuals - should be systems and processes to ensure that it's covered across the board.*

**Bereaved parent**

Information sharing *within* organisations tends to be much more feasible than sharing *between* organisations. Examples were provided of a larger Local Health District (LHD) in NSW that had implemented systems for sharing care plans for children receiving palliative care that encompassed all aspects of services provided by the LHD, including inpatient, ambulatory and emergency services. This initiative has been piloted and has been considered advantageous for both the treating team and to support children with life-limiting conditions and their families.

*Our health service is implementing a pilot to improve collaborative information sharing. We ensure that each family has specific information that they can take with them from planning meetings. There are key touch points for communication that are defined. We have one key pathway that we have for all healthcare workers in the hospital.*

**Paediatric palliative care provider/organisation**

*To promote family communication, they get a copy of what was discussed and clarity about when the next touch point is. We are trialling and evaluating it at the moment.*

**Paediatric palliative care provider/organisation**

Another healthcare provider identified the value of sharing care plans between members of the health care and support team.

*Copy of management plan provided which has all the clinician details, emergency plan for symptom management. E.g., includes a seizure management plan. All is in one place. There is the option to upload the document onto the home page of the health service. Clinicians can click and see what the management plan is. When the plan changes, they can update.*

**Paediatric palliative care provider/organisation**

The importance of information sharing within the palliative care team was emphasised with the view that care is required to ensure team members' views and perspectives are taken into account. The importance of team collaboration and communication was linked to the 'communicating for safety' standard<sup>2</sup> of the Australian Commission on Safety and Quality in Health Care.

*The services can be improved by fostering relationships and communicating for safety. Because paediatric palliative care nurses have not always been able to communicate directly with Paediatric palliative care specialist there is a risk the NSQHS communicating for safety is not being adhered to. The patient has a time lapse of care and information may not always be accurately passed to the consultant and the patients needs are at risk of not being met.*

**Healthcare provider**

The extension of a care plan for communicating expectations around ambulance callouts was highlighted as a valuable initiative. This is seen as a proactive way of communicating the preferences for setting of care and to prevent unnecessary transports to hospital.

*For example, the palliative care Ambulance plan. There are plans for situations if a child deteriorates. The plan has contact details for who the ambulance officers can contact. The plan may say that there may not necessarily be a requirement to take the child to hospital and that they can stay at home. It provides an opportunity for sharing of information with all clinicians. Gives the ambos details on who they can talk to.*

**Paediatric palliative care provider/organisation**

*In NSW there has been a huge step forward. Now you can call an ambulance and they can manage symptoms at home. It's a wonderful idea. It's a NSW Health and Ambulance document. You need a clinician to complete it.*

**Bereaved parent**

The challenge of information sharing between healthcare providers who are in different organisations is much greater.

*Information sharing happens through multidisciplinary team meetings. The barrier is sharing info across services beyond those that are Queensland Health services. It's difficult. AHPRA<sup>3</sup> accredited but still issues. Families do sign off confidentiality provisions to enable info sharing. But there's the difficulty of accessing data bases.*

**Paediatric palliative care provider/organisation**

*The interoperability between systems is needed to provide real potential.*

**Government**

QuoCCA has been identified as a flexible and responsive approach to enable information sharing strategies to be implemented with diverse service groups and settings.

*QuoCCA is an example of a successful approach in information sharing. It involved working side by side with health professionals. It's very relevant. Also, there is recognition that information sharing doesn't need to be restricted to health professionals. It's really helpful in connecting all those involved in a child's care and support needs.*

**Paediatric palliative care provider/organisation**

For some, there was a view that a consolidated, national, information exchange and clearing house would be optimal. Others sought ready access to a nationally consistent education curriculum.

*The peak bodies have a role here e.g., PCA, SCV<sup>4</sup> network. There are lots of these things that are working. Is there a one source of truth? A website that everyone goes to.*

**Healthcare provider**

*Easy access and low cost to education and workshops having a unified or national set of education workshops curriculum*

**Healthcare provider**

*Free e-learning that is offered nationally*

**Healthcare provider**

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2. ACSQHC Communicating for Safety Standard - Leaders of a health service organisation set up and maintain systems and processes to support effective communication with patients, carers and families; between multidisciplinary teams and clinicians; and across health service organisations. The workforce uses these systems to effectively communicate to ensure safety. <https://www.safetyandquality.gov.au/standards/nsqhs-standards/communicating-safety-standard>
3. AHPRA is the Australian Health Practitioner Regulation Agency
4. SCV stands for Safer Care Victoria which works with health services to monitor and improve the quality and safety of care delivered across Victoria's health system, with the goal of achieving zero avoidable patient harm.

Enhanced information sharing was identified as a way of enhancing knowledge and understanding of the benefits of referral to paediatric palliative care.

*There's a limited workforce and a limited ability for services to address the needs of paediatric palliative care. All healthcare professionals need to be aware of the needs of children with palliative care needs. It's a basic thing that needs to be embraced regardless of specialty. There's no way the workforce are going to be able to encompass all children... palliative care should be a concept we provide to everybody.*

**Paediatric palliative care provider/organisation**

*For timely and equitable access we need networking... it's important we're not working in silos. Then we know what they offer and they know what we do on the ground, then we can work together.*

**Paediatric palliative care provider/organisation**

*Communication needs to be improved and the gaps in care addressed... good communication includes identifying what's already been provided and what can be addressed through the referral.*

**Paediatric palliative care provider/organisation**

Streamlining the approach to information sharing – including through digital health and electronic health records – was highlighted by consumers as a way of enabling more efficient information exchange between all members of the care team. It was seen as having the additional advantage of reducing the burden on families of needing to repeat their stories on multiple occasions.

*Ideally, online live case notes, for families, therapists, clinicians, schools and doctors to add, access and share with all involved. Cutting out a lot of double handling, repeated discussions and painful re-hashing of information for the families who need to utilise their precious time together much more ideally than repeated conversations with many individual organisations involved.*

**Bereaved parent**

The challenges of information sharing were seen to be exacerbated for families living in regional and remote areas.

*Communication in remote areas is not that great. Resourcing to enable better communication, that is important.*

**Paediatric palliative care provider/organisation**

*There's a massive skill drain in the rural and remote. Knowledge and experience – these communities have workforce that is starting out and ready to retire – there's not enough in between. Need to pitch the information to people who have not much skill at all.*

**Paediatric palliative care provider/organisation**

Promoting awareness and understanding of the local service context is important to provide insights about the family support needs that are relevant when a child is discharged from a specialist setting – particularly if there are relatively limited health and social care supports available.

*You need to have an understanding of what resources are available in the town or region the child will be living in. Knowing what's the capacity and capability of the people in the area before they refer out is really helpful.*

**Paediatric palliative care provider/organisation**

*One of the things that we see for families is the lack of that continuity of care. There are some charitable organisations that do offer some support but within the hospital system, they need to be aware of that. And whether that's [because hospitals] don't know that [those] linkages are there. There's opportunity to have that support from that outside service while you're in hospital that can be really helpful for that transition to community care.*

**Paediatric palliative care provider/organisation**

To some extent there is scope with My Health Record to facilitate information sharing but this has yet to become used on a routine basis. Other examples of interagency information sharing were mentioned that enhanced coordinated service delivery.

*Queensland also has a patient summary sheet distributed to families and to teams who support them. Electronic information exchange means that the plans have currency. And they are accessible. E.g., easily found when someone comes to an ED.*

**Paediatric palliative care provider/organisation**

The outward focus of palliative care service planning and support was also highlighted as a key competency. Building connections with a diverse array of social and community-based organisations and support links is regarded as a key role. It also requires tailoring the support needs according to the individual requirements of children and their families.

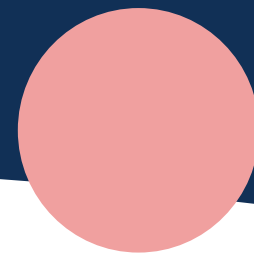
*Intersectoral meetings have been put in place since the start of the year with (organisations). We need to include kinders, schools, sporting clubs. It's a case-by-case basis.*

**Paediatric palliative care provider/organisation**

*It's important to establish the degree of information sharing that is relevant to the individual situation. For some siblings, they are comfortable for all [at school] to know. But for others, they don't want to share. For example, in some counselling sessions with kids, some are mortified about who knows about them. So, it's really important to know people's preferences.*

**Paediatric palliative care provider/organisation**

# Improving community awareness



There is a multitude of factors that are relevant to promoting greater community awareness about paediatric palliative care.

## ATTITUDES ABOUT DYING

Many identified that there were deep-seated fears held by people in the community about dying in general, and, in particular, for children suffering a life-limiting condition. Many people commented that there was a widely held view that it was perceived to be against the natural order of things for children to die. This contributes to a strong reservation to discuss or raise awareness of paediatric palliative care.

*On community awareness-the reality is before my child died I didn't want to hear about children dying... I do want to see something better for that referral process.*

**Paediatric palliative care provider/organisation**

*One of the big differences is society's perception of death and dying. People aren't willing to talk [about death and dying at all]... then add paediatric, which is outside of the usual order, that adds an added barrier.*

**Paediatric palliative care provider/organisation**

The absence of open communication about palliative care is explicable given community attitudes – nonetheless, stakeholders highlighted the negative consequences of this. Examples were provided of families who felt let down and excluded by the inability to openly share information about paediatric palliative care in community settings.

*People don't understand the meaning of the word palliative care. It's about living not dying, the best possible way you can. Embrace that! Turn it all around! It's just not there sadly. A whole of community approach is needed. Her friends could have been embracing her life. They could have educated their parents. Wake up!*

**Bereaved parent**

This is particularly the case in school settings where siblings may experience ongoing distress and feel unsupported by the school community, as relayed by bereaved parents:

*The term 'palliative care' was banned at our daughter's school. [Other parents] didn't want [palliative care] mentioned or to discuss what could happen for her, because that could impact on their kids. It made it hard for our family. And her siblings were upset – they were at the same school. The school response was "Don't mention that word [palliative care] to anyone – it could affect their educational experience." This [attitude] needs to be worked on. That's where more knowledge is required.*

**Bereaved parent**

This reticence to communicate openly about paediatric palliative care was not restricted to the general community. Many consumers and service providers commented that healthcare professionals were not immune from the stigma attached to paediatric palliative care and the fear of discussions about dying. Some consumers identified that this avoidance behaviour was a barrier to enabling and planning care to meet their needs.

*It's difficult to get community awareness about something that people would hope doesn't happen. [Health professionals don't undertake training] with the hope of helping people to die well. You want to help them live longer... [there's a] fear of not giving up on a child. That's the underpinning culture in Australia...*

**Paediatric palliative care provider/organisation**

Others expressed the view that the relatively small incidence of childhood death limited the applicability of broad-based awareness campaigns.

*Community awareness is something we might never achieve. Most families don't need to go through losing a child.*

**Paediatric palliative care provider/organisation**

Contrasting views were held by some who considered there was scope for raising community awareness.

*When you are in the thick of the last days a family needs to do and be how they wish to be, so conversations in the community around dying and grief needs to be normalised so this is not such a uncomfortable time for others around the family who are going through the most painful time of their lives.*

**Bereaved parent**

*Education and advocacy highlighting that paediatric palliative care has more of a focus on life (and making life the best it can be), rather than on death.*

**Healthcare provider**

Examples were given of demystifying death and challenging myths from education strategies used in Australia and internationally.

*(It involves) working with community agencies or CALD community centres to educate and open discussions within communities and to engage the help within communities to support families. More engagement with agencies (e.g. Groundswell) who are also trying to promote community discussion around issues of death and dying as well as palliative care.*

**Healthcare provider**

*There is scope to use public health palliative care models and innovations internationally. It's important to demonstrate the benefits. Tell stories; showcase positive stories. How teams and community have come together to make a change. It's opening people's hearts – improving the community by making it clear that dying is normal...The UK in particular has relevant learnings and initiatives... Hospice UK does some school education in death literacy.*

**Paediatric palliative care provider/organisation**

*Public education and death education in schools is important. This requires capacity building. It's important to normalise what happens.*

**Paediatric palliative care provider/organisation**

*Public awareness for paediatric palliative care? We have national palliative care week. Perhaps that's an opportunity to craft something for paediatric palliative care. There's a great myth – that children don't die.*

**Paediatric palliative care provider/organisation**

*St Christophers in the UK is an example of how to build the community knowledge that people do die - it's part of a skill set that the population as whole can embrace.*

**Government**

## Communication needs

For families living the paediatric palliative care journey, there was a view that there would be benefit from sharing stories about the journey with other families. Many spoke about the power of storytelling.

*We seek to learn from the way we've been working with families. We're trying to be more sensitive to the stories and images - and to be as inclusive as we can.*

**Paediatric palliative care provider/organisation**

*We were given a journey book. That was a book about different stages of palliative care. It was a clinical explanation of what can happen in different stages. But it's not suitable just getting a book. It's clinical. It didn't have stories. That would've been helpful.*

**Bereaved parent**

*Telling stories about when palliative care was done well. And what that means for the people who received the care. That would be a great place to start.*

**Paediatric palliative care provider/organisation**

For others there was a view that targeted communication would be beneficial to promote the meaning and purpose of palliative care to enable children and parents to more easily communicate.

*Community awareness is something we might never achieve. Most families don't need to go through losing a child. I think we struggled for people to know what palliative care is, even though it might be nice for people to know there are some information sheets we can give... for extended families to understand what paediatric palliative care is... families have to explain to their family [Grandma hears their grandchild is in the care of the palliative team and they think 'What?! She's dying?!'] ... information sheets [to explain to extended family, so our families don't have to, that would be very useful].*

**Paediatric palliative care provider/organisation**

A tertiary specialist paediatric palliative care service used this targeting approach for communication strategies to support families in defined geographic areas, where there are several families who would benefit from the intervention. The aim was to undertake local capacity building and skills sharing. The rationale was that because there are not large numbers across the state, it would not be cost-effective to undertake a state-wide campaign.

*We target a few families in a local area for information sharing (where there are instances of a number of families with paediatric palliative care needs). The local health professionals are primed. They have day trips to community areas, ACCHOs, GPs etc. works well because they've come together as a community.*

**Paediatric palliative care provider/organisation**

Some explicitly advocated strategies to normalise conversations about death and dying. These strategies include a focus on capacity building and consumer empowerment. Providing information beyond consumers to the broader range of support services was identified as a strategy to improve responsiveness.

*Normalising grief and dying in a death denying society (is the challenge). It's always relevant to approach from a community development perspective, (like) "Good Grief This Hurts" (a community education seminar). We use creative arts - it helps for people to be able express vulnerabilities and fears.*

**Paediatric palliative care provider/organisation**

*Good grief this hurts involves capacity building. It's used to show how people are impacted by death. They can relinquish responsibility from professionals back to community - that's where the power is.*

**Paediatric palliative care provider/organisation**

*Schools are being mobilised for death literacy. E.g., leaf life cycle program. Everything has a beginning and middle and end.*

**Government**



*Providing education in a sensitive way to schools and colleges to ensure death and dying becomes a norm in the curriculum*

**Healthcare provider**

Bereavement is a further area where communication needs are highlighted as highly relevant, and which are also challenged by community attitudes that may diminish or ignore family needs.

*Bereavement support is a really important topic. No one wants to talk about it (death of child) with them. No-one wants to hear about their child any more. It shifts and changes as kids move to adolescence. And big life events are important.*

**Paediatric palliative care provider/organisation**

*From a cultural perspective and from a geographic perspective. It (death of child) never goes away. And those sorts of (bereavement support) services are never available.*

**Paediatric palliative care provider/organisation**

*Bereavement and Mental Health is a massive gap. Grief wise – there's the before, during and after. Our service did everything within their power. I asked for help. In some ways I had to fight for it. Someone else may not.*

**Bereaved parent**

Culturally relevant communication was highlighted as a key priority.

*We need to ensure appropriateness for Aboriginal and Torres Strait Islander people. We need to consider health literacy for different populations – not one size fits all.*

**Paediatric palliative care provider/organisation**

*SA health has implemented an aboriginal health impact statement to ensure that they're involved in planning. It influences finishing up business and it's targeted across the life course.*

**Paediatric palliative care provider/organisation**

*Community awareness programs need to be First Nations Specific. There's a cultural taboo to speak openly about death and dying and finishing up business.*

**Paediatric palliative care provider/organisation**

*Culturally appropriate practice - increased funding of multi-faith and ethnic support workers, specifically to support paediatric palliative care. It is hard for individual health services to fund such positions to the fluctuations in caseload/demand, but families tend not to trust support workers from outside their communities at the toughest times.*

**Healthcare provider**

*Education that is culturally sensitive, ensuring health literacy and is delivered in different medium forms.*

**Healthcare provider**

*Culturally responsive care. It's lacking in the nutritional education and what we're taught. Particularly around feeding and around care. Sometimes we're a bit naive about these things.*

**Healthcare provider**

## **Social support and connection**

Many highlighted the advantages of tapping into social support systems to enable children and families to remain connected to friends and other community-based support organisations. Many respondents mentioned the relevance of continued connection with sporting clubs and other community groups.

*Our health service is doing a lot of developmental work around social mapping - asking families what they've got and building on the community aspects and training the community.*

**Healthcare provider**

# Improving research and data collection



Many identified the shortcomings in currently available data on paediatric palliative care and that research was relatively under-developed compared to adult palliative care.

## DATA ISSUES

The lack of comprehensive and accurate prevalence data at a national level on the number of children for whom paediatric palliative care would be relevant was identified as a key issue. This is considered a major priority to understand current need and to assess the extent of the gap between existing service use and service need.

*The data parts are really, really, tricky. There's no data about how many paediatric palliative care patients there are in the last year, decade.*

**Paediatric palliative care provider/organisation**

*There are so many data sets – but there is no national approach to the data.*

**Paediatric palliative care provider/organisation**

*Develop a standardised data set for collection of data to identify areas of need.*

**Healthcare provider**

*One of the things that is talked about is a registry - we have cancer registry but we don't have that palliative care registry*

**Healthcare provider**

*We need a national picture about who's on palliative care – without this it's a major obstacle. We need to know how long, why services are used. This helps all the charities etc. to know and plan.*

**Bereaved parent**

*Data is a major issue for palliative care. We've got to get it right. There are major gaps all over the place. Difficult to do research when don't understand demand or the servicing profile. We lack data on prescribing data and we're not able to identify palliative care service provision. There also differences between state and territory collections.*

**Government**

*If any area to be prioritised it's the demand to identify the unmet need - that would be warranted. That would then inform a range of things – we could get a sense of the baseline.*

**Government**

Other challenges are that outcomes data are considered not necessarily well validated for the paediatric context. This leads to concerns that outcome measures that are relevant to adult contexts are inappropriately applied to the paediatric context.

*Having a standardised way of collection information would be good. They don't have standardised tools for research. Need paediatric sensitive tools. Need to have meaningful comparisons.*

**Paediatric palliative care provider/organisation**

*In recent years PCOC is the most successful in terms of quality and outcomes data. But I'm not sure how transferable it is to the paediatric consumer.*

**Paediatric palliative care provider/organisation**

*Paediatric data is very sparse. But they (PCOC and others involved in the collection of information on service use) are trying to count it like they do [adult] services.*

**Paediatric palliative care provider/organisation**

The point was made that robust clinical data collections were pivotal to driving continuous performance improvement. In turn, more robust data collections can enhance quality improvements such as the use of clinical indicators, one of the strategies used to advance quality and outcomes in integrated cancer care.

*It's important to have data and clinical information for improving practice going forward. Not just sharing of info at an individual care plan level but at a national level.*

**Healthcare provider**

*If could strengthen the clinical indicators for palliative care and that would assist in monitoring best practice.*

**Government**

*By improving access to information at a national level this can inform best practice.*

**Government**

*Give consideration to capturing after death care and home community care; ICD codes life limiting disease, pall care and after death bereavement care; and a national database including NGO community care*

**Healthcare provider**



There is acknowledgement that there have been approaches to tailor the PCOC data collection for the paediatric context but that there were still unresolved challenges in this area to ensure nationally consistent and context-relevant collection of paediatric outcomes data.

Whilst all considered that there was insufficient data collection in general for paediatric palliative care, the sparsity of data collections was considered even more pronounced for children with rarer diseases.

*In Australia, data for most rare diseases isn't captured in health information systems or registries. There is currently no coordinated strategy to collect, measure, build and translate the data that does exist. More coordinated data collection and research into rare disease would also support more coordinated research into paediatric palliative care, and vice versa.*

**Bereaved parent**

Frustrations were expressed about the one-way direction of data flow to data repositories and that existing data collection strategies were hamstrung by the lack of application of clinical indicators.

*The paediatric palliative care sector has collected clinical indicators data for a while but have not used the indicators. It's all in Caresearch. And we can't benchmark against other services. Each specialist team is very different.*

**Paediatric palliative care provider/organisation**

Among the opportunities to address data shortcomings, there was a view that consideration should be given to area-based pilots to trial the collection of paediatric palliative care data. In a similar vein, the approach of survey-based data collections was mooted as a way of gaining insights and filling the data gaps. Over time, these one-off exploratory data collections/surveys can establish a baseline from which more established data repositories can be built.

Learnings from other data collection strategies that were identified as potentially relevant included the scope to consider data linkage across a range of administrative data-sets inclusive of health and social care services.

*Pooling the datasets with NGOs e.g., Carers ACT enables you to get a better overview of the kind of support and linkages outside the hospital environment. Sharing of data is always an issue.*

**Paediatric palliative care provider/organisation**

*Build the capability and accessibility to national clinical data through data linkage to improve outcomes and experiences for children and families in need of paediatric palliative care.*

**Government organisation**

Another innovative approach involved the consideration of greater use of artificial intelligence to reduce the administrative burden on clinical staff in order to routinely extract data from clinical reporting systems.

*Consider the use of AI to mechanize clinical data collection without burdening clinicians to enable easy access to information for children and families utilising paediatric palliative care, health professionals, policy makers and researchers.*

**Government organisation**

## RESEARCH ISSUES

Research domains relevant to paediatric palliative care were identified as spanning areas that are substantially different in many respects from adult palliative care. A particular challenge identified is that for non-specific conditions, there are challenges around unknown prognosis, widely diverse symptoms, and care planning requirements.

*Paediatric palliative care has such a diverse population. So, it's hard to have tools for relevance for say, an antenatal family vs a neurological patient vs oncology context.*

**Paediatric palliative care provider/organisation**

Many identified the importance of research that incorporates the child with a life-limiting condition and families' experience of care.

*We believe our work with families helps them cope with the inevitable death of their child and what happens after... our work helps the families maintain employment...[even if it's not both, at least one parent being able to have an income]... the same could be argued with siblings attending school... from a research perspective I'd love to see the outcomes for families who use our service versus those who don't...*

**Paediatric palliative care provider/organisation**

*We need consider how to include qualitative, lived experience data?*

**Paediatric palliative care provider/organisation**

*Speaking to families after the loss of a child would provide raw honest feedback.*

**Bereaved parent**

*Consider the power of peer connections and the voice of families. For example the peer mentoring program in Queensland. Similarly at Women and Children's at Adelaide. The voice of families in education is important. Need to have consumers around the table.*

**Paediatric palliative care provider/organisation**

*Research could prioritise existing knowledge gaps such as the rare disease families' experience of palliative care services. Most of our knowledge on this comes from lived experience rather than any rigorous research.*

**Bereaved parent**

The relevance of research that addresses the needs and experience of Aboriginal and Torres Strait Islander people was emphasised. This needs to consider beyond the needs of individual people to include the wider context of inter-generational trauma.

*There's the element of grief and loss. Aboriginal people are in complicated grief that is intergenerational. It's still happening, with suicides and terminal illness. There's constant death in your face. We never have a chance to grieve properly, our bereavement is constant. Facilitate it properly with all the considerations for our mob. That's the reality for a lot of our families, across the states.*

**Paediatric palliative care provider/organisation**

Several commented that there were competing priorities that meant that healthcare providers were less likely to have sufficient time and resources to dedicate to research.

*For me in terms of dream world, what it can be- what we all need to have for our hospices, paediatric palliative care, we need to have for a full time research nurse, a full time educator, and we need to have the opportunities for people to be able to spend the time doing the education, doing the research... also have access to that family centred care, families going through paediatric palliative care or bereaved family... [to have] input into policy. QuoCCA needs to be ongoing, because it's already developed such incredible resources. And we just don't have enough people or enough money in it. It's very obvious... we know what we need we just don't have the money in it.*

**Paediatric palliative care provider/organisation**

*We're very time poor. Difficult to do research with time constraints. Having an overarching support would be good.*

**Paediatric palliative care provider/organisation**

*As busy clinicians it's really difficult. Would love to share more and publish. We are all stretched and working really hard. But it (research) should be prioritised.*

**Paediatric palliative care provider/organisation**

*All services are small. Don't have a designated person to do research. Fortunate that QuoCCA exists. They have funding and people in positions to drive that. As for clinical services, it's difficult to take on projects on their own.*

**Paediatric palliative care provider/organisation**

*My colleagues and I are overworked, so support with extra funding is required. It would be good to have a central space to undertake research.*

**Paediatric palliative care provider/organisation**

A number of stakeholders emphasised that research priorities should be relevant to the practicalities of service delivery and that priority should be given to the translation of evidence to practice.

*The sector is growing - it's in a growth phase. Need to translate information into systems and practice.*

**Paediatric palliative care provider/organisation**

*Research needs to be driven by clinical need not just funding priorities. Voice of the service needs to be influencing research priorities.*

**Paediatric palliative care provider/organisation**

Others highlighted the importance of more research into ethics and palliative care.

The research agenda was considered to be currently diffuse, with different organisations across states and territories pursuing separate agendas and areas of local priority. Others commented that there was a lack of coordination, limiting the synergies between different researchers working across different settings.

*PCOC is active. But the issue is that there are many research initiatives happening. There's a sense that we're just doing things in silos - in both adult and paediatrics.*

**Paediatric palliative care provider/organisation**

*Some fantastic work across country is happening but because of federalism and different states/Territories, this is siloed. Paediatrics is a small specialty. Should be the first to come together to benefit from synergies. This includes hospices and palliative care units in hospitals. If research is undertaken, it needs to be collaborative and shared.*

**Paediatric palliative care provider/organisation**

*We need a national focus to support research and data to support every specialist service across the country.*

**Paediatric palliative care provider/organisation**

Notwithstanding the focus on collaboration across states, some still cautioned that there is a need to acknowledge the pragmatic reality that state-based systems are different and therefore that these differences cannot be ignored when researching the sector.

*We still need to acknowledge the nuances of state-based care.*

**Paediatric palliative care provider/organisation**

# Collaboration between governments



The role of government was identified as important both from the perspective of planning and policy coordination and funding the delivery of services.

## PLANNING AND POLICY COORDINATION

Many stakeholders consider that Australia lacked a national coordinating entity to advocate and coordinate policy, program development and research in paediatric palliative care. Some looked to PCA to play this role and others considered that this was partially a role played by PAPCANZ. All agreed that this was an area that the National Action Plan should address.

*Building PAPCANZ to the capacity required for autonomy is important – it's still a voluntary committee.*

**Paediatric palliative care provider/organisation**

*It's really hard for small specialist areas to get airplay at the national level – PCA has to drive.*

**Paediatric palliative care provider/organisation**

There was a view that the absence of a coordinating role was a limiting factor in many dimensions. Others highlighted the benefits of enhanced coordination to share the learnings across different states and territories.

*[There should be] mapping of jurisdictional opportunities – there are learnings across jurisdictions.*

**Paediatric palliative care provider/organisation**

For others, the disparity between states and territories in terms of service resourcing and models of care was problematic, reflecting the absence of a coordinated and agreed nationally consistent approach. The importance of national consistency in service models was emphasised.

*A critical enabler of the Action Plan is collaborative governance and leadership. Any national policies and practices to ensure paediatric palliative care is consistent across all jurisdictions must include people living with a rare disease.*

**Bereaved parent**

*We need a national charter so we're following a similar path – so we have an agreed set of principles in line with the PCA standards.*

**Healthcare provider**

There was also a view that governments are important but not sufficient to advance the development of paediatric palliative care. Other stakeholders are considered vitally important, and this includes the role of NGOs, sporting clubs and social networks.

*Partnering with philanthropic and industry and government and non-government to leverage opportunities that necessitate scale up for improving outcomes for children and families in need of paediatric palliative care.*

**Government organisation**

## FUNDING

Structural features of existing funding regimes were identified as problematic for many stakeholders. It was considered that aspects of paediatric palliative care were not able to be adequately resourced within existing mainstream funding models whether this be aspects of the Medicare Benefits Schedule for GP services or for activity-based funding of acute hospital services.

*If a person dies at home and you need a GP to go there, apparently that can't be billed from a Medicare perspective because the person's died... we shouldn't be asking someone to do something that's special and out of the ordinary- the GPs do it [out of their own sense of what is right].*

**Paediatric palliative care provider/organisation**

*And there's an anomaly with neonates in that a neonatal admission can't be changed to a palliative care admission. An ICU admission- once they're out on the ward that can be changed- but a neonate can never be traced? Tracked? Then what do you do with that?*

**Paediatric palliative care provider/organisation**

*When we have neonates transfer they don't have a Medicare number so we can't access any Medicare, but we get no funding- we're not going to hassle bereaved families to register their child. [And I've put in the time contacting other organisations, asking how they go about it, and as far as I can tell, they just don't get funding for neonates either.]*

**Paediatric palliative care provider/organisation**

*Medicare funding. This is a system level challenge. There is no way to bill for patients once they have died. It means the services can't offer bereavement support (and get Medicare funding for it).*

**Paediatric palliative care provider/organisation**

*When a patient dies in hospital – it is also problematic with activity based funding to recognise bereavement support.*

**Paediatric palliative care provider/organisation**

Others highlighted challenges of funding continuity and the uncertainties associated with fixed term program funding.

*Project-to-project funding is an issue that challenges continuity of programs.*

**Paediatric palliative care provider/organisation**

*We need permanent funding. For example the QuoCCA project – it lasted 3 years – and then we have to reapply for our job. It's a gap and it has a knock-on impact for the care delivered to kids at home.*

**Paediatric palliative care provider/organisation**

Despite these funding challenges, the point was made that there has been strong and sustained funding for paediatric palliative care and that pilots provide an important bridge to identifying a service gap and developing service initiatives. These can then be taken forward where the effectiveness of the pilot is confirmed.

*We have had robust national palliative care programs operating for long periods – some transform and mature and grow. We have opportunity to build into the commissioned activity. Project funding comes out of a need – we often discover creative ways to continue.*

**Government**

A further factor affecting resource adequacy has been the general disruption caused by the pandemic to mainstream fund-raising strategies.

*COVID-19 is having an impact on fund-raising. We've had to move to online events – these are not as effective and it's a challenging time for all. We rely on generosity and then get random grants around election time.*

**Paediatric palliative care provider/organisation**

## OTHER STRATEGIES

### Intersectoral collaboration

Intersectoral collaboration was emphasised as a vital element in maximising the value of the specialist role played by paediatric palliative care services.

*Collaboration matters – there needs to be lots of bridging – across adult and paediatrics; across specialist palliative care and ambulance; with Aboriginal health; and with refugee and migrant health.*

**Paediatric palliative care provider/organisation**

*[In Victoria] Palliative care consortia have been established. They do linkages between agencies and between clinicians.*

**Paediatric palliative care provider/organisation**

Stakeholders commented that where there is more than one service involved in care, such as disability services and health services, there is increased complexity in service coordination. Consumers identified that they faced significant hurdles in achieving coordinated services.

*I worked hard and fought and fought and fought. I can't believe how difficult it was. That's what I want changed. There should be pathways set out. I was the coordinator. Other parents shouldn't have to fight like this.*

**Bereaved parent**

*A lot of families are the ones advocating – no one else is doing it. You get used to receiving the standard letter from government "we'll look into it." Often you feel like you're forgotten. There's a lot of families out there but not everyone is speaking up.*

**Bereaved parent**

*There needs to be streamlining between the different funding bodies. Ideally all funding would come from the same bucket and be consistent across all states. This would ensure consistency of access to services.*

**Bereaved parent**

*Navigating for families – it needs to be coordinated by someone else other than the family. These families don't need any more stress. They should be focused on quality of life goals – not fighting for funding between buckets. For example, there could be an NDIS dedicated arm for rare diseases and palliative care families. There should be agreement about what is in and not. If not, then there's got to be another way identified for families to access these services if appropriate. The families shouldn't have to fight and be coordinators of care.*

**Bereaved parent**

### Carer role recognition

Several commented that greater recognition should be given to the pivotal role played by carers.

*Carers are underfunded and under-supported.*

**Bereaved parent**

*It's difficult to find time to access all these things – so compassion from the system is needed. To make our journey a little bit easier.*

**Bereaved parent**

### Financial support and Centrelink

Centrelink was identified as playing an important role in offsetting financial hardship for families. However, challenges in accessing Centrelink were considered stressful and time-consuming.

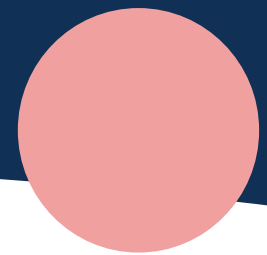
*Once I made 63 phone calls on one day to get onto Centrelink. I would have to put aside 1.5 hours to make the phone call. If after lunch, then it was not feasible. You have to start at 5 to 8am then wait in a queue.*

**Bereaved parent**

*Centrelink needs a compassionate red-flag for terminal kids.*

**Bereaved parent**

# Appendix 1: Online discussion paper questions



## CONSUMER DISCUSSION PAPER

### 1. Improving quality of services in the community and acute care

- » How can palliative care for infants, children and young people be improved?
- » How can the various services and individuals involved in providing palliative care to infants, children and young people work better together?

### Improving access to services

- » How can we make sure that infants, children and young people who need palliative care get it when they need it?
- » How can we avoid a situation where some people receive better support than others?

### Improving skills of the workforce, parents and carers

- » What do you think doctors, nurses and other health professionals need to know more about when it comes to looking after infants, children or young people with illnesses that may cause them to die at a young age?
- » How can health professionals better understand and include an infant, child or young person's family (parents, step-parents, siblings, grandparents and other key figures) in care?

### Improving knowledge of palliative care across the community

- » What would you like the general population to better understand about palliative care for infants, children and young people?
- » Improving collaboration between State/Territory Governments and the Commonwealth Government
- » What advice would you have for the State and Federal governments about working together to help infants, children and young people who need palliative care?

### Improving research and data collection

- » What would help to improve research in paediatric palliative care?

### Improving uptake of advanced care planning

- » How do you think we can help children, young people and families and carers share their goals, values, hopes, and fears about care with the doctors, nurses and others who care for them?

### Improving dissemination of information

- » What is the best way for doctors, nurses, and other health professionals to share information about an infant, child or young person's care?

## HEALTHCARE PROVIDER DISCUSSION PAPER

### Improving quality of services in the community and acute care

- » How can palliative care for infants, children and young people be improved?
- » How can the various services and individuals involved in providing palliative care to infants, children and young people work better together?

### Improving access to services

- » How can timely access to paediatric palliative care be improved?
- » What are the key requirements for achieving equitable access to paediatric palliative care?

### Improving skills of the workforce, parents and carers

- » What are the priorities for paediatric palliative care skills development for the clinical workforce, patients, and families and carers?

### Improving knowledge of palliative care across the community

- » What strategies are needed to improve knowledge of paediatric palliative care in the Australian community?
- » Improving collaboration between State/Territory Governments and the Commonwealth Government
- » What areas do you think should be a focus of collaboration between the States, Territories, and the Commonwealth to improve paediatric palliative care?
- » Are there examples from other areas of health which have worked well that should be considered in paediatric palliative care?

### Improving research and data collection

- » What strategies would improve research in paediatric palliative care?
- » What data would help improve quality of care and how can routine data collection be facilitated?

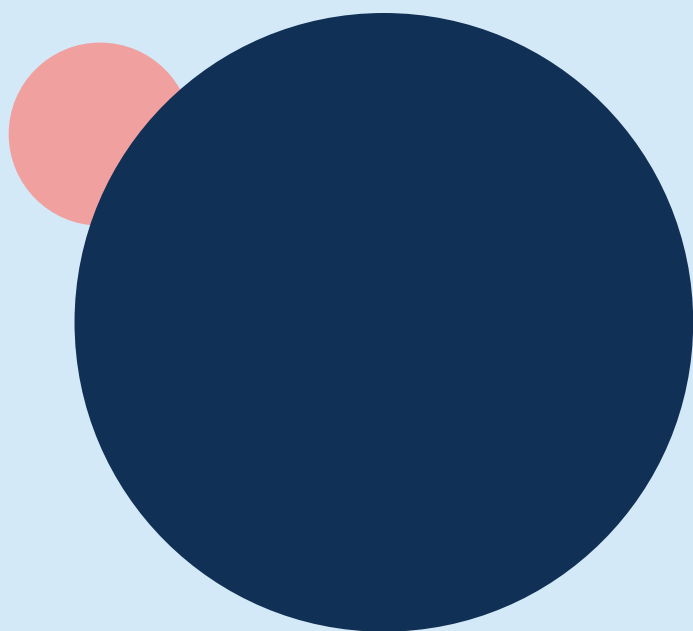
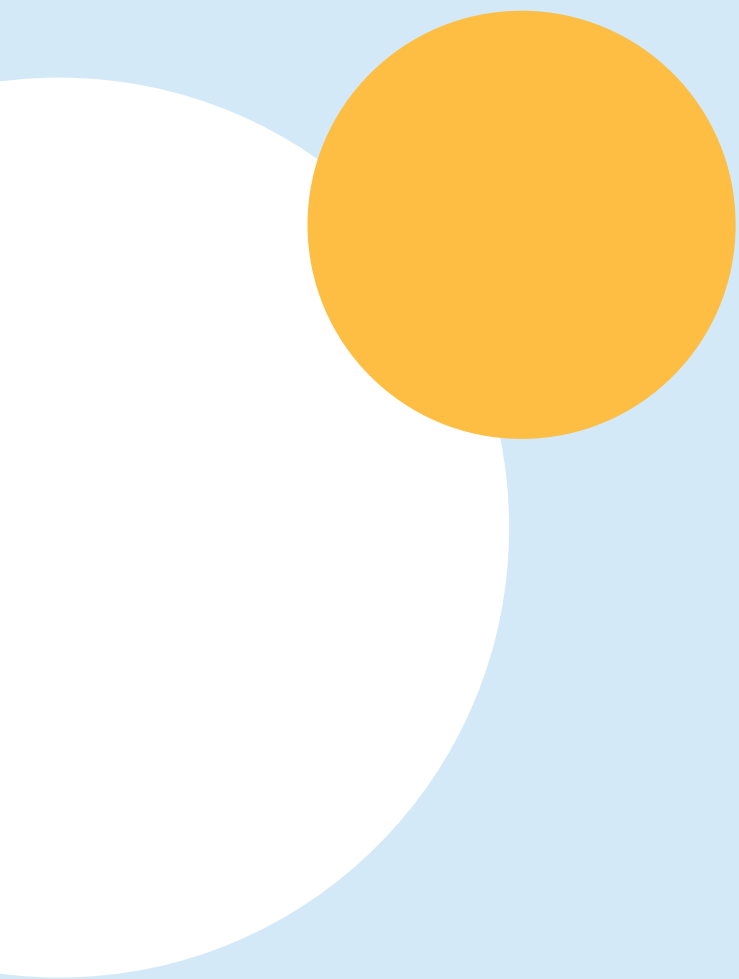
### Improving uptake of advanced care planning

- » How can patient or family-focussed advance care planning be improved in the paediatric setting?

### Improving dissemination of information

- » What are the best strategies to identify and communicate with everyone involved in an infant, child or young person's care?





**Paediatric  
Palliative care**  
NATIONAL ACTION PLAN PROJECT