

Imperial College  
London

# The children's palliative care provider of the future:

A blueprint to spark, scale and share innovation

**INSTITUTE OF  
GLOBAL HEALTH  
INNOVATION**



Suggested citation: Roland, J., Lambert, M., Shaw, A., Williams, I, Dale-Harris L., Fontana G. The children’s palliative care provider of the future: A blueprint to spark, scale and share innovation. London, UK: Imperial College London, 2022.

This report was produced by Imperial College London’s Institute for Global Health Innovation, with the support of Mais Research Center. It was produced in association with the International Children’s Palliative Care Network, Global Treehouse Foundation, Helix Centre, Isabella Seràgnoli Foundation, Mais Family Office Innovation Centre, ORTO Impact and Fondazione AIS.





## About this report

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This policy report sets out an optimistic vision of what a world-class provider of children's palliative care (CPC) could look like in the future. It proposes nine key features through which providers can innovate to improve access and quality over time, drawing on best practice and trends as described by 50 CPC service leaders in 27 countries, as well as insights from other healthcare sectors. Recognising that there is huge variation among CPC providers and the systems they work in, this 'blueprint' is intended for inspiration and challenge, not prescription. In addition to key areas for future innovation it also highlights many areas in which CPC providers are already exemplars within the healthcare sector. CPC leaders and other stakeholders are invited to reflect on the opportunities the blueprint describes and how their own organisations might benefit from pursuing these.

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# Foreword

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Care for children with life-threatening and life-limiting conditions is a true measure of any society. Yet despite being an essential pillar of every health system, not to mention a human right, children's palliative care has often struggled to get the support and recognition that it needs. This is true in rich and poor countries alike.

In the face of limited and often unreliable funding, providers of children's palliative care have, by necessity, had to innovate in all kinds of ways to deliver the services that children and their families so desperately need. As this report shows, these providers – hospitals, hospices, clinics, mobile teams, and communities themselves – have been pioneering all manner of new approaches with little funding or fanfare. This report celebrates their success and hopefully brings some much-needed recognition.

But in thinking about the future of children's palliative care this report also has a more ambitious message: that the scale and scope of this innovation needs to dramatically increase if there is to be any hope of 'health for all' being a reality for children with life-limiting and life-threatening conditions. On scale, the call is for new partners to join in the mission of improving children's palliative care: organisations from the technology and digital sectors, public institutions, private philanthropists, global health institutions, academia, medical devices, and many more. There are tremendous opportunities for these to make a huge social impact through partnerships with those already working in the space in the areas of untapped potential highlighted below.

On scope, the breadth of opportunities set out in the future 'blueprint' of this report is vast: the use of data to measure impact, 'porous' teams providing integrated care across organisational boundaries, digital service delivery, new entrepreneurial and payment models, and much more.

This expanded vision will not happen by itself – it needs health and other institutions to get alongside and contribute to it. The Isabella Seràgnoli Foundation is opening a new children's hospice in Bologna that embodies this innovative approach. In addition, in concert with the release of this report, we are announcing the launch of The Global Treehouse Foundation – an international institute dedicated to the promotion and sharing of innovation in children's palliative care – which will take up this challenge. Will you join with us?

**Maurizio Petta**  
Isabella Seragnoli Foundation  
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# Executive Summary

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Children's palliative care (CPC) is a relatively young discipline, with most dedicated providers around the world having been created in the last 20 years, and even the oldest organisations only going back to the 1980s. Most started on a small scale – typically a group of passionate clinicians wanting to address critical gaps in care for their patients, or a network of local families raising funds to create a specialist service, building or ward.

Despite little or no state support in most countries, CPC providers have steadily grown and matured over recent decades – professionalising clinical skills and standards, adopting new technologies, creating purpose-built spaces, and developing new business models. Yet there remains a chasm between the availability of quality children's palliative care and need – 90 percent of the estimated eight million children in need of specialist CPC care globally never receive it.

65 percent of countries globally have no known children's palliative care services, and even in most high-income countries CPC services are poorly funded and thinly spread, with major gaps in access compared to many other health services.

Despite these critical gaps, CPC providers have a promising future, and this report takes a forward-looking perspective at how the development of CPC providers can and should continue over the next decade. It outlines nine key areas of innovation where CPC providers should reflect on the biggest opportunities for them to accelerate improvement in quality and access.

This vision of the future is rooted in the leading practice of today – gathered through interviews with over 51 CPC leaders across 27 countries and six continents. It also takes lessons from other comparable areas of healthcare where transferrable improvements have been made.

This vision is unashamedly optimistic, and given the precarious existence of many CPC providers who 'struggle just to keep the lights on', to some organisations it may appear unrealistic. However, as the case studies from this report – which are drawn from high-, middle- and low-income countries alike – show, lack of resource is not necessarily a barrier to innovation, and sometimes may be a catalyst for it. It is precisely because of the vast chasm between needs and what is currently offered that CPC providers should be constantly seeking to expand their ambition.

There remains a chasm between the availability of quality children's palliative care and need – 90 percent of the estimated eight million children in need of specialist CPC care globally never receive it.

It is precisely because of the vast chasm between needs and what is currently offered that CPC providers should be constantly seeking to expand their ambition.

## Nine features of a world-class children's palliative care provider of the future

The research process involved in creating the blueprint in this study revealed the huge amount of small-scale innovation that happens every day on the front lines of paediatric palliative care – most often by individual staff members and families working independently to solve immediate practical challenges.

The uniquely diverse patient population served by CPC providers – from cancers to genetic disorders, new-born babies to young adults – means that 'beneath the radar' they are host to a huge amount of grass roots invention, adaption and innovative practice. However, few CPC providers have a 'culture of innovation' or systematic means of sharing, scaling and supporting innovations. This means that most often the innovative practice of one family or organisation stays there and does not benefit others by being adopted more widely. This is a key area where CPC providers can improve.

The lagging areas, where the strongest potential exists for innovation, include: the adoption of new and established technologies alike, the use of scaled organisational models, and data-driven care delivery. Areas where CPC providers lead, and should be more active at promoting their know-how, include how to de-medicalise the experience of care for patients, as well as creating innovative partnerships with local non-health organisations and community assets.

This blueprint does not provide a one-size-fits-all approach to the future CPC provider or programme. Different country and health system contexts, as well as organisational legacies, are too diverse and complex for that to be possible. Rather, it outlines nine critical components where the greatest potential for innovation and improvement exists, based on current best practice and emerging new models among CPC providers today, as well as lessons and examples from other areas of healthcare.

While intended to be applicable across contexts, many of the innovations mentioned in this report require CPC providers to work at greater scale than they are currently doing – through partnerships, networks, provider groups and other organisational forms. A further enabler is the development of more entrepreneurial business models which will allow CPC providers to expand into a more permanent and powerful presence within the healthcare provider landscape.

A huge amount of small-scale innovation that happens every day on the front lines of paediatric palliative care – most often by individual staff members and families working independently to solve immediate practical challenges.

It was also apparent from the research to create this blueprint that there are particular areas where CPC providers are lagging behind other healthcare sectors, as well as some where it is leading.

# Nine features of a world-class children's palliative care provider of the future



## Vision

A vision that is co-designed with children and their families, focussing both on those who are currently served and those whose needs cannot currently be met.



## Technology

Digital tools are integral to all activities, from parent education, to psychosocial support, to play. New technologies are embraced alongside much more systematic use of old ones.



## Place

Physical settings for CPC act as centres of excellence for training and service improvement across their region, as well as for treatment. They are leaders in de-medicalising the experience of receiving care.



## Services

Stewards and helps integrate the full spectrum of local CPC services. Uses new models of care to enhance choice, continuity and access in those services it provides directly.



## Organisation

New organisational models are used to increase the provider's size and footprint, with economies of scale savings reinvested to increase capabilities and fuel further growth.



## Partnerships

A network of strategic partnerships with payers, providers, community and industry allows the provider to leverage substantial external resources to expand and improve its service.



## People

Its workforce is multi-disciplinary with increased specialisation of roles. Extensive use of in/out-reach services means many more staff are 'part of the team' than are directly employed.



## Culture

A culture that institutionalises innovation, centred on children, families and staff as the engine of ideas, which the organisation scales and shares.



## Leadership

Excellence and innovation are not just applied to local care delivery, but advocacy, research, and education. The provider plays a leading role in developing the CPC sector at a regional, national and international level

## Recommendations for the wider system

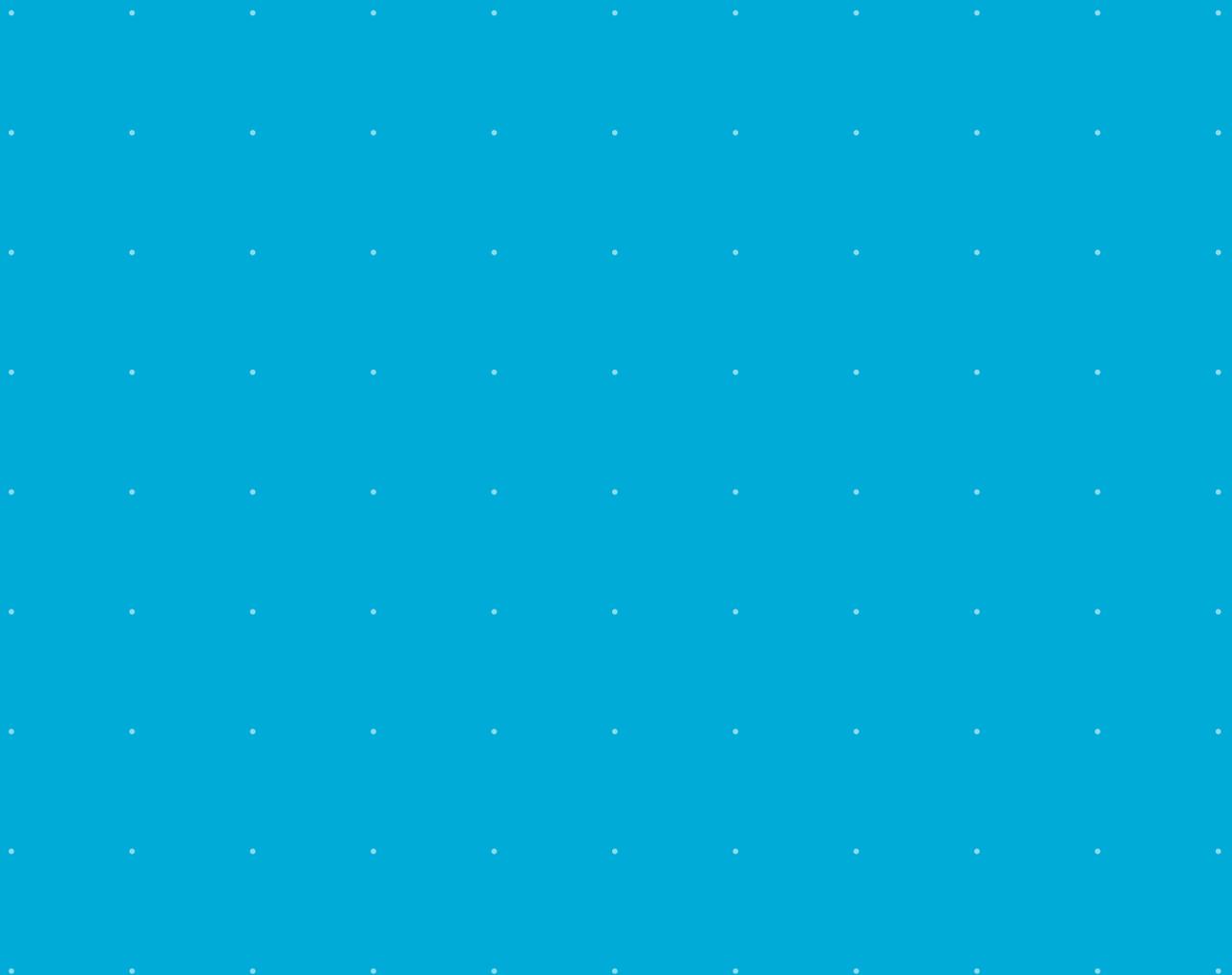
Specific recommendations for CPC providers are not given in this report – largely because the blueprint itself is offered as a tool for their consideration and response. The insights it contains were largely gathered through listening to providers talk about their current best practice and hopes for the future, with the key themes brought together into this report. Far from being a ‘recommendation’ of what they should do next, providers are instead invited to consider this blueprint against their own visions for the future, and take what ideas and inspiration it offers.

At a cross-sector level, however, a number of specific recommendations stand out from this blueprint where actions by other key players are needed to support the shift this blueprint outlines:

- **For global health institutions:** There is a need for an accessible, engaging and popular global platform on which CPC providers can share their innovations, collaborate on projects of common interest, and support scale-up.
- **For technology and digital partners:** Explore partnerships with CPC providers as a means of applying technical knowledge and skills towards social good.
- **For payers:** Include CPC services as an essential dimension within national benefit packages and universal coverage, and look to where CPC providers can be funded or contracted to expand and improve their services.
- **For donors:** Recognise the untapped potential for scalable innovations in CPC, and seek to catalyse their invention and adoption through product development partnership grants and challenge funds.
- **For researchers:** Increase the quantity and diversity of cross-sector, inter-disciplinary and multi-stakeholder cooperation around CPC innovation and improvement.

# Methodology

The research methods used to create this policy report can be found on page 90, but included a literature search of research and written resources on children’s palliative care globally and wider publications on future trends in healthcare delivery. This was followed by 50 hour-long, semi-structured interviews with CPC leaders and other health, innovation and design experts in 27 countries. These were analysed thematically to produce a framework for key opportunities for innovation in CPC which was refined among the research team and with input from selected global CPC experts.



# Selected case studies featured in this report

As a young sector within healthcare, in which ‘all countries are developing countries’, there are examples of excellence and innovation in high-, middle- and low-income contexts alike. The following map lists some of the case studies featured throughout this report.



**Canuck Place Children’s Hospice**  
(Canada)

An integrated, multi-disciplinary approach to appointments across a hospital and children’s hospice.

**Boston Children’s Hospital / Dana-Faber Cancer Institute**  
(USA)

A ‘floating clinic’ working across inpatient, outpatient and home settings. Teams attend consultations by other providers to upskill primary care and increase appropriate referrals for complex cases.

**East Anglia’s Children’s Hospices**  
(UK)

Organisational merger used to fuel growth and service improvement, including new facilities, roles, funders and service models.

**Helix Centre** (UK)

**Seragnoli Children’s Hospice** (Italy)  
Applying new technologies to CPC using a human-centered design approach, including a ‘connected garden’, onboarding chatbot, digital platform for memory-making and augmented reality play therapy.

**Paediatric Palliative Care Unit, Pereira Rossell Hospital Center**  
(Uruguay)

Virtual model of peer education for all CPC staff working across the country, with monthly case presentations, discussion and recommendations.



**Julia's House**

(UK)

Respite provider focussing on the provision of choice. Families are offered 200 hours annually, which can be divided any way across any setting. Operates an ecosystem approach to supporting staff as a 'top 100' UK employer.

**Pallium**

(India)

Community engagement and empowerment model in which volunteers work through link centres to offer a wide range of CPC services.

**Rachel House**

(Indonesia)

An entirely home-based model of CPC, using trained nurses deployed on motorbikes.

**Bayt Abdullah Children's Hospice**

(Kuwait)

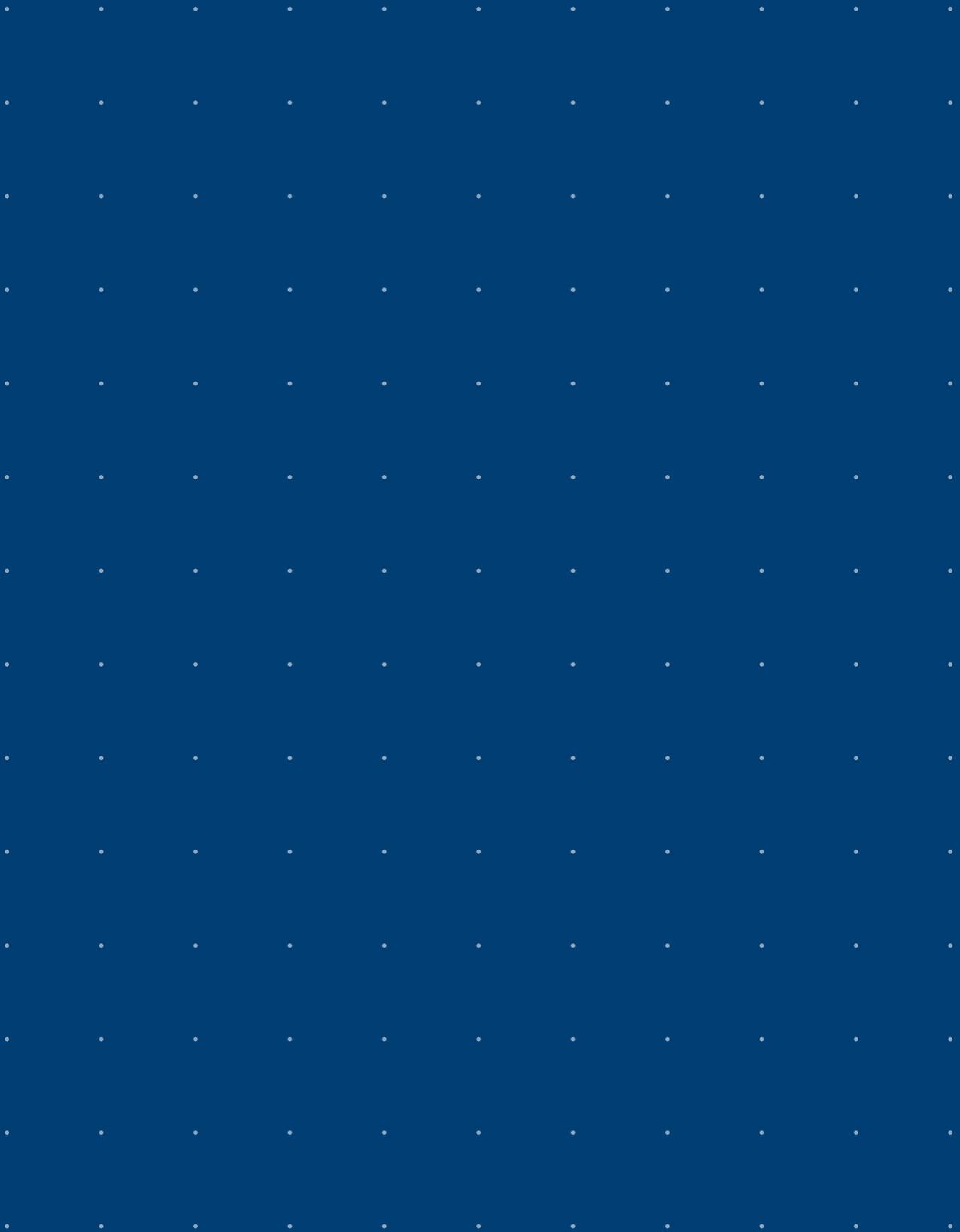
Operates an integrated in/outreach model with other providers, and a dual system of clinical and psychosocial keyworker for each child.

**Hummingbird House**

(Australia)

Operate a peer-mentoring and support group, by providing training to bereaved families. Unique modular facility created through a user-centred design process.

# What is children's palliative care (CPC) and who provides it?



## What is children's palliative care?

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Children's palliative care (CPC) is a sector of healthcare concerned with the 21 million children worldwide estimated to be living with life-limiting and life-threatening conditions (LLCs and LTCs).<sup>1</sup> CPC is a holistic and multi-disciplinary approach to care, focussed not just on medical treatments but the full range of physical, emotional, social and spiritual needs of children and young people with LLCs and LTCs, as well as their family. It begins at the point of diagnosis, and extends either until the child's transition into adult services, or to the end of their life – as well as beyond in the support given to family members after their death.

Access to CPC can be transformative for children living with life-limiting and life-threatening conditions, helping them and their families to live a better quality of life for the time they have. It can reduce pain and suffering among children, improve their development, and give spiritual and emotional support to the whole family during unimaginably challenging times.

The availability of children's palliative care varies hugely by the geographical and socio-economic situation of the child, with some having access to state of the art palliative care and others lacking even basic medical services.<sup>2</sup> It is estimated that at any one time approximately eight million children with LLCs or LTCs need specialist children's palliative care globally.<sup>3</sup> This number is likely to rise as more children survive for longer with increasingly complex conditions and therefore consideration needs to be given to new methods of access, care, and sustainability of these services. Despite this rise, the children who need access to CPC are a relatively small patient group in most countries, meaning CPC providers must often seek to cover a large geographical footprint, including children in remote, rural areas.

**A life limiting condition (LLC) is defined as 'one where there is no reasonable hope of cure and from which children will die.'**

**A life-threatening condition (LTC) is defined as 'one for which curative treatment may be feasible but may fail.'**<sup>4</sup>

## **The World Health Organization (WHO) defines children's or paediatric palliative care as follows<sup>5</sup>:**

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

## **What is innovation?**

Following the World Health Organization<sup>6</sup>, this report takes a broad definition of health innovation as encompassing the novel creation, adoption or adaption of policies, practices, systems, technologies, services and delivery methods within CPC, to improve the efficiency, effectiveness, quality, safety or affordability of the care available.

The profile of children likely to benefit from CPC is extremely broad, spanning from birth to young adulthood, and a wide range of conditions from genetic disorders through to childhood disease, both communicable and non-communicable. Because of this almost uniquely diverse patient population, it can be helpful to think about four main categories of conditions that are likely to benefit from CPC – see Box 1. However, a particular feature of CPC services is the principle that every child is unique and has individual needs, creating an imperative to adapt different solutions that are tailored to their specific needs rather than a generic ‘patient profile’.

**Box 1:** Four categories of life-limiting and life-threatening conditions affecting children and young people<sup>7</sup>

**1. Life-threatening conditions:**

Curative treatment may be available but may not be successful. Palliative care often needed during an acute phase or when treatment is exhausted. E.g. cancer, organ failure

**2. Conditions where premature death is inevitable:**

Attempts may be made to prolong life. E.g. cystic fibrosis, muscular dystrophy

**3. Progressive conditions with no curative treatment:**

No treatment available other than palliative care, may last a number of years. E.g. Batten disease

**4. Irreversible but non-progressive conditions causing severe disability and therefore leading to susceptibility to poor health outcomes:**

Complex health needs, high risk of sudden life-threatening event, increased likelihood of premature death. E.g. severe cerebral palsy, brain injury

Though they share a label, there are distinct differences between paediatric and adult palliative care. In the provision of CPC the focus is on enhancing the quality of life for the time they have – regardless of whether death is an immediate or even likely prospect.<sup>8</sup> Although there are some similarities between CPC and adult palliative care, important differences include communication methods with children, consent issues, medication dosages, transitions through age group services, the nature of disease requiring palliative care such as genetic diseases and the health professionals who needed to be involved in their care as shown in Figure 2.

**Figure 2. Elements of palliative care for adults and paediatrics (BDAU)<sup>9,10,11</sup>**

## Palliative Care

- Includes but is not limited to, end of life care
- Should include advanced care planning
- Can start at the beginning of an illness and be given along with treatment meant to cure
- Can be delivered across multiple settings including care facilities, hospice, home and hospital
- Is medical care, but it also involves a multidisciplinary team which includes doctors, nurses and social workers and others
- Should include emotional, social and spiritual elements
- Aims to improve quality of life by relieving distressing symptoms

### In palliative care for adults

- There are large numbers of patients
- Patients usually make their own medical care decisions
- Patients are typically referred late in their disease trajectory, therefore the emphasis is on end of life care
- Most patients will present with known conditions (cancers, cardiac disease, Alzheimers)

### In paediatric palliative care

- There is a relatively small number of patients, geographically spread out
- Medical decisions are sometimes made by the patient but often by the family/caregivers
- As patients are often referred earlier in their disease trajectory, often there is more emphasis on quality of life and less on end of life care
- Many patients have rare and undiagnosed conditions with uncertain disease trajectories
- Care may involve a play therapist, child life therapist and/or child behavioural specialist
- Care will require liaising with education as well as social care
- Care may involve dealing with complex emotional and bereavement processes and often includes support for parents and siblings

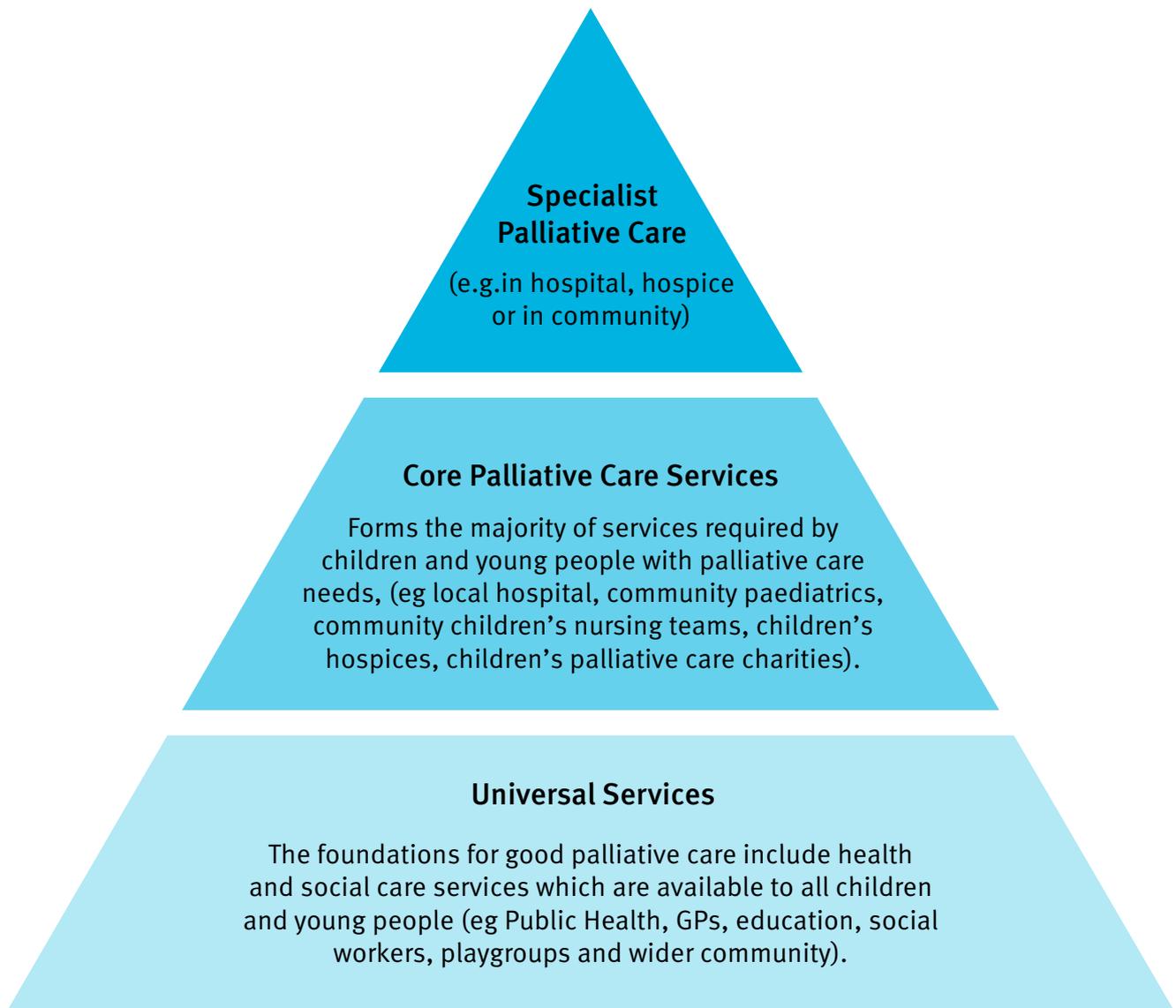
## Who are children's palliative care providers, and what do they do?

There are various forms of specialist CPC provider – the focus of this report – but it is important to understand them in the context of wider systems of care that are vital in ensuring the full spectrum of CPC services that children with LLCs and LTCs will have over their lifetime.

Children's palliative care services are commonly framed as: universal services, core services and specialist services, as described below<sup>12</sup>:

- Universal services include the initial care offered to children and their families by primary care and social services providers. It is important that these professionals have a basic foundation in the CPC approach, as well as that all healthcare professionals in all settings understand how children with LLCs and LTCs that they see may have differing needs.
- Core palliative services are provided by health and social care workers with additional training and expertise in this area, and form the majority of care for children with LLCs and LTCs during their life. The main focus is on quality of life and holistic care with symptom control and family-centred care, in addition to the provision of short breaks for the child, their siblings, or the whole family (known as respite care). Provider organisations may include a child's local hospital and community nursing team, a specialist children's hospice, or bereavement support and counselling for family members.
- Specialist palliative care is provided by health and social care workers whose dedicated focus is the provision of palliative care, often in centres of excellence or specialist units, such as a dedicated department or outreach team run out of a referral hospital, or an independent children's (or sometimes adult) hospice.

**Figure 3: The scope of children’s palliative care (Together for Short Lives)<sup>13</sup>**



It is also important to recognise that family members and caregivers of the children are far and away the largest ‘providers’ of CPC. Families themselves often become experts in their child’s care. Many children who require access to CPC have rare conditions and diseases for which they may be one of only a few with that condition in the world, and which parents may quickly surpass local clinicians in their understanding of this care. So, while not part of the formal workforce, it is important to factor in the enormous amount of labour and expertise that families, care givers and children and young people themselves contribute.

It is also important to recognise that family members and caregivers of the children are far and away the largest ‘providers’ of CPC.

This report focusses on specialist CPC providers, who are dedicated to CPC service provision as the core of their work – though these can take a variety of forms, from independent charities focussed on CPC, to a dedicated outreach programme funded by the state, to a team or ward of a much larger hospital provider who are predominantly focussed on CPC.

While the organisational forms vary greatly, most of these dedicated CPC providers – even in high income countries – lack sustained and significant government funding, and therefore much of their work is funded through business models that rely on charitable or philanthropic giving.

## **Box 2:** What is a ‘children’s hospice’?

‘Children’s hospice’ is a term that means different things in different systems, but in its broadest definition is a dedicated facility for CPC that offers a family-centred structure, with a holistic approach to care offering a range of services throughout the whole of a child’s life – not just around their death. These services may include on-site care (inpatient and outpatient), respite breaks, home support, sibling counselling and a variety of therapies alongside end-of-life care and bereavement support<sup>14</sup>. Some countries, such as the UK (which has 54 children’s hospices offering a range of services covering this scope) have a comparatively large network of children’s hospices, which are predominantly charitably funded and work to fill gaps left by the state-funded National Health Service (NHS), with some providing some NHS-funded services. In other systems, the term can have a narrower definition of a specific ward that is used to care for children at the very end stages of their life. In other countries there may be no providers using the ‘children’s hospice’ term at all, with these services instead provided by community healthcare teams, hospitals, or programmes that offer care in the community without a dedicated space. The term ‘CPC provider’ is used in this report to avoid confusion that can be caused by these differences in terminology, because even organisations with dedicated CPC buildings have typically evolved well beyond ‘bricks and mortar’ services to provide care across hospital, home and hospice settings, using a multi-disciplinary and collaborative approach.

**Figure 4: CPC provision in four countries compared<sup>45</sup>**

	United Kingdom	Canada	Uganda	Argentina
<b>CPC Provision</b>	<ul style="list-style-type: none"> <li>• Network of Children's Hospices (45 inpatient hospices), hospital palliative care teams (eight programmes), specialist CPC community teams (45 teams), and general community teams</li> </ul>	<ul style="list-style-type: none"> <li>• Paediatric Palliative Care in most major centres (12 centres have recognised paediatric palliative care of 17 centres which have paediatric programs)</li> <li>• Tertiary centres provide outreach across extensive geographic regions</li> <li>• Seven Children's Hospices</li> </ul>	<ul style="list-style-type: none"> <li>• A total of 13 standalone hospices in the country. Generally focusing on adult palliative care but some do see children</li> <li>• Two patient hostels offering accommodation for children from upcountry districts receiving treatment from Uganda Cancer Institute (UCI)</li> </ul>	<ul style="list-style-type: none"> <li>• 58 CPC Teams – most of them in tertiary hospitals – with 50 Paediatric Palliative Care Subspecialists nationally</li> <li>• Two CPC Units with bed provision for children with life-limiting conditions.</li> <li>• CPC provided to children with a range of conditions and not just those with cancer</li> <li>• No hospice for children</li> </ul>
<b>CPC Education</b>	<ul style="list-style-type: none"> <li>• Recently launched the Children's Palliative Care Education Standard Framework and Self-Audit tool to help standardise learning</li> <li>• Children's Palliative Care specialisation for doctors and nurses</li> </ul>	<ul style="list-style-type: none"> <li>• First subspecialty program for CPC received accreditation in 2021</li> <li>• Pallium Canada provides extensive palliative care education – paediatric module released in 2021</li> </ul>	<ul style="list-style-type: none"> <li>• Higher Diploma in Paediatric Palliative Care with at least 27 practicing graduates</li> <li>• Some other palliative courses offered that have components of CPC</li> </ul>	<ul style="list-style-type: none"> <li>• Courses for first level CPC education</li> <li>• Diploma and Masters degrees</li> <li>• Four CPC Fellowships and two places for Residence</li> <li>• Official accreditation of the specialisation in palliative medicine 2015</li> </ul>
<b>Access to Medicines</b>	<ul style="list-style-type: none"> <li>• Generally there is good access for the medicines needed for children's palliative care and in paediatric formulations</li> </ul>	<ul style="list-style-type: none"> <li>• Generally there is good access for medicines needed for children's palliative care in paediatric formulations</li> </ul>	<ul style="list-style-type: none"> <li>• Limited access to medicines for palliative care in paediatric formulations due to financial strain on parents and caregivers</li> <li>• Some level of improving access to medicines for childhood cancer at the Uganda Cancer institute</li> <li>• Oral liquid morphine available free of charge paid for by government. Some challenges impacting supply</li> </ul>	<ul style="list-style-type: none"> <li>• Generally there is good access for opioids but not always in paediatric formulations</li> <li>• There are more challenges with access to adjuvants</li> </ul>
<b>Funding</b>	<ul style="list-style-type: none"> <li>• There is some government funding for CPC services from local commissioning arrangements and grants</li> <li>• The majority of hospice funding is raised by the organisations from donations and shops</li> <li>• Services are free of charge to the user</li> </ul>	<ul style="list-style-type: none"> <li>• Government funding for CPC services in hospital and home care (availability for home care may be limited in some areas).</li> <li>• Hospices require at least 50% of support from fundraising</li> </ul>	<ul style="list-style-type: none"> <li>• No government funding specifically directed to children's palliative care</li> <li>• Some direct government funding that goes to Uganda Cancer Institute, sickle cell clinics and HIV/AIDS to public health facilities sometimes supports palliative care interventions in these specific conditions</li> <li>• Hospices and home care programmes depend on donor funding</li> </ul>	<ul style="list-style-type: none"> <li>• The majority of CPC teams belong to the National Health System with few CPC teams within social security or the private health system. A handful of national NGOs also exist with some or all of their focus on CPC</li> </ul>
<b>Policy Context</b>	<ul style="list-style-type: none"> <li>• Increased focus on integration of CPC services between non-profit and NHS providers</li> <li>• National standards and norms for the provision of children's palliative care exist, as well as other national policy documents that influence the provision of CPC</li> </ul>	<ul style="list-style-type: none"> <li>• National and Provincial initiatives for palliative care in general, some for CPC</li> <li>• National standards and norms for the provision of children's palliative care exist</li> </ul>	<ul style="list-style-type: none"> <li>• Palliative care policy still to be passed</li> <li>• Various government documents recognise palliative care, but CPC is not emphasised</li> <li>• Political will to advance palliative care generally but CPC is not so pronounced</li> </ul>	<ul style="list-style-type: none"> <li>• National CP strategy that includes CPC</li> <li>• Included in the Argentine Association of Medicine and Palliative Care policy</li> <li>• National standards and norms for the provision of palliative care from the Ministry of Health but are not specific for children. Some policies on paediatrics influence or cover CPC</li> </ul>
<b>National Bodies</b>	<ul style="list-style-type: none"> <li>• Association of Paediatric Palliative Medicine</li> <li>• Together for Short Lives</li> <li>• Hospice UK</li> </ul>	<ul style="list-style-type: none"> <li>• Canadian Hospice Palliative Care Association</li> <li>• Quality End of Life Care Coalition of Canada</li> <li>• Canadian Network of Palliative Care for Children</li> <li>• Canadian Network of Pediatric Hospices</li> </ul>	<ul style="list-style-type: none"> <li>• Palliative Care Association of Uganda</li> <li>• Uganda Cancer Institute</li> </ul>	<ul style="list-style-type: none"> <li>• Pediatric Palliative Care National Committee of the Argentine Pediatric Society</li> </ul>

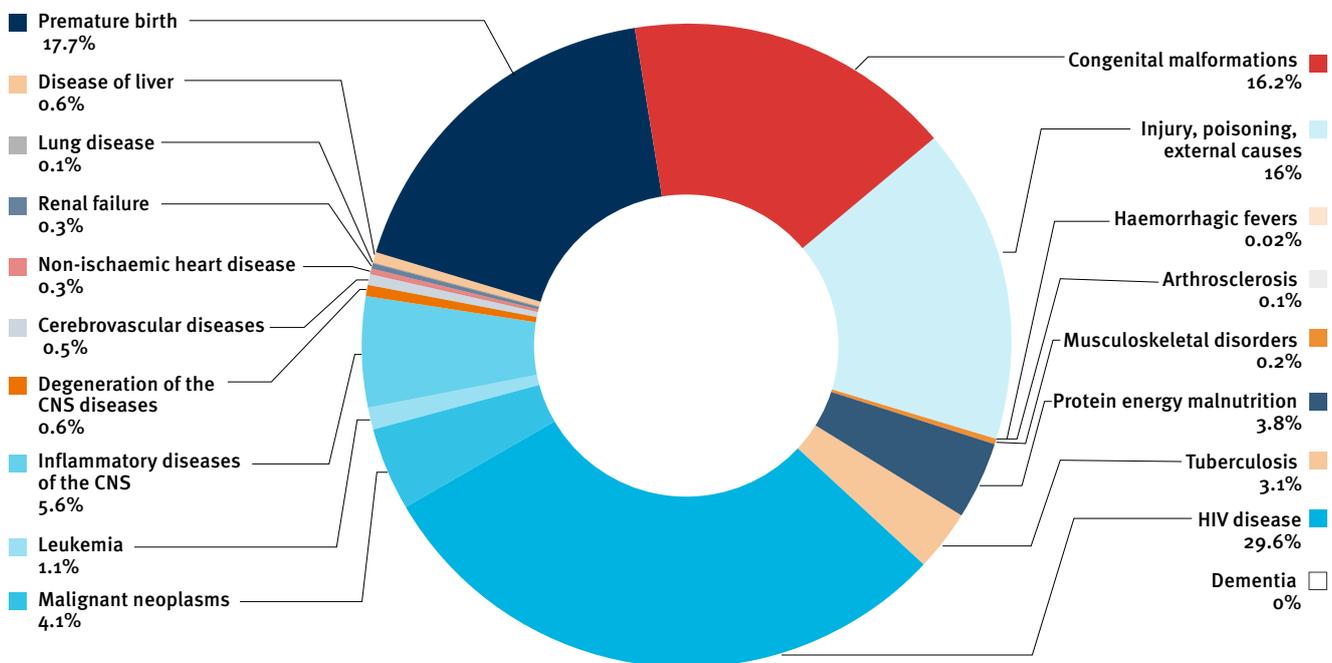
## The global need for children’s palliative care innovation and investment

The global need for children’s palliative care is challenging to calculate, however research suggests that around 90 percent of children who could benefit from CPC services never receive such care<sup>16</sup>.

around 90 percent of children who could benefit from CPC services never receive such care

Of the estimated 21 million children with LLCs and LTCs globally, around eight million require specialist CPC services at any one time<sup>17</sup>. The Global Atlas of Palliative Care estimates that children living with HIV/AIDS make up the largest group of these children (29.6 percent), followed by premature birth and birth trauma (17.7 percent), congenital abnormalities (16.2 percent), and injuries (16 percent), with cancers making up 4.1 percent), as shown in Figure 5.

**Figure 5: Worldwide need for palliative care for children by disease<sup>18</sup>**

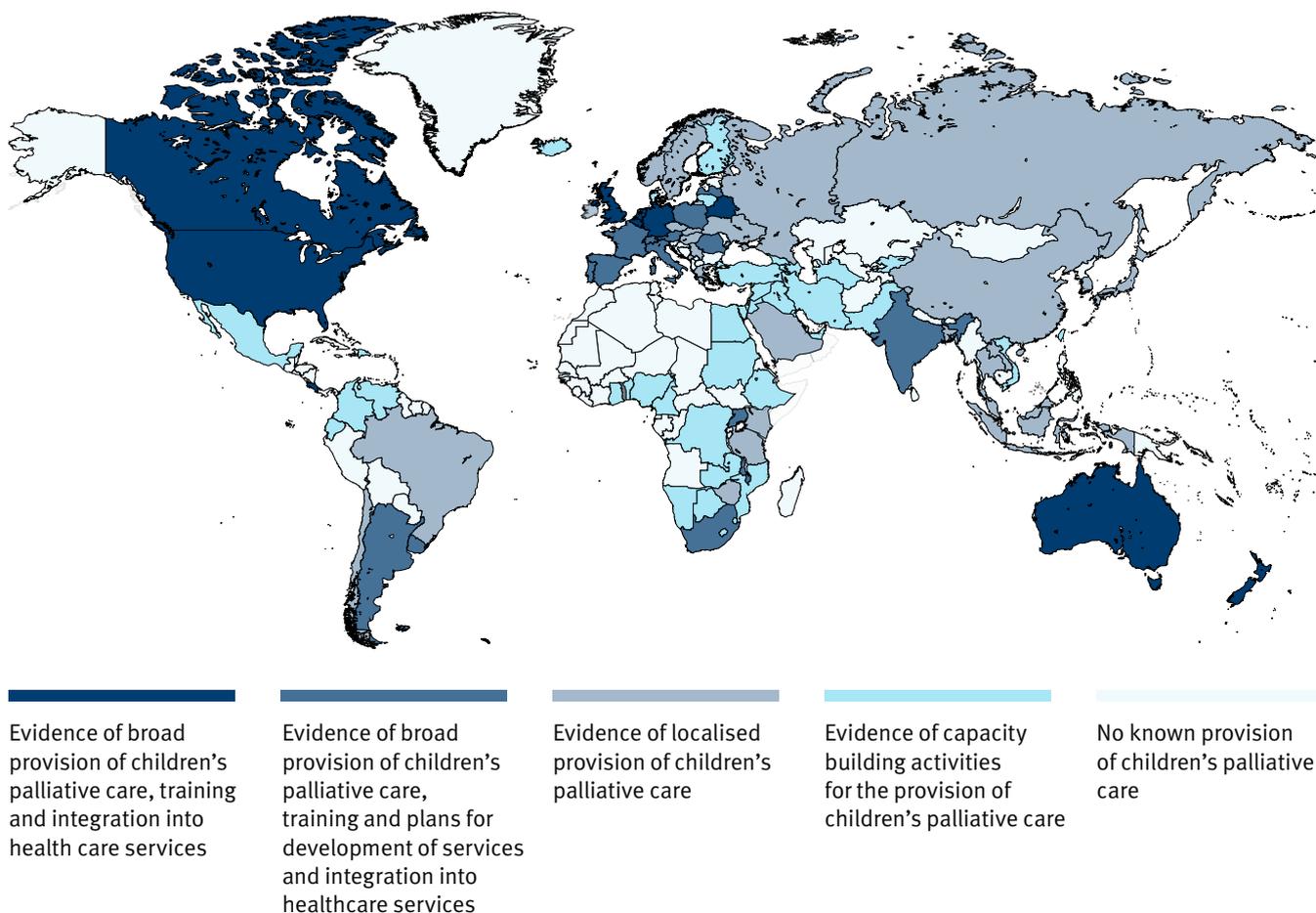


Although provision is inadequate in almost all countries, including the vast majority of high-income countries, there are stark inequalities in both the need and availability of CPC (See Figure 6). Systematic reviews have suggested that around 65 percent of countries globally have no known children’s palliative care activities<sup>19</sup>.

around 65 percent of countries globally have no known children’s palliative care activities

The dearth of CPC services in LMICs is due to a variety of reasons, including the lack of recognition of the need for CPC, a lack of financial resources, staff shortages and non-availability of essential medicines, including opioids<sup>20, 21</sup>. There is a lack of infrastructure and funding for the provision of palliative care and a shortage of specially trained health workers with an understanding of palliative care. Although some non-governmental organisations (NGOs) provide palliative care, this often focuses on people with HIV and cancer, with little provision for children with genetic conditions, or palliative services are for adults only.

**Figure 6: Levels of provision and integration of children’s palliative care globally (ICPCN)**



Even in high income countries, the provision and uptake of children’s palliative care is often extremely low. In New Zealand, there is only one CPC service and no children’s hospices due to the number of people living in rural areas<sup>22</sup>. Although 680 CPC services across 51 cities have been identified in the European region (including 133 hospices), it is estimated that 170,000 children in Europe who need CPC die every year without access<sup>23</sup>. In the United States although more than half of children’s hospitals have a CPC program, most are understaffed and underfunded, and only operate inpatient services, mostly only during the working week<sup>24</sup>.

The WHO acknowledged the importance of palliative care, including CPC, by passing a resolution at the 2014 World Health Assembly to improve access to palliative care across the continuum of care and health service provision, with an emphasis on primary and community and home-based services.<sup>25</sup> Despite this, and the seismic reforms underway in countries around the world in pursuit of universal health coverage (UHC) by 2030<sup>26</sup>, CPC services are often omitted from benefit packages – even in many countries which would otherwise consider themselves to have achieved ‘health for all’. At most, governments provide limited funding, meaning that third sector parties are often responsible for filling this gap. Other challenges to the provision of care include shortage of specialist health care staff, small numbers of referrals, inadequate training and ethical issues<sup>27</sup>.

This policy report seeks to identify the most promising candidates for this innovation, and in doing so to examine how an individual CPC provider should seek to maximize its impact on the critical gaps faced by the CPC sector as a whole.

With such a daunting gap between needs and current provision, the core focus of much of the global effort around CPC is establishing a basic level of service for as many children as possible. Education of non-specialist CPC health workers in core CPC skills forms the backbone of these activities, as it is more resilient to peaks and troughs in funding – a phenomenon which has affected CPC services in many countries over the years, making it hard to sustain gains made. Support of innovation in service delivery and business models is another lever which can be used to catalyse rapid improvements in healthcare access and quality, and which has been less systematically explored. This policy report seeks to identify the most promising candidates for this innovation, and in doing so to examine how an individual CPC provider should seek to maximize its impact on the critical gaps faced by the CPC sector as a whole.

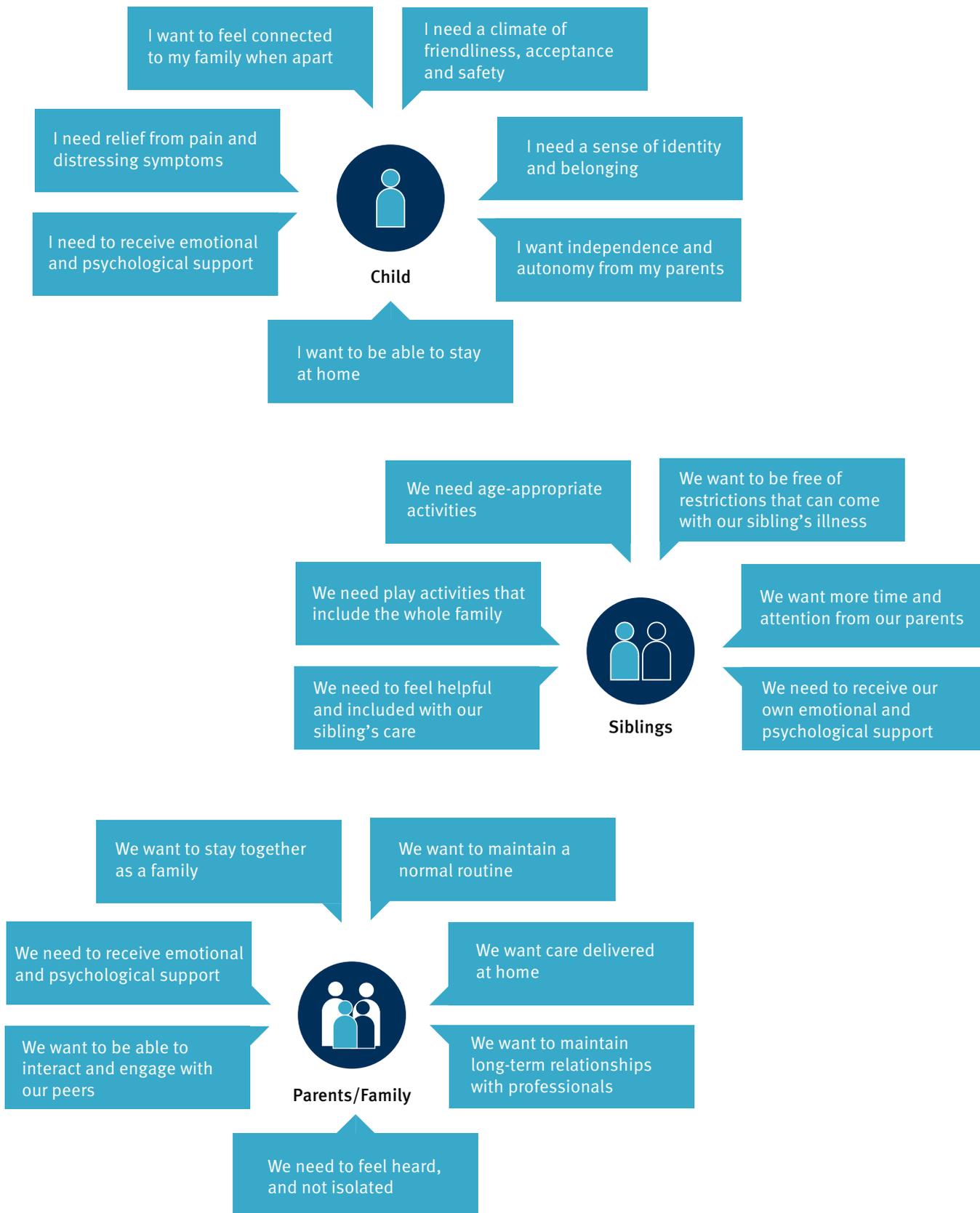
## **What do children and families need?**

In exploring the most important needs and gaps within the UK's system of CPC – the country that in many ways gave birth to the sector – the Helix Centre at Imperial College London's Institute of Global Health Innovation set out to understand the perspectives of CPC service users through a range of qualitative research techniques. The resulting paper – Designing a technology powered future in children's palliative care<sup>28</sup> – gives voice to many of the needs of children and their families, with themes that will resonate with service users in many countries<sup>29,30</sup>, including how to keep the family system able to function alongside the complex needs of the child. Parents often care for their child around-the-clock, existing on little sleep for many years. This takes an immense emotional and physical toll. Parents are often able to juggle meeting the needs of their ill child, other children, marriage and other aspects of their lives in an incredibly delicate balance that is continually being reassessed and adjusted. As a result, they live in a unique rhythm, working mostly on their own. The experience does not end with the death of a child.

Siblings also have their own unique set of needs that are distinct and should not be lost in the understandable focus on the child who is unwell. Some adolescent siblings can come to resent the restrictions placed on the family by the child's illness. Understanding of these needs is growing, and many providers are now seeking to include services for these siblings as a core part of their service scope.

From a compilation of meetings with parents, formal interviews and a search of pre-existing literature, the study distilled some of the most important needs of children with LLCs and LTCs, their siblings and parents as follows. These reflect the UK context of a system with comparably good CPC services, but many of these themes will resonate globally.

**Figure 7: Common expressed needs of children, siblings and parents in CPC<sup>31</sup>**





# Nine features of a world-class children's palliative care provider of the future

How can CPC providers, as comparably small players in the health system, seek to address the critical gaps in quality and access that exist in high, middle and low resource settings alike? The following blueprint proposes nine areas in which CPC providers should seek to grow, innovate and improve over the coming years in order to more effectively achieve the vision of world-class care for children with life-limiting and life-threatening conditions, in their locality, country and around the world. These ideas are based on the current best practice of today, expressed plans and strategies of CPC leaders for the future, and lessons from other areas of healthcare innovation.



# Vision

A vision that is co-designed with children and their families, focusing both on those who are currently served and those whose needs cannot currently be met.

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## Summary:

Children's palliative care has from its foundations put the notion of shared decision-making and personalised care at the heart of its approach. Some CPC providers have sought to extend this to the way they set the higher-level organisational vision and goals, for example, by conducting consultations with their service users as part of the design of their strategy, or having family members or young people involved in their governance or the board. These mechanisms are essential, but only involving those who currently have access can limit their vision to the small proportion of families who are already benefitting. Given the huge gaps between need and available provision, CPC providers should have an ambitious and urgent vision to grow and extend their reach towards those whose needs currently may not even be heard, let alone met.

CPC providers serve a patient group with a spectrum of needs broader than any other area of healthcare, and a population that will continue to grow and diversify as innovations in corresponding areas of medicine make it possible for children to live longer and with more complex care conditions. Even in the most well-served health systems, unmet needs can seem limitless, while resources are anything but. In the face of this contrast, it is vital that CPC providers have a robust and well-defined vision to guide them through the difficult choices about what kind of organisation and services they should strive towards.

A flexible and empowering ethos that treats each child and family as unique has always been core to the CPC approach and philosophy. Many CPC providers are world leaders in making 'patient empowerment' and 'shared decision-making' a reality in the delivery of an individual's care, rather than a buzzword as in some other areas of the health system. The CPC approach, properly executed, is distinct in considering the family as an integral part of the decision-making team, and empowering them to make well-informed decisions guided by their own priorities rather than of a system, institution, or physician.

As CPC providers have developed over time, many have sought mechanisms to try and instil this user-centredness beyond front line services and into the way that the organisation's overall strategy is designed. Their aim is for the structure and vision of the CPC provider to be informed by its users, as well as the services offered to each family.

Different mechanisms are being used to achieve this user-centred strategy and vision. For some, it is a periodic but intensive consultation exercise as part of a regular three- or five-year organisational strategy design process. Several CPC providers interviewed for this study noted that board members with market research or equivalent backgrounds had been key to advocating and shaping this process, and that it had resulted in genuinely unexpected findings that fed directly into the resulting vision. Other providers select more ongoing means of user input, such as having designated user representative positions on their board, or dedicated sub-committees of young people, family members, or parents of children who have died but who wish to remain in contact with the provider.

it is vital that CPC providers have a robust and well-defined vision to guide them through the difficult choices about what kind of organisation and services they should strive towards

Providers need to be careful not to put additional burdens onto families with already extremely stretched lives, but it was clear that achieving a genuinely user-centred strategy was a key area in which CPC providers are attempting to develop. One striking feature of the mechanisms reviewed for this study was that almost all centred on listening to the needs of families currently or previously served by the CPC provider. This is understandable, since these are the organisation's primary users, and will have the most insight into how its services could improve. However, given the scale of unmet need described in the last chapter – even in high income countries – in future more CPC providers may wish to absorb the perspectives of *all* who would benefit from CPC, regardless of whether they currently do, at least if they are able to identify them. This is so as to properly calibrate their ambitions for the future, and ensure that their vision and mission take proper account of those currently without access.

It may lead them, for example, to make different trade-offs between deepening existing services and broadening access, raise ambitions for growth, or shift additional resources towards advocacy and business development activities that will enlarge their footprint over time. This is particularly important given that in all but a handful of countries there is no representative body to speak for the CPC provider sector as a whole – meaning that this leadership, training, and campaigning function is invariably performed by individual providers themselves. There is also very often no formal 'payer' for CPC services either. In the absence of this role which in most systems is responsible for making these kinds of trade-offs between new and existing need, the task falls to providers to make sure they are performing with a suitably broad lens.

Given the scale of unmet need [...] in future more CPC providers may wish to absorb the perspectives of *all* who would benefit from CPC, regardless of whether they currently do



# Services

Stewards and helps integrate the full spectrum of local CPC services. Uses new models of care to enhance choice, continuity and access in those services it provides directly.

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## Summary:

The ideal scope of services for the CPC provider of the future will necessarily vary between circumstances, depending on what is fundable, what services are offered elsewhere, and where families' needs are greatest. No providers offer the whole spectrum of CPC services, and some will specialise in just one. Regardless of this, CPC providers have a responsibility to help children with LLCs and LTCs navigate what is available, and act as a steward of these services across the local health system – working to improve integration, access and quality of all CPC services, not just their own. For those services which they deliver directly, providers should seek to support new models of care that enhance choice, consistency and accessibility – working towards a menu-based approach whereby families are presented as early as possible with a clear list of services from which they can decide the location and format that best suits them.

A key feature of children's palliative care is that it is an approach that stretches across a whole range of different services, which no one provider can deliver on its own. For dedicated CPC providers, there will be ongoing discussions around what services they should provide, which will be guided principally by what funding is available as well as what the rest of the healthcare system already provides. This means that dedicated CPC providers can look very different from one another – with some choosing to provide a broad suite of services and others focussing on just one, or only to a particular sub-group of children with palliative needs.

Regardless of the scope of services which the provider opts to directly deliver, working in an integrated fashion with all organisations involved in CPC service provision is essential. A particular responsibility rests on dedicated CPC providers to help steward the full scope of services by highlighting gaps, transferring skills and working to instil the CPC approach across local providers – who have many other competing priorities. Children with complex medical needs are at particular risk of poorly integrated care, with families often reporting feeling like a 'travelling circus' around different appointments. The best CPC providers act as catalysts to integrated care – helping those involved with a particular child to work together and strengthening existing networks and resources rather than seeking to replace them.

One model of realising this is to create a key worker system, in which this staff member is responsible for helping to coordinate all the providers delivering care for the child. Another is to adopt a hub and spoke model in which one team or provider takes the lead role in coordinating a child's care, with people, information, best practice and sometimes money shared according to what will create the best service rather than what works best for each provider in isolation. The aim of this is that, from the family's perspective, care appears seamless despite involving multiple teams and organisations. In deciding what to provide directly, there are five main service areas that dedicated CPC providers tend to select their focus from – home care, respite care, outpatient services, inpatient services and integration of psycho-social-spiritual support with physical care. Trends, best practice and innovation opportunities for each of these are described in the next section.

The best CPC providers act as catalysts to integrated care – helping those involved with a particular child to work together and strengthening existing networks and resources rather than seeking to replace them.

In whichever of these areas that a CPC organisation provides directly, their responsibility is to specialise and improve as much as possible, and in particular to develop new models of care that can advance towards three key features that are viewed by many CPC providers as key to the next generation of CPC services:

- **Choice:** A broad patient portfolio, coupled with CPC's focus on personalised care, necessitates flexibility from CPC providers and a commitment to providing care that is as personalised as possible. Providers should strive to place a strong emphasis on the provision of choice, something many patients and families have frequently been deprived of, across a wide menu of services. As new care models are developed, choice of services should also be matched with choice of format in terms of when and where services are delivered.
- **Consistency:** Continuity of care is another priority that traditional service delivery models have struggled to achieve. Families continuously reiterate that familiarity of the provider with their child and their circumstances is among their top priorities and vital to a positive care experience. Yet, often they report that when they need help the most the professionals available do not know their child or their condition, and so they find themselves having to explain everything from the beginning – often in the middle of a crisis.
- **Accessibility:** Even the most impressive CPC services will be ineffective without communication, promotion and outreach to ensure uptake. There is a continuing issue with families being introduced or referred to CPC services only when they have reached a crisis, rather than at the point of diagnosis. CPC should be normalised as an integral part of the child's medical care, so that families can gain access to the support they need. For specialist CPC providers, who may be independent organisations, outreach to colleagues across the formal health system is an important part of changing the perception of CPC as a 'last resort', so that all healthcare staff are trained to identify children and families who may benefit.

## Home care

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Home care is among the most rapidly growing and exciting areas in healthcare broadly, but it has enormous potential for children with LLCs and LTCs, who frequently require complex or bulky equipment that can be difficult to move and often see many different providers across a wide geographical spread. For these families, especially those in rural or remote areas, offering services in the home that might previously have been as an inpatient or outpatient can dramatically improve quality of life.

Families differ widely in their preferences and needs, but in many contexts they will opt to keep their child at home to allow them to spend time together as a family in a non-medicalised environment, and reduce their travel time and expenses. Others might prefer to receive certain types of care in a provider setting – more and more this is a personal as well as a clinical choice, and one that providers should seek to empower families to make for themselves.

Home care can be provided by a variety of caregivers. In many cases, family members provide the majority of the care with varying models of support from the CPC team, such as scheduled support visits from community nurses or 24/7 hotlines to a specialist provider in case of emergency; in others, home care is provided by community health workers (CHWs) or community volunteers serving a set geographical area; still others use a mobile model and deploy small teams to provide regularly scheduled visits to patients across their catchment area.

As the case studies in this chapter, from Indonesia and India show, home-based delivery models are one area where CPC providers in low- and middle-income countries have a lot to share.

In the absence of resources to build dedicated centres and with travel costs a major barrier to patient access, they have had to operate staff using a ‘mobile first’ model from the outset (See Boxes 3 and 4) – giving them an insight into what works and does not.

home-based delivery models are one area where CPC providers in low- and middle-income countries have a lot to share

### **Box 3: Pivoting to Home-Based Children's Palliative Care (Rachel House, Indonesia)**

Founded in 2006, Rachel House is the first paediatric palliative care service in Indonesia. At its inception, Rachel House was piloted as a 3-bed inpatient hospice ward within a hospital as a nurse-led service. During the pilot, in response to their patients' expressed desire to go home and be close to their families and loved ones, Rachel House made the decision early on to pivot to an entirely home-care based service. Now Rachel House has touched the lives of over 10,000 mothers and children throughout Jakarta and its surrounding cities of Bekasi, Depok and Tangerang, with special attention to providing care free of charge to some of the most marginalised communities in these areas. Nurses travel out to the families' homes on motorcycles not only to provide medical care but also psychosocial support and strengthening the patients' network of community resources, including preparing local health clinic officials, checking for the availability of required medications at the local pharmacy or checking in with other non-profit organisations about nutritional support for the child. Communication, collaboration and working with hospitals is also central, with the teams acting as a link with acute care services that creates a more integrated and holistic continuum of care, while also enabling families to spend more time at home.

While a purely-home based model was not the founders' original vision, it has proved a highly effective and scalable way to deliver CPC. In addition to clinical skills, nurses are also trained in business management and required to operate their own budget lines. The intention is that if they leave the organisation wishing to move back to their home provinces, they will have the confidence and skills to set up their own 'satellite' providers – scaling up the organisation's impact across the country.

Source: Interview with Lynna Chandra

### **Box 4: Providing Home Care Through Mobile Teams (Pain Relief and Palliative Care Society, India)**

One emerging CPC home care model involves the deployment of mobile teams that travel to the patients' homes. In Hyderabad, India, the Pain Relief and Palliative Care Society provides home-based palliative care to patients that have been treated in a partnering hospital and have been identified as potentially benefitting from follow-up via home visits. They primarily serve cancer patients, both children and adults, but also include other children with life-limiting conditions. This home care service is delivered through five mobile vans, each staffed with a driver, a nurse and a paediatric care counsellor, with one physician rotating between the vans. These vans drive throughout the city and provide home care to patients living within a predefined geographical radius, serving anywhere between 270 to 330 registered patients at a given time, with all five vans conducting an average of about 20 visits a day. Patients and families can access a 24/7 telephone service for any emergencies or concerns that are not managed during the home visits.

Source: Interview with Megan Doherty

For families with children who have complex conditions requiring advanced care, the biggest barrier to taking services that would have been provided in healthcare settings into their home is ‘what happens if something goes wrong’. Giving up the physical presence of a healthcare professional can be a challenge, and providers and parents alike consistently cite the need for families to know that they have access to a 24/7 lifeline for emergency support, according to interviewees for this study.

This lifeline, whether a telephone number or a physical place, is an essential component of any home care programme. Staffing is the most critical element of this – specifically that the clinicians who they get through to know the child and are familiar with their condition and needs. This familiarity is not only logistically useful in terms of not having to explain the child’s condition (which may be quite rare, or difficult to explain) to a brand-new provider in the midst of a medical crisis, but it is also essential to building trust by parents in the programme.

In many contexts these ‘lifelines’ can also be transformative in allowing providers without a CPC specialism, such as general practitioners, primary care nurses, social workers and community volunteers, to take on a higher proportion of care for children with LLCs and LTCs. Providing these staff with a specialist point of contact can increase their confidence and skills, allowing them to ask questions if they are unsure about a particular course of action. Properly implemented, this expands access to many more children than a dedicated provider could treat directly, shifting them into a catalytic role in addition to focussing specialist support to those with the most complex needs. Historically, these lifelines have been challenging to fund as most of the support is via telephone, however, with many countries having changed reimbursement rules around tele-consultations during the COVID-19 pandemic, new opportunities may have emerged for sustained funding of these services.

providers and parents alike consistently cite the need for families to know that they have access to a 24/7 lifeline for emergency support

## Respite care

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Families' needs are especially variable for respite services, where they may prefer care delivered in the home or a hospice, for a few hours or a few days, to leave siblings in the care of the provider or to remain with them, or indeed to not use respite services at all<sup>32</sup>. The hallmark of any world class CPC provider of respite care should be the maximisation of choice – to offer families a wide menu of options of when, where and how they can access respite care.

Access to respite care is uneven both within and between countries, and in many contexts the largest innovation is the provision of any respite care at all. The concept itself is not universally relevant – in some cultures leaving a child with a non-family member for a reason not strictly medical is outside the norm. But for many families, the impact of constant care for a child with a life-limiting condition cannot be underestimated, and respite care can provide a necessary chance to recharge and take the time to care for their own needs that may often go neglected. For these families, respite care must be considered an essential component of effective palliative care.

For those CPC providers who are able to offer respite care, there is huge variability in service delivery models in terms of staff (nurses, community health workers, volunteers or others), place (generally at the home or a standalone hospice centre, or sometimes as a funded holiday) and lengths of time (from hours to days). Given the wide variety of families' situation and priorities, the most important feature of a world class CPC provider of the future is to be flexible and offer as wide a choice to families as they can.

Additionally, while many programmes that provide routine respite care operate on a scheduled basis, parents and families frequently express a need to access respite care under extremely short notice in case of an emergency.

Many current providers offer families a set amount of time that they can access respite care, which is often a predefined service that must be booked weeks or months in advance. Parents express the need to access this type of care 24/7, if only for a few hours at a time, and for this service to be offered with more flexibility than usually considered, in order to accommodate their schedules – a vision that is already a reality for families being cared for by Julia's House in the UK (see Box 5).

Access to respite care is uneven both within and between countries, and in many contexts the largest innovation is the provision of any respite care at all.

parents and families frequently express a need to access respite care under extremely short notice in case of an emergency

**Box 5: Providing flexible respite care (Julia's House, United Kingdom)**

Founded in 2003, Julia's House, the Dorset & Wiltshire Children's Hospice charity provides frequent and flexible respite care for children and support for their families, offering respite support at home, in the community and in their freestanding hospice. Two-thirds of their care is provided in the home, and respite comprises 95 percent of their total care. Julia's House offers their families 200 hours of respite annually, which can be distributed in whatever manner is most useful to the family: they can choose to use it all at once at the physical hospice, short weekly sessions, or anything in between. Julia's House also provides extraneous emergency respite care that is not included in the 200-hour package, and additional respite care for end-of-life support. Most parents choose to access this care in the home, as their children may be very difficult to move.

The respite care service is staffed primarily by nurses, as many of these children require complex clinical care. For each child and family, a regular team of 6-8 staff per child (up to two staff any one time) may provide respite care at the location and timing of the family's choice. Within this small group, each child and family is assigned a primary person from the respite care team, who is deeply familiar with the family and the child's condition and coordinates with the rest of the team. In the past, Julia's House's respite has been limited to care of the sick child, leaving parents responsible for the care of the siblings, but more recently they have begun offering sibling support services wherein siblings can also be left in the care of the staff. Parents can choose to access this service simultaneously and synchronise respite for the sick child and sibling support services, or hold them separately to prioritise spending time either with the sick child or the siblings.

Source: Interview with Martin Edwards

## Integration of psycho-social-spiritual support with physical care

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Palliative care involves a focus on more than just the management of symptoms and includes a holistic view of mind, spirit and emotions. By the standards of other healthcare organisations, many CPC providers are already world-class in the focus and attention that goes into psychosocial and spiritual support services.

Even so, resource constraints mean that many are not able to give it the attention they would like, and as communities become more diverse in terms of their cultural and religious mix, finding the right way to deliver this support is increasingly challenging.

Psycho-social-spiritual support is not a substitute for the care of physical symptoms. Nonetheless it is an area which many CPC providers integrate into their clinical services, through a variety of innovative means which other healthcare providers would benefit from studying. The aspiration which many CPC providers describe working towards is a model that mirrors the same 'pyramid' concept as in Figure 3, page 15, such that:

- All CPC professionals should be equipped with the confidence and skills to engage with and direct help for psychosocial or spiritual issues, in addition to their clinical responsibilities;
- More dedicated 'in house' competencies exist among a core group of staff, including specialist roles appropriate to the wider service scope; and
- A range of partnerships are formed with external specialist organisations and providers that can be called upon for more complex needs, with co-learning between these so that these external services can learn more about the needs of children with LLCs and LTCs, and the CPC provider can better improve its approaches.

By the standards of other healthcare organisations, many CPC providers are already world-class in the focus and attention that goes into psychosocial and spiritual support services.

**Box 6: Psychosocial Care and Child Life Programmes (Kuwait Association for the Care of Children in Hospital)**

The Kuwait Association for the Care of Children in Hospital (KACCH) provides psychosocial support to children in the hospital, at home and in hospice, as part of its children and family centred care model. KACCH has been providing psychosocial support to children in Kuwait in hospitals since 1989 through their hospital-based Child Life programmes, and opened the freestanding Bayt Abdullah Children's Hospice (BACCH) in 2012. The only children's hospice in the Middle East, BACCH provides the full complement of clinical and psychosocial support to patients.

Within the hospital, psychosocial care for children and families are led by Child Life Specialists and Play Leaders. These staff support children and families undergoing incredibly difficult experiences through child life, therapeutic play services and expressive therapies such as music and art therapies. Providers promote children's normal growth and development through play, helping children to still be kids even within the walls of the hospital, preparing children emotionally for clinical procedures, helping children and families develop useful coping strategies and understand their illness, and providing sibling support and bereavement support when needed.

At BACCH, each child and family are supported by a robust clinical team as well as a psychosocial team (using a dual key worker system) – both are considered equally valuable parts of the child's care team. Each child has a clinical and a psychosocial key worker assigned to them, and these teams coordinate internally to ensure they are providing consistent and appropriate medical and psychosocial care. The clinical and psychosocial teams meet on a regular basis to discuss their patients' developments and next steps. Children and families start with a comprehensive psychosocial assessment to identify their needs and existing networks; this assessment is revisited every two weeks by the psychosocial team and discussed with the clinical teams.

Source: Interview with KACCH team (See Contributors)

Today, the best CPC providers offer psychological, social and spiritual support as an embedded focus for all their contacts with a child and family, and offer it proactively from the time of diagnosis, then consistently monitor and adjust to reflect the evolving needs of the child and family.

Two important – and related – areas of innovation among CPC providers are the increasing diversity of psychological, social and spiritual support services, and their increasing specialisation.

Firstly, the range of psycho-social-spiritual services that different CPC providers have begun providing to support their families continues to increase, and now includes counselling services focussed on children, parents and siblings; music, art and play therapy; financial and educational advice and bereavement support. These are delivered either with in-house specialists or partnerships with external organisations. There is also growing, but largely unresearched, use of guided meditation and sleep apps, mood trackers and other digital tools not necessarily developed for CPC but used by many children with LLCs and LTCs and their families. Sometimes these are recommended by professionals but often not, creating a largely unexplored area of unmediated, or bottom-up learning and innovation by service users themselves.

Secondly, the specialisation of staff roles around different psychosocial support disciplines is also increasing. This is especially the case among larger CPC providers who can afford to invest in in-house specialists, such as full-time art, music or play therapists, child life specialists, spiritual counsellors or professionals with a particular expertise on children from a particular ethnic or religious community. Such specialisation can lead to rapid improvements in the quality of support given, and contribute to the development and implementation of more formalised quality standards<sup>33</sup>. These staff can be a huge asset to the wider organisation too, as they can be used to upskill other staff in critical soft skills.

Another important model of psycho-social-spiritual care, as old as CPC itself yet with many promising new models, is peer-delivered support. Professionally trained counsellors and therapists certainly play their role in CPC psychosocial support, but the power of the connection between peers facing similar challenges when they may feel otherwise alone cannot be underestimated. Many bereaved parents and families find the opportunity to connect with other parents who have or had children with LLCs and LTCs a vital lifeline. Whereas some providers take a less formal approach in allowing peer support networks to develop, others are investing in a more systematic approach to training peer-led volunteer services, such as Hummingbird House in Australia.

Two important – and related – areas of innovation among CPC providers are the increasing diversity of psychological, social and spiritual support services, and their increasing specialisation.

### **Box 7:** Peer Support Services at Hummingbird House, Australia

Hummingbird House was founded in 2011 as Queensland's only hospice, offering a variety of peer support services. They have a longstanding tradition of holding a biweekly tea or lunch, where current patients and families as well as long-bereaved families can come to the hospice for tea and a meal. By making this social event as easily accessible as possible, including easy transportation, free parking and free food, this biweekly event yields consistently high turnout rates and provides a source of community to these families for years to come. Recently, they have initiated a formal peer mentoring and support group that offers parent-led engagement and interaction. Rather than having a trained counsellor facilitate conversations around bereavement, they provide training to bereaved families that wish to connect to other families that have more recently lost their child or are currently undergoing similar issues. This form of peer support can provide comfort that may not always be best delivered from medical professionals, providing a different type of space for families to explore their feelings and circumstances with peers facing similar challenges that may be unimaginable to their loved ones.

Source: Interview with Elham Day

Many CPC providers also focus on creating an ecosystem of much smaller psychosocial interventions which accumulate to gradually build up a network, culture and atmosphere of positive connections and support. Some hold annual retreats or celebrations with current and former families, citing these events as highlights of their work, providing spaces for families to socialise and have a sense of normalcy, while having the security of medical resources on standby. Others hold social events such as inviting fathers to come watch a sports game together, holding mindfulness classes, and hosting movie nights or group meals for all families to come together. In Singapore, one hospice sends recently bereaved families a “comfort box” a few months after they have lost their child (in response to parent feedback that they preferred not to hear from the hospice immediately), which include notes from formerly bereaved parents to provide some comfort. They continue with sending an anniversary card every year, to let these families that the staff is thinking of them and that they still have this support network.

Such investments into community building can yield dividends in building trust amongst families and helping them to support each other in a way that professionals cannot replicate.

Many CPC providers also focus on creating an ecosystem of much smaller psychosocial interventions which accumulate to gradually build up a network, culture and atmosphere of positive connections and support.

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## Inpatient and Outpatient Services

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The scope of future hospital-based CPC services will be heavily shaped by clinical advancements in medicine that are hard to predict and mostly specific to individual conditions rather than CPC providers as a whole. Aside from the physical environment (Page 70), staffing (Page 45) and technological (Page 50) aspects, the key feature of any world-class CPC inpatient and outpatient service delivery model is integration. Three particular forms of integrated CPC show the greatest promise for improvement and innovation here: inpatient-outpatient, outpatient-outpatient, and inpatient-inpatient.

### **From inpatient to outpatient**

As medical advances lead to children with LLCs and LTCs living longer, specialist inpatient and outpatient services must work together to spend a greater proportion of their time on those with the most acute and complex needs. Most children with CPC needs can be cared for most of the time in primary care settings, but these providers often do not have the confidence and skills they need, meaning in many systems children are

referred to specialist providers by default. These specialist providers are already often overburdened, and caring for all children with CPC needs leaves them without resources for those who require more intensive attention.

Thus the ideal future CPC provider actively supports primary care providers to address the vast majority of CPC need, allowing more focus of specialised resources on those who most need it.

This requires a lot more than simply running some training courses for primary care providers, but an active partnership to work alongside them and their patients to increase knowledge, confidence and skills, as demonstrated by the ‘floating’ clinic in Boston, USA.

Thus the ideal future CPC provider actively supports primary care providers to address the vast majority of CPC need, allowing more focus of specialised resources on those who most need it.

**Box 8: “Floating” Clinic at the Boston Children’s Hospital/Dana-Farber Cancer Institute<sup>34</sup>**

The Paediatric Advanced Care Team (PACT) is staffed by six paediatricians, two social workers, two paediatric nurse practitioners, and a program nurse. The team “floats” to follow patients across hospitalisations and routine clinic visits, providing inpatient, outpatient and home-base consultations. PACT meets families at their scheduled oncology units. When working with oncologists familiar with PACT, this model increased referrals for complex cases to PACT and decreased referrals for issues that could be handled by primary care providers.

## From outpatient to outpatient

Outpatient clinics can be delivered at a hospice, a palliative care clinic of a community or primary health care centre, or a palliative care outpatient clinic of a hospital. Outpatient CPC often fills the gap for children that do not require hospitalisation yet still have a high symptom burden or could benefit from significant supportive care<sup>35</sup>.

However, some CPC providers are finding ways to make it possible even for children who are able to stay out of hospital thanks to competent and successful outpatient services, life can often feel like being ferried from one appointment to the next. Multi-disease clinics and ‘one stop shops’ are being increasingly used among adult chronic conditions, but are even more difficult to coordinate in CPC, due to the varied patient profile. However, some CPC providers are finding ways to make it possible – even if just for the most common groupings of disease, symptoms or needs, as the Vancouver case study below shows.

Multi-disease clinics and ‘one stop shops’ are being increasingly used among adult chronic conditions some CPC providers are finding ways to make it possible too

### Box 9: Filling Gaps in Patient Need with a Collaborative Outpatient Paediatric Palliative Care in Vancouver, British Columbia

In Vancouver, the Canuck Place Children’s Hospice (CPCH) and the British Columbia Children’s Hospital (BCCH) collaborated to run a multi-disciplinary outpatient clinic addressing expressed gaps in families’ demands. The free-standing children’s hospice facility and the tertiary children’s hospital are just 1.5km apart and had a prior history of collaboration. A group of clinicians, programme leaders and families identified several major gaps in services, including how to help families engage with CPC services earlier, and also how the extent of symptom management to outpatients.

Initially, the collaboration took the form of a named, physical location, the Madison Clinic, which was created to:

- Coordinate between the family and caregivers across the continuum of palliative services being offered in both facilities;
- Support the early introduction of CPC to children and families
- Maximise CPC specialist physician time and clinic space at the children’s hospital.

The joint clinic was successful at increasing care coordination and access to CPC services among families. However, having it distinct from other appointments meant that it was yet another appointment which families had to fit into their schedules. For this reason, the teams now use a different model of having staff attend key appointments held by the other provider, in addition to regular (daily) interactions between the different teams. This also has been found to break down barriers, as it allows health professionals to visit other providers’ ‘turf’ and directly see and coordinate with the full scope of the care being given elsewhere in the system.

Source: Interview with Betty Davies, Co-founder, Canuck Place Children’s Hospice (CPCH), with input from Camara Van Breemen, Enhanced Community Care Lead, CPCH and Hal Siden, Medical Director of CPCH

## From inpatient to inpatient

In the context of CPC, inpatient care can be delivered within the hospice or within the hospital. Within the latter, CPC specialists may provide advice to the patient's responsible physician, who can then implement the advice; or specialists may attend to patients directly in a room or ward devoted entirely to palliative care.

Even within the same inpatient provider, however, it can be difficult to coordinate CPC services, and this is particularly the case within tertiary hospitals which are huge in size and diversity, making it easy for niche disciplines such as CPC to be lost. In many hospitals, simply creating awareness of the existence of CPC services among non-CPC staff would be a major step forward. In high-, middle- and low-income countries alike many families do not access CPC services not because of availability but because no-one thought to tell them about it – an issue which Mulago Hospital in Uganda sought to address through its palliative care link nurse programme.

In high-, middle- and low-income countries alike many families do not access CPC services not because of availability but because no-one thought to tell them about it

### Box 10: Inpatient Services at Mulago National Referral Hospital, Uganda<sup>36</sup>

Mulago National Referral Hospital established a palliative care link nurse program, in which nurses throughout the hospital (in paediatric and adult units) were trained to deliver basic palliative care and refer patients requiring more intensive care to the hospital's specialist palliative care team. The hospital saw drastically higher numbers of patients receiving palliative care, 86% of whom required only basic palliative care from nurses. By integrating basic palliative inpatient services into generalist care, the hospital increased usage of palliative care services throughout the hospital and reached more patients than the specialist team could have on their own. This intervention proved an efficient usage of time and resources by addressing most patients' needs with nurse-led care and reserving the most complex cases for the specialist team.

# People

Its workforce is multi-disciplinary with increased specialisation of roles. Extensive use of in/out-reach services means many more staff are 'part of the team' than are directly employed.

## Summary:

The composition of the ideal future CPC workforce obviously depends on the scope of services offered, but three general trends mark the most promising areas where providers are seeking to develop their teams: broadening and deepening skill mix, creating 'porous' teams, and supporting staff wellbeing. This means that over time, the CPC provider workforce will have a greater diversity of roles, and specialist professionals that are able to support and develop particular aspects of care across the organisation's services. Teams will collaborate more closely with other providers, with extensive use of in- and out-reach arrangements with other services. Finally, providers will adopt more systematic methods for helping staff through the unique stresses of CPC work – reducing burnout and supporting them to maintain compassion in their care.

Compared to most other areas of healthcare, the children's palliative care sector is already a pioneer in nurse-led services. Dedicated CPC providers have traditionally been majority nurse-led, and CPC organisations around the world continue to cite their nurses as the most important workers. CPC services are often exemplars of using nursing staff for the top-end of their professional skills, often supporting them to develop and deploy a huge array of specialist capabilities, including clinical interventions and decision-making, psycho-social-spiritual support, service leadership, and training of other staff. Social workers likewise are deployed with particular flexibility and responsibility by many CPC programmes, acting as counsellors, financial advisors, advocates, and other emotional and social support roles.

### **Broadening and deepening skill mix**

Into this mix is an increasing diversity of other disciplines and roles, focussing on deepening particular CPC skills and improving quality through greater role specialisation: child life specialists; occupational therapists with a special interest in CPC; dedicated administrative personnel that can ease the burden of families and frontline staff; care navigators; art, music and play therapists; as well as dedicated advocacy, innovation, research and education staff (see 'Leadership'). New disciplines are also being added at the management level, such as a manager responsible for data analysis and insight in Kuwait (See Box 11).

This added breadth, depth and professionalisation of the CPC team is to be encouraged as a broader team of deeper expertise will lead to improved quality, albeit this will almost certainly require most CPC providers to work on a larger scale (see 'Organisation').

At the same time as these more specialist roles are introduced, CPC providers must also find opportunities for them to task share towards less highly skilled staff who can bring scale and reach to these value-adding new capabilities. Many of the cases presented throughout this study, especially those from low-resource settings, attest to the impact that can be achieved with task sharing to clinical assistants, community health workers, village health technicians or volunteers with close knowledge of particular communities. Critically, these workers must have a dedicated support network or helpline to contact in case of an emergency as well as opportunities to routinely debrief.

The other – crucial – element of the CPC workforce that providers are seeking to better support is the family. Parents and other family members play by far the largest part in the care and treatment of their own child, serving three key roles as part of the CPC team: they are part of the decision-making team; they are centres of clinical expertise with regards to their child's condition, frequently having more familiarity with their child's condition than many physicians; and they deliver more clinical care than any other team member. While great strides have been made in delivering CPC education to primary care professionals and other health and social providers, there is a great deal of untapped potential in innovations that can more effectively and efficiently upskill family members in the care of their children. This is an area where some adult non-communicable disease services are further ahead, creating professionally-produced training resources aimed at family members, sometimes in partnership with industry.

#### **Box 11: Porous Staffing Models and New Disciplines at Bayt Abdullah Children's Hospice, Kuwait**

Several features of the staffing model at BACCH in Kuwait are unique to the region. First, their integrated model of care is rare and innovative within the Middle East. As discussed in Box 6 above, BACCH runs a dual key worker system, in which each child is assigned a key worker from both their clinical and psychosocial teams to serve as the main point of contact for their care. A core psychosocial team is based at the hospice, but they have psychosocial teams located within seven (and growing) hospitals throughout Kuwait as well. Those teams form a link with the medical teams from both the hospice and the hospital. This unique staffing model greatly promotes referrals to BACCH, as the hospital-based psychosocial team often identifies children in need of CPC most quickly.

Second, BACCH features a broader team with a wider range of professionals than many CPC providers. They run their own pharmacy and employ their own pharmacists, an advantage in a sector that still faces battles to access appropriate medicines. In accordance with BACCH's vision for their future activities, which includes research as one of three fundamental pillars to this future, they now employ a dedicated data manager, and are pushing the centre to participate in research activities at the national and international level.

Finally, building off their experience in coordinating multi-disciplinary team meetings with hospitals for the care of patients with epidermolysis bullosa, BACCH is planning to pilot a consultancy service for their patients. Children and families would be able to stay in one physical location at BACCH and have all their other specialist appointments and providers come to them at the hospice, saving them time and traveling expenses. In support of this collaboration is BACCH's Memorandum of Understanding (MoU) with the Kuwait Ministry of Health (MoH). The MoH supplies BACCH with medicines, materials, doctors, nurses, and other staff; and in return, BACCH trains those providers in basic CPC.

Source: Interview with KACCH team (See Contributors)

## Creating porous teams

The expansion and deepening of CPC teams will require the providers to consider their workforce as increasingly porous or permeable. This means making arrangements for external professionals to link up with core CPC services (such as running clinics within the children's hospice), as well as sending CPC staff out to work with other providers. While shared staffing and joint clinics can add complexity in some systems (not least clinical governance and rostering challenges), the benefits can be substantial. It is a leaner way to bring specialist clinical expertise into the providers services than employing these directly, it is an effective model of promoting CPC awareness, skills and values in the wider health workforce, as well as integrating CPC services from the family's perspective. A multitude of examples of these models exist globally, in low-, middle- and high-income country contexts alike – from the palliative care link nurse program in Uganda to (See Box 10), to area-wide joint posts such as the pan-London lead nurse for neo-natal palliative care<sup>37</sup>.

## Staff support

Whatever staff comprise the CPC team of the future, the support structures provided to them by providers are a key area for innovation and improvement. Care of seriously ill and dying children places a huge toll on staff, who require strong systems of support to keep resilient without losing their vital compassion and empathy. Stretched teams must be equipped and supported to handle the volume of children and families, each with individual and complex needs, all while acting with understanding towards the family, and working well together with other professionals and organisations. It is no surprise that burnout is a common feature in the CPC workforce.

This is an area where all providers can improve, but many are working hard to develop better approaches to supporting staff emotionally and physically – both formal and informal. Different staff will respond best to different types of support, and so the best providers think in terms of an ecosystem of support tools – from structured offerings to five-minute debriefs – so that there is something that will appeal to different needs in different staff at different times. Some leaders provide a confidential support line for staff and family members of staff to call in case of concern, utilise anonymous feedback to gain insights as to staff's needs, include meditations or mindfulness exercises in daily routines, or bring in psychiatrists to support and evaluate staff on a regular basis. Whatever form of staff support is provided, it needs to be culturally responsive and appropriate.

Some leaders provide a confidential support line for staff and family members of staff to call in case of concern, utilise anonymous feedback to gain insights as to staff's needs, include meditations or mindfulness exercises in daily routines

**Box 12:** Staff Support at Julia’s House, UK

Julia’s House provides multiple avenues for providers to ask for and receive support. Staff and family members of staff have access to a confidential support line in case of concern, which is accessed by 11-12% of their staff annually. Emotional intelligence modules have been incorporated into management training at all levels. Julia’s House also has an employee forum and an anonymous survey conducted for staff by an external organisation, capturing their feedback and insights and allowing leaders to identify common issues or trends. Most of these interventions are inexpensive, but the time spent caring and supporting staff pays dividends in terms of retention and the ability of staff to care. This approach has been a significant contributor to Julia’s House being named 13 years in a row by The Sunday Times as one of the UK’s top 100 non-profit organisations to work for.

Source: Interview with Martin Edwards

**Box 13:** Self-Compassion Training for Staff at Strandbakkehuset, Denmark

Strandbakkehuset is a fairly new children’s hospice recently opening in Denmark, closely tied to the adult Hospice Djursland. The former manager of the adult hospice for 15 years, Nurse Dorit Simonsen was granted the opportunity to develop the staff culture from scratch in the new children’s hospice. From her experience, the most important component of her work involves fostering compassion and self-compassion within staff. She found that many providers at the adult hospice faced burnout after just three to five years, and that training staff to care for themselves, in order to take care of the families, resonated within the ethos of CPC. Simonsen’s new hires undergo two-year training in compassion and self-compassion, which includes guest lectures from external experts and exercises in mindfulness and meditation that are provided as audio files for providers to listen to any time.

Source: Interview with Dorit Simonsen



# Technology

Digital tools are integral to all activities, from parent education, to psychosocial support, to play. New technologies are embraced alongside much more systematic use of old ones

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## Summary:

COVID-19 has been a wake-up call to many CPC providers as to the sheer variety of applications for digital technology in the services they provide – including consultations, psychosocial activities, play, peer-support and CPC training. There is still huge untapped potential in the use of everyday technologies to improve CPC, from telephone calls to WhatsApp and other social media. However, there are enormous opportunities to leverage new technologies as well, including 3D printing, artificial intelligence, augmented reality, and data-driven care. As a niche and often fragmented sector, CPC providers are not currently in a strong position to realise these – a wave of industrial and academic partnerships, as well as collaboration between providers, is needed to make real progress.

Technology is revolutionising healthcare, and while CPC providers are following in some of these trends, there are huge untapped opportunities to better use new and old technologies alike.

While the importance of compassion, touch and continuity of care have meant that face-to-face service delivery has rightly remained at the core of CPC provider activity, digital technologies have numerous advantages to improving quality and access, including:

- Helping to bridge distance and mobility challenges – vital given the large geographical areas often served by CPC providers, and the difficulties of moving some children with LLCs and LTCs around
- Providing better access to the limited availability of specialist clinicians – both to families and more generalist staff
- Creating and maintaining networks between families to share support and experiences
- Generating new ways for children to engage in the world around them, including giving greater independence to older children with palliative care needs
- Giving families and staff access to information and e-learning resources
- Offering decision aids to help choices about treatment choices
- Creating more engaging modes of play and distraction therapy
- Gathering and analysing more detailed real-time data on children and families' outcomes and experiences of care
- Automating some repeatable tasks to reduce the administrative and logistical burden on staff and families

In these and many other ways, technology can act as an enabler with the potential to empower children, families and staff through information, connection and flexibility. One key advantage of digital tools for CPC's hugely varied patient population is their customisability – allowing them to be individually adapted to specific needs.

### **Box 15:** Adapting existing technologies: Lifelites (UK)

Lifelites is a UK charity focussed on adaption and access to assistive technologies for children with LLCs and LTCs. It started in 1999, initially focussing on simple technologies such as raised desks, wireless mice and touchscreen devices that could be adapted and installed into children’s hospices. These offerings have evolved dramatically as technology itself has transformed over the years – becoming more powerful, more robust, more portable and cheaper. Key products now include eye gaze and voice-command technologies for interaction and play, a ‘magic carpet’ device that projects interactive images onto a bed or floor, and ‘tilt and touch’ screen tables. Many of the technologies are now installed on wheelchairs, at the bedside or in the home, rather than fixed in one position in the hospice.

The charity is not primarily a developer of the base devices but rather seeks to adapt and give access to existing technologies that will give children with LLCs and LTCs the tools and expertise to live their lives to the full. Their activities are centred on five key areas:

1. Adapting off-the-shelf and specialist/assistive technologies to the expressed needs of children using UK hospices. Before installation, each hospice goes through a consultation process in which they talk about their needs, which Lifelites and a service company listen to and then either provide the products or research how this could be done.
2. Donating and installing the requested packages of technology according to the particular needs of children using each UK hospice. The charity’s technologies are now present in all 57 of the UK’s children’s hospices, with the intention of replacing each package every four years.
3. Maintenance of all the technology that they donate, in addition to offering a troubleshooting helpline.
4. Training hospice and other CPC staff in how to use the technology.
5. Fundraising to secure the finances needed to all of the above.

Lifelites saw a particular challenges and spike in demand during the COVID-19 pandemic, when many families were moved into ‘bubbles’ within hospices (and so could no longer move freely around the facility) or could no longer come into hospices as often. This was where portable technologies that could easily be moved to the bedside or home became even more vital, such as Lifelites’ wheelchair compatible eye-gaze system and a ‘tech trunk’ of specially adapted portable technologies such as iPads with a range of selected apps, controllers and virtual reality.

The charity continues to work to identify and adapt new technologies coming through that could have value of CPC. One future technology they are watching closely are thought controlled systems using neuro nodes and other technologies – these are not market ready yet for the CPC sector but hold much promise for the coming years. They stress though that the possibilities even of existing technologies have so much more potential to be realised. Chief Executive Simone Enefer-Doy said “the technology improvements we work on are promising, but innovation isn’t just about new inventions but how things are used and finding new ways to apply what is available already”.

Source: Interview with Simone Enefer-Doy

The rollout of digital tools in CPC received a boost during the COVID-19 pandemic, when many providers were forced to accelerate changes that they were planning, and others to innovate from scratch. The three main areas where providers interviewed for this study said that change had occurred were the use of teleconsultations for clinical interactions; device-based art, music, play and other therapeutic or social activities; and moving CPC education and training for health workers online. Many of these approaches were rolled out in rapid time, and as the pandemic subsides most providers are in a process of working out what changes should be permanent and which were a temporary measure<sup>38</sup>.

Despite this period of experimentation and digital adoption, most CPC providers did not undergo the extent of digital breakthrough that many other kinds of healthcare providers describe, and thus far the use of digital service delivery for CPC remains limited. Existing research overwhelmingly focuses on the use of digital technologies for video consultation, but this is just the tip of the iceberg<sup>39</sup>. Changing this requires CPC providers to remove two distinct barriers that inhibit change – one that inhibits the application of new technologies, and one that inhibits the systematic use of old ones.

### **New tech**

The first barrier concerns the invention and commercialisation of new technologies to CPC. The small scale of the CPC sector currently makes it unattractive as a market for technology companies to target. This hampers innovation as individual CPC providers are very limited in what they can develop themselves – they simply do not have the resources or skills required.

Playtech is one such underexplored area - play therapy practitioners frequently use iPads to deliver different kinds of games and other digital tools for direction or pleasure, but typically these tools are rudimentary compared to how gamification is being employed in other areas of healthcare today. Trials of some of the first purpose-built, professional-quality video games for CPC have been growing in number over recent years, including a multi-national collaboration to develop a gamified version of the Children's Palliative Care Outcomes Scale<sup>40,41</sup>.

Existing research overwhelmingly focuses on the use of digital technologies for video consultation, but this is just the tip of the iceberg.

individual CPC providers are very limited in what they can develop themselves – they simply do not have the resources or skills required

Virtual reality is another under-explored area, with research showing it can reduce the significant isolation that can come with serious illness for young people<sup>42</sup>. The latest telepresence technologies may also have potential applications in helping children who are regularly unwell in continuing with school<sup>43</sup>. 3D printing of bespoke aides – such as postural devices are another tool with limitless applications given the need for individualised devices for many children. Similarly, CPC providers have generally been late to explore the use of real-time service-level and user data to deliver services and help them improve. The use of artificial intelligence and natural language processing to create virtual aides and chatbots is another high potential avenue (see Box 16).

The most effective way at changing this picture is for CPC providers to work together to more actively create a market for these kinds of innovations. Approaching developers and designers as a block of providers with specific needs and ideas, coupled with advanced purchase agreements – perhaps matched funded by donors – could create a much more attractive proposition. Universities and academic health science centres could be included in the partnership if more early-stage research and development is required. Where in-house solutions have been created, CPC providers should be ambitious about commercialising these. Whether or not they develop into significant sources of revenue, it will at least create a more sustainable basis and incentive for providers to share and scale innovations than is currently the case.

The most effective way at changing this picture is for CPC providers to work together to more actively create a market for these kinds of innovations.



## Old tech

The potential of new technologies should not distract from the much greater opportunities from systematic use of older, established ones – such as telephone, basic apps and social media – many of which require little or no external costs to develop or implement.

Uses of established technologies for CPC include virtual consultations to bring multiple professionals together, or see a child in their home, online peer networks, engaging and interactive educational content for families and staff, and real-time feedback from service users on their experiences and outcomes. None of these applications are new to CPC but rarely are providers found to be systematically implementing them<sup>44</sup>. The barrier here is CPC providers' approach to technology adoption itself, covered in more detail in 'Culture'.

To take one example, the use of video consultations for CPC can reduce inequalities, improve

access to specialist care and allow for real time communication<sup>45</sup>. Evidence thus far suggests that telemedicine applications such as teleconsultations for CPC may result in increased clinical effectiveness, cost benefits and savings and improved quality of care and communication<sup>46</sup>. However, even with the COVID-19 pandemic most CPC providers continue to use teleconsultations only at the margins, seeing it as a 'future' technology to move towards. While some face genuine barriers – such as bandwidth in very remote areas, or the costs of data in low resource settings – these are not significant barriers to adoption for many providers. Safeguarding and data privacy issues are likewise important but not insurmountable. In future, the best CPC providers will have a robust suite of technology tools that are routinely deployed across all activities – clinical and non-clinical – which are linked to individual child records and offer choice to staff and families alike as to how they interact.

### Box 17: Development of the Children's Palliative Care Outcomes Scale

Another evolving area is the development of systematic collection of outcomes from children and families. This is an area where innovations in other areas of healthcare have been in widespread use for some time, but only recently has a coordinated effort across the CPC sector led to significant progress being made.

Building off the success of their developing, piloting and validating an outcome scale for adult palliative care in Africa<sup>47,48</sup>, the African Palliative Care Association began development of the multi-dimensional African Children's Palliative Outcome Scale (C-POS) in 2009<sup>49</sup>. The draft instrument was completed in 2017, making it the first validated outcome measure for CPC worldwide. The drafting process involved organisations from across eight African countries alongside the International Children's Palliative Care Network (ICPCN) and King's College London.

CPC experts from across these organisations identified key domains to include with a focus on the multidimensional nature of outcomes that matter. These domains included pain, symptoms, distress, quality of life, communication and family support<sup>50</sup>. After drafting and piloting, the tool is undergoing revisions based on the validation and psychometric testing that wrapped in 2017. The draft currently contains 12 questions, eight for the child and four for the parents. This tool has already been used in various medical and research settings, with many CPC providers in high-income countries now looking to adapt it for their setting. This includes the development of a UK version, a French adaptation<sup>51</sup>, along with apps for recording data at the user's convenience, such as the MyPalChild game which asks several of the questions included in the C-POS<sup>52</sup>.

Thus far there is no network for benchmarking data from the C-POS across providers as exists within adult palliative care, however this may be a future development once enough providers have adopted the measure. Other future applications could be to create real-time monitoring systems that are capable of triggering alerts for particular patients, and the inclusion of patient experience measures when the user interacts with a CPC provider's services.

# Organisation

New organisational models are used to increase the provider's size and footprint, with economies of scale savings reinvested to increase capabilities and fuel further growth

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## Summary:

Adopting the vision and innovations set out in this report requires most CPC providers to work at far greater organisational scale than is currently the case. Increased organisational scale can be achieved through vertical or horizontal means, or a blend of both, and has many degrees of intensity, with models including networks, franchises, joint ventures, shared services, joint appointments, as well as mergers. There are tremendous benefits available to providers who have done this, including administrative economies of scale which can be directed towards new investments such as more specialist roles, data analytics, business development, research and higher quality staff and family training. A larger provider organisation is also able to have a more influential and useful role in discussions with other healthcare providers and payers, as well as engage with larger funders.

Redesigning organisational models allows healthcare providers to expand their reach and capabilities without expanding their infrastructure or funding. Most CPC providers are small – whether that is as an independent standalone children’s hospice, palliative community nursing team or, even if they are part of much larger providers such as tertiary hospitals, they are a relatively small department or ward within it. This small scale is a major limitation on the prospects of most CPC providers to grow and develop in the ways outlined in this blueprint – small providers are less able to make investments, less able to take risk, less able to include specialist roles and in terms of voice are more easily lost in the shadow of bigger players in the health system.

There is some history of smaller CPC providers using organisational mechanisms such as mergers, groups and networks to work at a bigger scale – particularly in the UK and Italy as described below. However, often consolidations have been reactive in response to declining funding or staffing pressures rather than proactive in seeking to realise a more ambitious and expansive vision. For countries where dedicated CPC providers are few, the option either exists to form vertical partnerships with other providers in the CPC delivery chain, or to form an international group. Despite being relatively common among non-CPC hospital, clinic and lab providers (both for-profit and non-profit) in many emerging markets, there are currently no multi-national provider organisations for CPC, insofar as the authors are aware.

Redesigning organisational models allows healthcare providers to expand their reach and capabilities without expanding their infrastructure or funding.

## **Box 18: Expanding service range and reach through organisational scale, East Anglia's Children's Hospices, UK**

Originally two independent providers, the Cambridge and Quidenham children's hospices began to explore the potential for joint working in the mid-1990s. Initially conceived as a loose alliance, an independent report was commissioned, which found that the overwhelming evidence pointed to a full merger as the only way to achieve the synergies they desired. The choice was a difficult one, but both organisations had big ambitions for the future – most immediately to fill a serious gap in service coverage for families in the neighbouring Suffolk area and to significantly ramp up CPC education and skills training of the wider healthcare workforce. Realising that they would be far more able to achieve this together, the two boards agreed, and East Anglia's Children's Hospices (EACH) was created in 1998.

The newly merged organisation found it had significantly greater fundraising and service delivery capacity, and a period of rapid growth ensued – starting with the opening of a new children's hospice in Ipswich in 1999, and a dedicated CPC education centre in 2002. The merged organisation was able to invest in new capabilities and resources – launching home care and a community end of life care service, levelling up areas where access was previously a 'postcode lottery', and investing in more professional online resources for information and training. They were also able to expand their data analysis capabilities, as well as launch a library and information service that helps produce evidence to support EACH's clinical work, board governance, fundraising and advice to parents.

The increased scale also had a catalytic effect in securing further growth. They were able to hire a dedicated business development manager to secure more sustained funding from the NHS. They were also able to graduate to a larger tier of national-level donors and funders, such as the Big Lottery Fund, national grant-giving trusts and NHS England. It has also made them a more effective partner within the local health system, as their footprint now matched the major regional referral hospital, allowing them to more easily integrate with their specialist hospital teams including medical, nursing, psychology and pharmacy, as well as securing long-term funding to establish a new regional symptom management end of life care specialist service.

This collaborative approach and system leadership on CPC issues was instrumental in securing EACH a royal patron, the Duchess of Cambridge, in 2012, which led, in turn, to an international partnership with Hospis Malaysia and a 'twinning' relationship with Hummingbird Children's Hospice in Australia.

When a funding crisis hit the UK CPC sector in the mid-2000s, EACH found that it was more able to reorganise services across the region into more efficient multi-professional teams working between the inpatient hospice, family home and providing in-reach care and support to children in hospital, as well as quickly replacing lost income. The diverse workforce delivers different elements of the service including nursing, symptom management, end of life care, short breaks, wellbeing support, physical therapies, play, counselling, music and art therapy. Likewise, during the COVID-19 pandemic, EACH was more able to weather critical staff shortages as there was a larger pool of professionals from which to draw from.

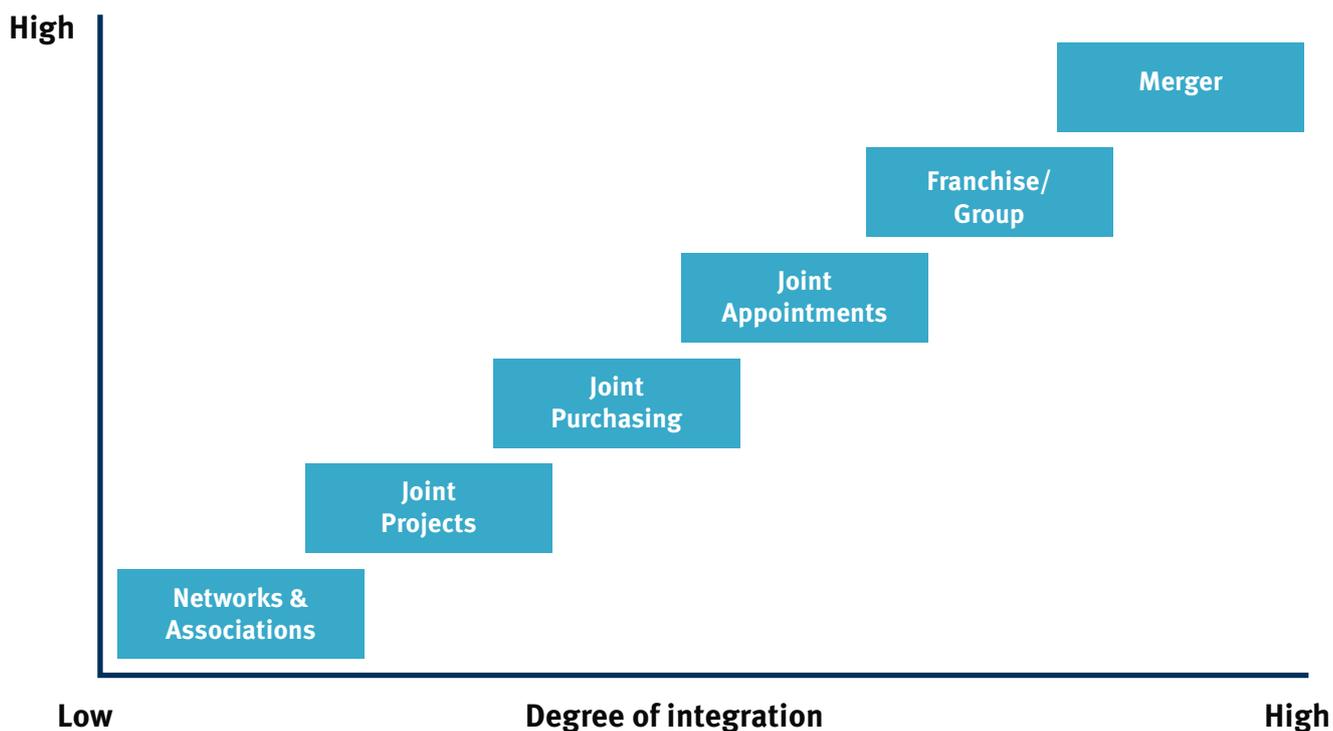
Today, EACH also hosts a regional managed clinical network model which brings together teams from hospices, NHS community teams and hospitals to ensure that children have access to specialist symptom management and end of life care 24/7 whether they are at home, in a hospice or in hospital. Its symptom management service has been able to demonstrate the savings generated to the NHS by avoiding hospital admissions and minimal use of GP out-of-hours services, helping to attract further state-funded support.

According to Tracy Rennie, Director of Care for EACH, it is hard to see how this growth and improvement journey would have been possible without the organisational scale and opportunities created through its original merger, and the capacity and savings that freed up to reinvest elsewhere.

Source: Interview with Tracy Rennie, Director of Care, East Anglia Children's Hospice

The models of achieving greater organisational scale through partnership are many and varied, but some of the key ones are shown in Figure 8. These are displayed as a stepped journey showing the level of integration versus the level of control ceded by the partner organisations – this shows a range of options from more focussed partnerships to full merger.

**Figure 8: Stepped model of organisational scale-up available to CPC providers**



The first level is the creation of formal networks or provider associations, often supported by a Memorandum of Understanding (MoU), in which providers agree to meet to share information and plans, identify areas of common interest and potentially provide a united front for advocacy. This can be taken further into specific joint projects, in which two or more providers agree to work together on an initiative of mutual benefit. One example here is in London, UK where children’s hospice providers have formally established a paediatric palliative care network with the aim of ensuring palliative care and pain therapy are delivered in a consistent manner at equal, high levels of quality.<sup>53</sup> The network works to share knowledge and evidence, but members also work jointly on fundraising initiatives, as well as projects to improve pathways and standardise quality and access. The third level is more formal partnerships among providers to jointly procure or outsource together – a relatively contained way for multiple providers to generate efficiency savings without ceding a large degree of control.

The most substantial levels of collaboration – and potential scale benefits – occur at the next levels, beginning with joint ventures as a model of expanding into new services or geographies. Here two providers might agree to share the investment and risk on a major project, such as a new facility or technology. Joint appointments are the next level, such as a joint director of finance, specialist therapy practitioner, or chief technology officer. The penultimate level is a provider franchise, in which an individual franchisee organisation retains its legal identity and some independence and autonomy, but agrees to adopt certain standardised ways of working as well as a paying a fee to the franchiser for a host of back office and strategic functions such as finance, HR, IT etc. While there are no examples of this in CPC, it has been a common model for primary care organisations in the UK to gain scale, for example the Modality Partnership in Birmingham that lists some 50 general practices within its group. Finally, there is a full organisational merger in which two or more organisations legally become one and move to one executive team, governance structure, and employment model, as demonstrated in the EACH case study above.

While administratively complex and sometimes facing resistance from local stakeholders who fear a loss of identity and institutional roots, there are tremendous benefits available to CPC providers who can shift to larger scale organisational models. They free up bandwidth and resources that can be reinvested in many of the other ideas and innovations in this blueprint – from workforce, to technology, to new business models. Such arrangements will make the most sense in health systems with plenty of options for organisational partners (e.g. equivalent CPC organisations or other health providers with a natural fit of geography and service scope). However even relatively isolated CPC providers can look to international partnerships for potential models.

Thus, while perhaps the least eye catching of the dimensions in this blueprint, scaled organisational models are an important potential enabler of the innovation opportunities described elsewhere in this report.

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These benefits include:

- Increased specialisation of roles – with a larger overall workforce, organisations have the ability to introduce increased staff specialisation of roles, increasing quality and adding capabilities and services.
- Specialisation of sites – working across more than one site allows organisations to specialise their differing roles, for example having one site lead on more complex care, another on symptom management and another on respite and psychosocial support.
- New managerial roles – savings from only needing one set of finance, HR, IT or estates functions can be reinvested in new roles to improve organisational performance, such as a business development or data analytics managers.
- Procurement savings as a result of purchasing in larger quantities, and internal investments – such as training materials – can be better resourced.
- Increased market power as a result of covering a larger footprint and volume of patients, meaning a greater ‘seat at the table’ in the local health system, and the potential to attract larger funders.
- A larger asset base against which to borrow for new investments.

Of course, there are plenty of examples of organisational partnerships not delivering these benefits – and organisational change also carries risks of mission dilution, diseconomies of scale and loss of local ‘feel’ which is important to many families. There will be opportunity costs to all of the above options for achieving greater organisational scale which need to be carefully compared against the potential benefits listed above.

# Culture

A culture that institutionalises innovation, centred on children, families and staff as the engine of ideas, which the organisation scales and shares

## Summary:

Creating an organisational culture of innovation is one of the most important aspects of a future vision for CPC providers. This is partly because so much innovation is already happening at the front line which is never scaled or shared, and partly because while no one can predict the future technological, political or funding landscape, a culture of developing shared solutions to important problems will keep a provider resilient and on a trajectory of continuous improvement. As the engine of most CPC innovation and ideas today, children, families and staff should be central to the process, supported by a broad array of other professional disciplines: designers, makers, clinicians, technologists. Eight stages of this co-design methodology are described, including recognising the need to create spaces where all experiences, competencies and opinions count; reciprocal recognition of everyone's unique expertise; sharing of real world needs and; at the end, the obligation to scale and share what is produced. Systematising these approaches can be achieved through institutionalising service user input across the organisation, training staff in design thinking, and investing in targeted innovation expertise.

The CPC sector is in urgent need of innovations that can lead to a step-change in access, empowerment and quality improvement if it is to come close to achieving high quality palliative care for all children who need it. The challenge is one of both invention and adoption, and CPC providers have a leading role to play in both through their own internal culture, which should seek to drive innovation across every aspect of their operations: clinical, non-clinical and managerial. Furthermore, a culture that institutionalises innovation processes will make CPC providers more resilient and adaptable in the long-term, sustaining improvement beyond the immediate opportunities, technologies and tools described in this report towards whatever the future brings.

CPC providers are already highly innovative, in that – for those who take the time to look – they exhibit huge amounts of small-scale invention and adaptation at the front line. But most of this is conducted out of necessity rather than systematically supported, scaled and shared, as many of the best providers in other areas of healthcare do. There are many philosophies and methodologies for promoting innovative cultures within organisations, but for healthcare – and CPC in particular – the methodology of ‘human-centred design’ is especially appropriate. This is because it is already the case that staff and service users are the principal engines of most innovation in CPC today, and also that because palliative care, above all other fields, holds that the human experience and quality of life of the patient is as important as any narrow clinical conception of ‘outcomes’.

Human-centred design is a methodology to problem solving that places the lived experiences and ideas of users and beneficiaries at the centre of the analysis, working through stages of: understanding problems in their real-world context; identifying opportunities and ideas with potential users; and then co-designing prototypes to arrive at the best solutions. It is a highly participatory design process that begins with the people that the designers want to create for – professionals, children, and their families – and combines this with a broad array of different professional disciplines who can each add their own skills and perspectives – designers, engineers, clinicians, and many more. Most importantly, potential users are supported to play an equal and participatory part in each stage of the innovation process.

CPC providers are already highly innovative, in that – for those who take the time to look – they exhibit huge amounts of small-scale invention and adaptation at the front line. But most of this is conducted out of necessity rather than systematically supported, scaled and shared

This methodology can be applied in a variety of ways depending on the level of professional design expertise required<sup>54</sup>.

- **Professional design:** Skilled designers with varied expertise work together in teams to create a user-centred experience
- **Co-design:** The practice of partnering with patients in design activities, so that the patient becomes an active part of the design team
- **Design thinking:** A structured approach for people who do not identify as designers to focus on their users, gain insight from a completely different perspective and address insights with creativity

This approach is not always about inventing something ‘new’, but rather is a lens through which healthcare providers can aim to continuously improve all aspects of their services and operations. This is the true essence of an innovative organisation.

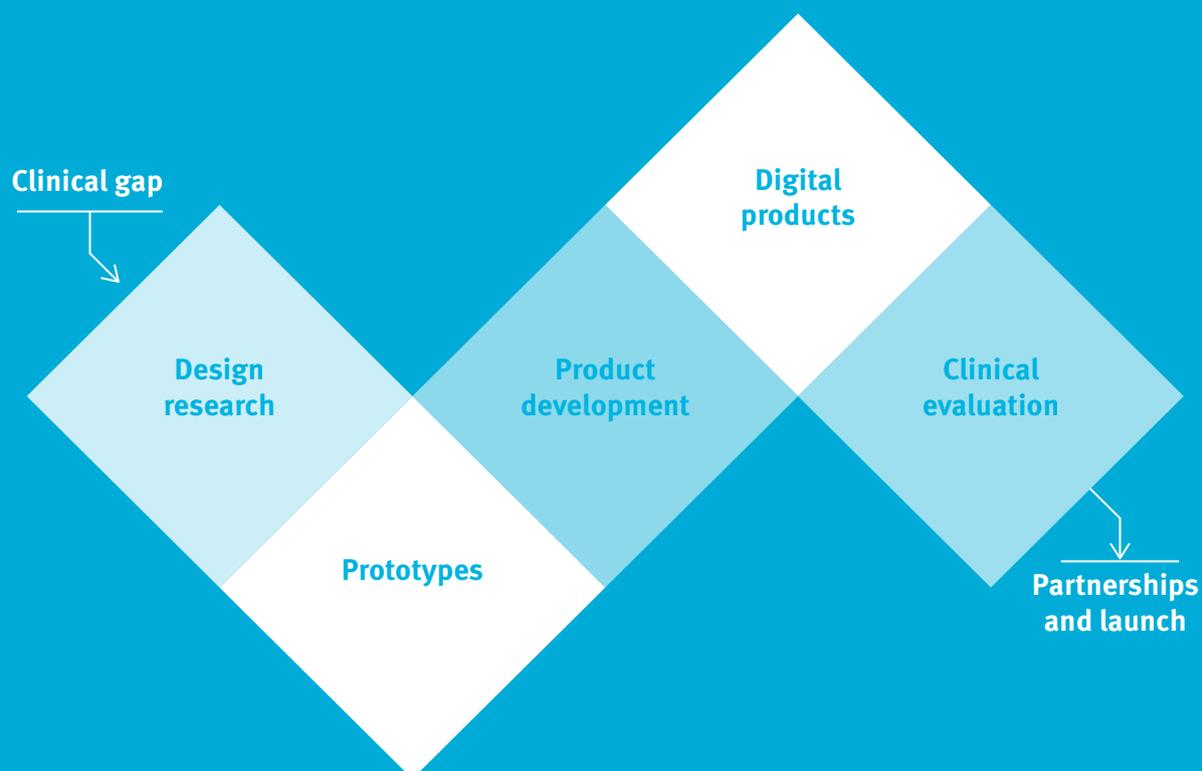
### Box 19: Human-centred design in practice: Imperial College London’s Helix Centre, UK, and the Seràgnoli Children’s Hospice, Italy

Since 2018, a team from the Helix Centre, a health design innovation lab at Imperial College London, have been creating prototypes to apply emerging and innovative technologies to CPC services for the forthcoming Seràgnoli Children’s Hospice near Bologna, Italy.

The specific CPC prototypes that have been developed so far include touch-responsive plants for an interactive garden, an AI-powered chatbot, an augmented reality play therapy and a digital memory-making platform (See Box 15). However, throughout their work the team have been focussed on refining a human-centred design methodology that works in CPC – an equally important goal as the individual prototypes. This, they believe, is as important an output as any specific technology or tool, as its applications are limitless towards all manner of new solutions across CPC providers globally.

Central to their methodology are the principles of human-centred design, a creative process that begins with gaining a deep and considered understanding from the people they want to design for (and with) – professionals, children, and their families – and ends with innovative, tangible solutions tailored to meet their needs. It is widely used across healthcare, and in many other sectors, however the team have found it especially suited to palliative care. This is because by necessity palliative care services have less of a strong focus on narrow clinical outcomes – since most individual will eventually die from their condition – but rather consider user experience and other more ‘human’ dimensions of care as central.

The process itself has five key stages. It starts with attempting to gain a clear understanding of the ‘problem space’, that is, the specific need or gap and the wider context within which it exists. This uses generative research methods including open discussion meetings combining lots of different perspectives and observing users in the real world where relevant. Next is a process of ‘design sprints’ – rapid prototyping and solution testing as a team composed of all the relevant people, including children, families and professionals. Next, having decided on the simplest and best solution, comes a more rigorous period of product development and refinement, including the viability of potential business models and the feasibility of technological execution and scale up. This is then followed by rigorous scientific evaluation before finally being launched – with business model and scalability have also been considered as a key factor from the start.



One of the most powerful distillations of the human-centred design methodology that is applicable to healthcare is the Manifesto of Co-Design for Health and Care, created by OpenDot (See Box 20), an Italian design and innovation studio. It proposes eight stages of applying this thinking in a healthcare organisation, accompanied by a toolkit of practical resources to assist organisations at each stage. This approach is now being applied directly towards the design of eight experimental treatment rooms, known as ‘special spaces’, in the forthcoming Seràgnoli Children’s Hospice near Bologna, Italy – these include art and music therapy rooms, a multi-sensory room, a meditation room and a multi-media room.

#### Box 20: The Manifesto of Co-Design for Health and Care

1. Listen and observe: Create a space where all opinions, competences and experiences count and have space and time to be listened to.
2. Teach and learn: Reciprocal training in each stakeholders’ area of expertise (everyone has one).
3. Speak the same language: Break down the wall of technical jargon, in favour of a common language that everyone can understand.
4. Share real needs: The size of need doesn’t matter, what counts is focusing on the reason. The “how” comes after.
5. Think and design together: Moments of sharing, exchange and collective design guide the group towards a final idea, stimulating everyone’s creativity when it comes to devising new and innovative solutions.
6. Materialise the idea: The production of a first prototype allows the group to touch, explore, and test the idea.
7. Prototype, prototype: The prototyping phase is a spiral process in which projects improve by increasing versions, and through continuous dialogue on how to perfect the object
8. Replicate, scale and share: Sharing the process and final solution with others who may benefit is an important way to further improve the concept as well as amplify its social impact.

Source: <https://wikifactory.com/+fab-care/stories/opendot-manifesto-of-co-design-for-health-care>

## Systematising human centred design across an organisation

The above describes a methodology that can be applied to any individual need or innovation project, but how can this approach be systematised across a CPC provider organisation of the future? Working with innovative healthcare organisations of many kinds around the world, a global committee of healthcare innovators and designers working for the World Innovation Summit for Health have proposed three actions which, together, can most powerfully transform these principles from individual projects, to an organisation's fundamental culture<sup>55,56</sup>.

- **Institutionalise service user input and perspectives across the organisation:** Incorporate the experiences and insights of patients and the workforce in policymaking, governance and major projects. All projects which result in a service experience or health outcome for a patient should involve input from both patients and professionals. This might also involve mandating the use of a specific design methodology for service improvement projects, and should involve careful consideration of support that might be required to help these often-stretched individuals to contribute meaningfully.
- **Teach design thinking principles to every staff member:** Most importantly, to focus training on two key skills, empathetic research methods and prototyping. These form the foundation of human-centred design. This training should involve practical exercises to hone these skills rather than strictly didactic teaching.
- **Invest in targeting design expertise:** larger providers can consider embedding design professionals or teams with skillsets most relevant to the innovation goals of the organisation. For smaller providers, establishing partnerships with external design teams as preferred partners who can get to know the organisation over time is a leaner approach, as is sponsoring a design challenge or community of practice to bring together a variety of professionals from outside of the organisation and focus minds.

## Scaling and diffusing innovations

Creating internal cultures that foster innovation within individual CPC providers is only one half of the challenge. As with the healthcare sector more broadly, diffusion of innovations across individual providers and national systems is often an even greater challenge than the invention stage, with well-publicised figures as to the number of years that even the most robustly proven innovations take to scale up to become standard practice.

The factors that determine the speed of scale-up of innovations among healthcare providers are complex, but a multi-year research project by the Global Diffusion of Healthcare Innovation (GDHI) initiative has identified three levels of enablers that have the biggest impact<sup>57-58</sup>:

1. **Healthcare system characteristics:**  
Fundamental structural and environmental elements in which providers operate, including the economic, legal and regulatory environment; IT infrastructure; size of the research sector; and overall health system structure.
2. **Institutional enablers:**  
Agents or agencies to diffuse innovation that are initiated by collective, corporate or government action.
3. **Frontline cultural dynamics:**  
Organisational behaviours and attitudes among delivery staff regarding adoption and adaption of innovations.

Clearly, some of these elements are much easier to change than others, but a wide range of interventions can be put in place to accelerate diffusion, including standards and protocols; awards, rewards and incentives; accelerators and innovation funds; IT capability and interoperability; and networks of academic, commercial, clinical cross-fertilisation. A further in-depth analysis of eight highly successful healthcare innovation scale ups across high-, middle- and low-income countries distilled these potential interventions into four categories – all of which were present to some degree in the most successful case examples<sup>59</sup>. These enablers of innovation are: vision and strategic leadership; a specific organisation, program or initiative to promote diffusion of innovation; funding for research, development and diffusion; and communications channels and networks across healthcare, other industries and the public. All four interventions to accelerate innovation scale up show potential in the CPC sector, where there are significant opportunities to expand each.

All four interventions to accelerate innovation scale up show potential in the CPC sector, where there are significant opportunities to expand each.

# Place

Physical settings for CPC act as centres of excellence for training and service improvement across their region, as well as for treatment. They are leaders in de-medicalising the experience of receiving care

## Summary:

From purpose-built CPC centres to little touches of design thinking in general healthcare settings, the physical places in which families and children receive care can make a huge difference to their experience, as well as what services are made possible. While physical infrastructure in which to deliver care will always have a role, CPC centres have an increasing importance not just in direct service delivery but as regional and national centres of excellence for training and quality improvement. CPC providers are also a treasure trove of innovations in how to create healthcare environments that are less medicalised, less likely to provoke fear, and more fun – often through a co-design process with families and children that other healthcare providers would do well to learn from.

The general trend in CPC is toward the decreasing importance of the physical hospice building or hospital unit as models of care shift to the community and the families' home. However, for inpatient, outpatient and respite services that must be delivered in an institutional setting, the physical design of the space can dramatically improve families' care experience. And in addition to the direct services they can offer, dedicated physical spaces have increasing roles as regional and national centres of excellence that can draw in staff and organisations from across the health system to develop CPC skills and make service improvements.

The increasing number of purpose-built children's hospices around the world is showing what a dedicated building is capable of creating, including flexible, modular spaces that can be modified to accommodate a variety of families' preferences such as kitchens and communal eating areas, the integration of play throughout a facility, and creation of environments that will promote positive experiences, memory-making and a 'wow' factor. A range of powerful architectural statements have been made in recent facility designs, from the children's hospice built around a central Ferris wheel in Kuwait, to the forthcoming glass treehouse design of the Serágnoli Children's Hospice in Italy. Designers have found particular inspiration in the creation of dedicated CPC centres in recent years, with a growing number of architecturally breath-taking CPC structures around the world, and award-winning designs even in resource-constrained settings such as Uganda (See Box 21).

A range of powerful architectural statements have been made in recent facility designs, from the children's hospice built around a central Ferris wheel in Kuwait, to the forthcoming glass treehouse design of the Serágnoli Children's Hospice in Italy.

### **Box 21: Design Award for Mildmay Uganda**

In 1993 Mildmay was invited by the Government of Uganda to start training on HIV/AIDS and palliative care in Uganda and to look at the feasibility of setting up a centre in Kampala. The Mildmay Centre was built as a Ministry of Health Facility with initial funding from the British Government through the Department for International Development (DFID) to offer comprehensive HIV/AIDS palliative care and training. The Centre, opened in 1998, was designed around the availability of local resources, and to meet the needs of adults and children needing palliative care, alongside the idea that the building should be bright and airy, with lots of outside space, and good ventilation throughout. It was also intended to inspire those using it through its beauty, through facilitating positive interactions and cultural relevance for its occupants<sup>60</sup>. Whilst built on hill, which provides its own challenges for those with HIV/AIDS and those needing palliative care, the architects won an award for its design, which combined practicality and elegance whilst enabling privacy and good ventilation. Throughout the initial building of the centre, and further extensions as services expanded, the needs of those, especially children, were considered, with Noah's Ark being a unit specifically built around the needs of children, providing a safe space for them, where no medical procedures were undertaken, and where they could relax and play. The award-winning design was one that was then utilised in other settings in Uganda, for example CURE children's hospital in Mbale which opened a few years later.

However, it is the process of the design of these physical spaces which is the most important innovation, with inclusion of children and families from the early visioning stage through to finishing touches. Current and former users of the CPC system not only affirm and sense-check the major design components of the infrastructure, but frequently contribute insights that an architect or a physician may never think of. If a programme is able to involve children and their families in the design of the building itself, simple insights such as constructing larger private bathrooms for multi-use purposes, or the inclusion of a kitchen or cooking area for families to use to give a sense of normalcy can improve the quality of families' experiences. User insights are valuable at every stage of the design process, no matter how late – such as the choice of dark towels and sheets that will easily wash out stains, which can better families' memories of being in this space with their child.

It is this process of user-led design that is accessible to all CPC providers in thinking about the design of their physical spaces – even general healthcare settings that they don't operate.

Many hospitals and CPC providers put special effort into the creation of 'butterfly rooms' – sensitively designed spaces that are often in a general hospital where families can be with their child in the final moments of their lives. It is these kinds of innovations and desire to make healthcare settings as non-medicalised as possible that makes the CPC sector such a rich seam of design ideas for other healthcare providers to learn from. These kinds of innovations are not just a 'nice to have', as many children who receive CPC have been in and out of healthcare facilities for their entire lives, and medical-seeming environments can be a genuine sense of trauma for them.

It is this process of user-led design that is accessible to all CPC providers in thinking about the design of their physical spaces – even general healthcare settings that they don't operate.

## **Box 22: User-Led Design at Hummingbird House, Queensland, Australia**

Hummingbird House (see Box 7) involved users in the design process of its physical space at every stage. They made sure to hire architects familiar with user-centred design processes that were passionate about capturing insights from patients and families. Users were involved in the furniture choices for the patients' rooms, enabling small but effective design changes, such as utilising a wooden bedframe for the patient's bed to imbue a sense of warmth to the room or picking out bright, colourful bedding and curtains to liven up the space and distance it from such a medicalised setting. Parents and families also spoke about what resources they needed to feel comfortable and secure in the hospice setting. In accordance with families' expressed desires, most of the rooms in the hospice are capable of a full suite of symptom control management services available at a moment's notice.

Overall, the design of the physical building speaks to three key principles: rest, privacy and flexibility. First, the building was designed by the architects to imply a sense of relaxation and spaciousness. Wide corridors and spacious common areas speak to this objective. Second, the designers understood that privacy or the lack thereof is an important consideration for families, and that the need for privacy or socialisation is highly variable from family to family. The space is intentionally designed with a clear delineation between private and public space, such that families could choose to essentially be isolated and have staff deliver services to their door, or they could socialise amongst other families in common spaces. This speaks to the final principle, flexibility. Families' desires and priorities vary greatly, and the hospice serves a number of families in any given week. Thus, many of the hospice's spaces are designed to be completely modular and flexible. One suite, a temperature-controlled room with a private bathroom and courtyard, is commonly used by families for grieving their child. This room is designed to be a blank slate, with very little decoration but plenty of built-in spaces to display pictures, artwork, and truly adjust the space to whatever the family desires. Likewise, their covered rooftop can be used for any number of activities, including annual gatherings, movie nights, or other engagements.

Source: Interview with Elham Day

## **Box 23: User-Led Design at Strandbakkehuset, Denmark**

The recently built Strandbakkehuset (see Box 25) children's hospice also involved users in the design process. The first iteration of their physical building involved a 20-person brainstorm session, including a parent of a former CPC patient as well as a former CPC patient, as well as children's hospital employees including physicians and nurses, asking the question: "What spaces would the best children's hospice in the world include?"

They concluded the following considerations. Separate rooms were needed for the child and the family, such that medical staff can attend to the child at night without disturbing the family. Families need large bathroom spaces to comfortably fit in any necessary equipment. Kitchenettes are provided within the family suite, and were considered an essential part of making the space feel less hospitalised to children and families and allowing families to take part in regular everyday activities such as cooking and enjoying meals together. For common areas, spaces for younger children, older children and adults (without any children) were all considered necessary.

Source: Interview with Dorit Simonsen

Outside of the buildings themselves (literally), many CPC providers around the world have invested in garden and other outdoor spaces as important tools in care. Nature can be both highly beneficial and highly inaccessible to many children with LLCs and LTCs. Due to bulky medical equipment or the inability to be without access to medical care for long periods of time, many families find it difficult to spend time together outdoors with a sense of normalcy and privacy. A well-designed garden provides families a rare opportunity to enjoy the benefits of nature together, in a space that accommodates the needs of the child, with the security of knowing that medical care is close at hand if needed.

The other standout feature of many CPC settings is the inclusion of areas for play, for both children with LLCs and LTCs, and their siblings. As health care trends towards de-medicalising children's and families' experiences, more and more CPC providers are acknowledging their role in 'helping children be children' in spaces where traditionally childhood has been made inaccessible. While dedicated play areas are a common feature of many children's hospices and hospitals, others have sought to include play in a more integrated way throughout the whole facility, as demonstrated by at the Mary Elizabeth's Hospital, Copenhagen, currently in development in Denmark.

Nature can be both highly beneficial and highly inaccessible to many children with LLCs and LTCs.

#### **Box 24: Integrated play at the Mary Elizabeth's Hospital, Copenhagen, Denmark**

At the Mary Elizabeth's Hospital, Copenhagen in Denmark, which is currently undergoing development, the building design resembles two hands when viewed from above. The palms represent the common spaces, whereas the fingers that extend outwards each comprise six private rooms. These private rooms are quite a bit larger than average hospital rooms providing space for one or two people to sleep comfortably in addition to the child. At the tip of each finger is a large, highly modular space for play that is planned to differ by age group and play activity as development continues. The ethos is that play across various age groups is an integral part of how children learn skills to cope with their illness, and that the structure of health facilities serving children should reflect the importance of play.

Source: Interview with Lars Hyldagaard Olesen

# Partnerships

A network of strategic partnerships with payers; providers, community and industry allows the provider to leverage substantial external resources to expand and improve its service.

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## Summary:

Many CPC providers are already exemplars in how to leverage external partnerships to offset their small scale, such as with local schools, businesses and community volunteers. This role as a catalyst is central to any future CPC provider, but the best are building these partnerships more strategically, sustainably, and with a more entrepreneurial mindset - this means developing business models that can tap into healthcare payers as major funders of care; creating hub-and-spoke delivery models with other healthcare providers; coordinating volunteers as a part of the CPC workforce; and working with industrial partners such as medical technology and software development companies.

Partnerships are many CPC providers' most important asset, and an area where many are already outstanding. For all their relative niche size in the health system, and difficulties many have in securing funding, the mission of CPC providers is one that many other organisations find inspiring, and rewarding to be a part of. Most existing CPC providers have a network of partnerships with whom they work, but there is still scope to grow these in future – with the ideal future provider having built up a strategic network of partnerships with four main groups: payers, providers, community assets and industry.

### **Partnerships with payers**

Funding for the CPC sector has seen significant peaks and troughs over the last three decades, but most providers are still heavily dependent on relatively small-scale local fundraising – a model more common to niche charities than the essential healthcare infrastructure that CPC providers are.

In the era of universal health coverage, healthcare payers (such as national health insurance funds or social health insurers) are increasingly important in controlling a larger share of total health spending – including who and what this goes towards. There are substantial opportunities during this period for predominantly donor-funded CPC providers to grow a much larger share of their income from insurers and the state by delivering contracted CPC services. These contracts typically offer greater size, scale and longevity compared to grants and donations. However, making this shift requires a change in both capabilities and organisational mindset. Service contracts take a significant amount of capacity to win, deliver and sustain, not to mention the ability to take risk. Some providers fear the complexity and, in some cases, constraints that come with delivering payer-funded services, but these must be balanced against the potential for rapid growth and closing the access gap.

Partnerships are many CPC providers' most important asset, and an area where many are already outstanding.

There are substantial opportunities during this period for predominantly donor-funded CPC providers to grow a much larger share of their income from insurers and the state

One key constraint is whether CPC services are explicitly included in the national benefit package (i.e. the services payers are obligated to fund). In systems where they are not, providers can consider four potential strategies to overcome or work around this:

1. Creating an individual business case for investment based on savings likely to be generated to the payer through reduced need elsewhere in the health system. For example, demonstrating that the investment in CPC services results in reduced emergency room attendances, bed days or long-term costs of care.
2. Identifying the areas of service they provide for their patient population which are included in the benefit package (i.e. billable services for the specific population) and seeking to have these remunerated.
3. Developing into a vertically integrated provider for children with LLCs and LTCs. This means delivering a wider range of services, including those recognised by the payer, to the provider's core patient population and seeking to have these funded. Though it is important these do not distort the organisation's mission toward what is billable rather than what is needed.
4. Advocacy work to seek the explicit inclusion of CPC services within the benefit package, and to make the case that there is no universal health coverage without palliative care as a basic component of people's human right to alleviation from suffering (see next chapter).

Hiring dedicated business development resources to lead on payer relationships is a likely first step in this process, but it requires new skills across the workforce too. One example of this entrepreneurial approach in practice is Rachel House in Indonesia, where nurses are trained in business management and required to operate their own budget lines. The intention is that if they leave the organisation wishing to move back to their home provinces, they will have the confidence and skills to set up their own 'satellite' providers – scaling up the organisation's impact across the country.

Another shift is that payers (and larger donors) typically require more documentation and evidence of impact from their investments, compared to small-scale local fundraising. Making investments in data collection and reporting systems is another important prerequisite to growing in this way.

## Partnerships with other providers

One of the defining features of the best CPC providers today is how they collaborate and engage with the other providers who are caring for a particular child. As noted in Chapter 2, collaboration can take a wide variety of forms, from integrated outreach services to data-sharing agreements, to shared staffing and care navigation. Formalising these partnerships is an important way of ensuring that they outlast any given set of relationships, although strong interpersonal relationships are an essential component too.

Collaborating with other providers helps drive the expansion of CPC services, by familiarising referring clinicians with the need for CPC and normalising CPC as a potential part of the healthcare package from diagnosis. This is already central to the approach of most CPC providers, but there are still many potential improvements and innovations to explore that can create more integrated shared services, reduce points of friction in how one provider works with another, and reduce the burden on families. These can take the form of formal mechanisms such as joint guidelines and agreements, or informal ones as demonstrated by Strandbakkuset in the Netherlands (see Box 25).

### Box 25: Team Meetings at Strandbakkuset, Netherlands

At Strandbakkuset (see Box 23), the palliative care team from the children's hospital Zoom with the team from the children's hospice. Parents also join this team meeting. This weekly check-in ensures that the team is well-aware of the child's situation across different settings, and emphasises the importance of all members of the team being equally vital.

Source: Interview with Dorit Simonsen

One area of particularly strong potential for scaling up partnerships with other providers is the formation of hub-and-spoke model for delivering CPC services<sup>61,62</sup> These models seek to address two of the most pressing needs in shifting to community-based, nurse-led CPC – seen as one of the most efficient and effective future models for CPC. The first need is a desire for an expert point of contact or 'lifeline' that they can call upon in case of concern. The second need is for networks of other professionals to prevent those working in the community from feeling isolated.

Developing and improving ‘hub-and-spoke’ care models was a key ambition for many of the CPC providers interviewed for this project. For those in the initial stages, it might simply take the form of a monthly meeting to check in with staff delivering CPC services across hospital and community providers locally, and perhaps provide space to talk to an expert<sup>63</sup>. These engagements can serve educational purposes, but also begin to form a community of other providers facing similar challenges and asking similar questions, as well as opportunities to connect with experts and feel like they have the support and security of a specialist they can call in case of emergency. Other systems are working towards much more formalised ‘managed clinical networks’ in which different providers relinquish some sovereignty in order to offer a more shared or integrated set of services together, to deliver a shared set of objectives, often explicitly geared towards a more patient-centric, rather than organisation-centric mindset<sup>64</sup>.

### **Partnerships with community assets**

A central function of any CPC provider should be as a catalyst to help communities care for one another. As a sector of health so deeply concerned with the holistic health and wellbeing of the child and family, CPC providers have the unique responsibility to work with other resources to improve families’ overall quality of life. CPC providers should seek to empower local institutions, businesses and neighbours to take care of each other – strengthening families’ existing networks and connections.

Many CPC providers excel at this so-called ‘assets-based’ approach already, in that institutions and individuals in the community are all viewed as potential partners and contributors to the organisation’s mission. CPC providers might commonly have partnerships with a range of local businesses and organisations to support families’ (as well as their staff’s) psychosocial needs – negotiating free or discounted services for their families with entertainment providers, food distribution networks, funeral directors and many others.

Deploying volunteers or workers from the community is another area where many CPC providers excel. These individuals are not only cost and resource-effective, but also can build trust among children and families in CPC services – especially as many volunteers will have had their own experiences with palliative care. Volunteers can be especially powerful as a means of improving access for populations who do not currently engage with CPC services, perhaps because they feel they are not a good cultural fit. The use of community health volunteers and workers from these groups can be an immense asset in bridging these divides and helping to make the right adaptations to how services are designed.

Many CPC providers excel at this so-called ‘assets-based’ approach

Deploying volunteers or workers from the community is another area where many CPC providers excel. These individuals are not only cost and resource-effective, but also can build trust among children and families in CPC services

A well-organised volunteer programme can provide all kinds of vital help and support to children in need of CPC and their families, for relatively little resources on the part of the provider to coordinate this. Services include basic CPC medical care such as stretching or wound care; using retired teachers to help with tutoring of siblings while the parents focus on the sick child; cooking or gardening in the family's home – or even using local chefs to cook for families staying in a hospice<sup>65</sup>.

The ultimate vision is to build up a broad network across the community of people with the skills and support to care. This is best exemplified in the 'compassionate communities' concept which was first developed in India but now being adapted by palliative care providers around the world.

### **Box 26: Compassionate Communities Model, Pallium India**

The Compassionate Communities, originating in Kerala, is a widely recognised and replicated CPC community care model globally, and has been adapted across low-, middle- and high-income contexts. In the city of Trivandrum, the organisation Pallium India provides inpatient and outpatient care, home care, and a host of other psychosocial support services, as well as education and training for other healthcare providers. It also advances favourable policies by working with government, institutions and individuals to catalyse growth of palliative care access anywhere in the country. They cite community engagement, using the compassionate communities model, as an integral part of their success. The role of the community in this model is as follows:

- Identifying children and families that may benefit from CPC, having more trusting relationships with these families and being able to refer them
- Assisting psychosocial assessment of children and families' needs, and providing psychosocial care
- Supporting children and families in their community financially or providing food or other resources
- Acting as a link between the palliative care institution and the child and family
- Providing support to the siblings of sick children, especially emotional and education support and ensuring that siblings continue attending school
- Organising annual events and gatherings for families

At Pallium India, these services are provided at link centres throughout the catchment area, which form a vital connection between Pallium India and the communities. These centres are manned by volunteer groups from within the communities, who are passionate about providing access to palliative care and have completed the Pallium India training program. Link centres also provide formal avenues for communities to support socio-economic needs of families by engaging and mobilising local self-government and other agencies to provide last mile solutions to these families. Link centres usually are stationed at a primary school, a library or a community centre, where providers can conduct outpatient care in the area.

## Partnerships with industry

An avenue that is much less well exploited by CPC providers is partnerships with relevant industrial organisations – not for donations but to access their skills and services at no or low cost. Few CPC providers have partnerships with large corporations to try and apply the community assets-based approach at a national or even international level. This is principally because of a mismatch in scale – getting the attention of a multinational corporation is very difficult as a small local CPC provider. Yet many of these organisations are increasingly keen to give their own staff the opportunity to undertake meaningful and impactful projects as a means of increasing their own workforce retention. One solution would be for larger networks of CPC providers to make the approach.

There are a wide range of industrial partnerships that could strengthen CPC providers' services in this way, for example:

- Video game designers and app developers to create bespoke software
- Management consultancies to support the growth of new business models
- Medical device companies to create bespoke, more child-friendly product runs
- Marketing and public affairs agencies, to design more impactful campaigns and influencing strategies
- Patient data companies to create new systems for tracking child and family experience of CPC services

Few CPC providers have partnerships with large corporations to try and apply the community assets-based approach at a national or even international level.

# Leadership

Excellence and innovation are not just applied to local care delivery, but advocacy, research, and education. The provider plays a leading role in developing the CPC sector at a regional, national and international level.

## Summary

As a sector that is still maturing, and still to be securely accepted as an essential service, providers of CPC have a particular responsibility for system leadership. This means that, alongside their many other responsibilities, the best providers fulfil functions that ordinarily would be performed by other organisations: advocacy for the field of CPC, education of the wider health workforce, and research to gather evidence and improve standards.

For many healthcare providers, externally facing activities are considered a value-adding nicety which enhances their reputation along with other side benefits, but are by no means ‘core’. CPC providers, however, belong to a sector which is still nascent in many ways – being far from universally accepted as an essential health service, with few umbrella organisations who will fight the case for sufficient funding, training and research if they do not. For CPC providers, therefore, these externally-facing activities are a necessity if the sector as a whole is to continue growing in size, stature and sustainability.

World class CPC providers must, therefore, be system leaders at a regional, national and international level, and seek to make a contribution across three particular areas: advocacy, education and research. These should be given the requisite coordination, strategy, resources and responsibilities within the organisation to ensure these functions are taken seriously. Though, of course, providers may wish to specialise and not do all three equally.

With so many other pressures, it is easy for these family’s voices to be lost or ignored, yet sometimes fighting an individual’s case can be catalytic in creating a precedent that benefits all children.

## Advocacy

Advocacy on behalf of their own organisation is a common function of many CPC providers, mostly out of necessity. However, the status of the sector as a whole and the children and families who stand to benefit are often equally precarious. Thus, there are two less common forms of advocacy that are just as worthwhile giving attention and investment to. First is advocacy on behalf of children with LLCs and LTCs, to ensure their rights are taken seriously, and they receive at least what they are entitled to from the state. This is very often not the case, and requires political and sometimes even legal intervention to change.

Anna Garchakova, Director of the Belarusian Children’s Hospice, sees the advocacy that her organisation undertakes on behalf of individuals as among its most important functions. This includes ensuring that their family receive the financial benefits they deserve, that schools live up to the educational rights of the child, that wheelchairs and other assistive devices are properly supplied, as well as their access to medicines and care. With so many other pressures, it is easy for these family’s voices to be lost or ignored, yet sometimes fighting an individual’s case can be catalytic in creating a precedent that benefits all children.

Second is advocating on behalf of the sector as a whole. The pre-requisites of success here are, according to Zodwa Sithole, Head of Advocacy for the Cancer Association of South Africa, high quality evidence on need and impact; engagement and active support of the affected communities; and champions both inside and outside the CPC sector. In her experience, a top-down and bottom-up strategy works best, coordinating action between grassroots organisations and senior policy makers at the same time.

### **Box 27: ICPCN providing leadership in advocacy with the World Health Organization**

The International Children's Palliative Care Network (ICPCN) is the global umbrella organisation for children's palliative care working to improve access to palliative care for the 21 million children worldwide who need it. ICPCN's vision is that all children living with a life-limiting or life-threatening condition and their families, will have seamless access to palliative care in order to alleviate serious-health-related suffering and enhance their quality of life. ICPCN is recognised globally as the leader for CPC and has a globally renowned expert leadership, a wealth of educational resources and a network of members in over 130 countries. Through this network ICPCN are uniquely placed to advise, educate and support at a national, regional and international level and to strategically advocate for children's palliative care globally. ICPCN is recognised as the leader for CPC by the World Health Organization, and has a Memorandum of Understanding to work with the WHO with regards to CPC globally. This provides a great opportunity for ICPCN to advocate for CPC and has involved working on strategic projects such as:

- The Global Initiative for Childhood Cancer (GICC);
- The development and dissemination of resources linked to the recently published guidelines for managing pain in children;
- The development of other guidelines, such as those regarding access to medicines;
- The development of the guide for health care implementers and managers on integrating palliative care and symptom relief into paediatrics and the ongoing development of e-learning resources to support this handbook;
- The development of global indicators for measuring palliative care development;
- Speaking platforms at a variety of WHO led events on palliative care, including round-table discussions with the Director General; and
- A wide range of other activities ensuring that the voice of CPC is heard.

## Education and training

As a young and often neglected specialty, CPC providers often take the lead in educating and training clinicians across the health system in CPC, especially in the provision of basic CPC training to providers that will deliver this care to the vast majority of children with CPC needs. The best programmes are investing across a wide spectrum of workers not limited to doctors and nurses, but also social workers, counsellors, and psychosocial support staff. As a field with growing demand and highly limited supply, education and training of external staff is an essential approach in fulfilling a CPC provider's vision.

Historically, the major constraint on this training activity was that it has been predominantly conducted in-person, requiring multi-day conferences and travel costs as well as administrative expenses. COVID-19 has already spurred much innovation in this field, with many CPC organisations significantly expanding online modes of training which, although not appropriate for every situation, are more scalable and carry much lower costs. Providers interviewed for this study felt strongly that virtual learning methods will become increasingly default in future, but also increasingly professional as the lessons from the pandemic about what works filter into common practice – ideally building out more engaging systems of live and on-demand training, compared to what were often rapidly 'pivoted' courses as a result of COVID-19. One less-explored route is to leverage the increased use of telemedicine in CPC to give student doctors and nurses better access to these interactions – allowing them to be in the (virtual) room as well or watch a particularly instructive consultation afterwards.

### Box 28: In-Country Collaboration for Online Peer Education (Proyecto ECHO, Uruguay)

As the first CPC program established in the country of Uruguay, the Paediatric Palliative Care Unit at the Pereira Rossell Hospital Center has played the role of an educator for subsequent CPC programmes. Because of this, they have relationships with every other CPC team in the country, and all new teams were effectively students of the programme. Solidifying these connections, every second Thursday of the month starting from 2016, all CPC programmes in Uruguay meet over Zoom for 1.5 hours. One CPC team presents a clinical case of a child they are caring for, and during the remaining time, the entire community comes together to discuss the case and exchange ideas. Afterwards, a summary of recommendations is sent to the presenting team.

Source: Interview with Mercedes Bernadá

Of course, in-person training can take many different forms as well. One of the most powerful models is rotating secondments of the CPC provider's staff into other healthcare settings, and their staff vice versa. This builds mutual understanding of the wider health system that improves care integration, as well as giving a first hand, indelible experience on the part of external staff on the importance of the CPC provider's work.

One of the most powerful models is rotating secondments of the CPC provider's staff into other healthcare settings, and their staff vice versa.

### Research and data-led insights

Lack of funding is one reason why CPC is seriously under-researched in comparison to other healthcare sectors. Providers frequently do not have the capacity to collect data systematically for their own internal use, let alone for research purposes or sharing. Future CPC programmes must be sufficiently capable to consider research a core responsibility on their part, not only for their own programme's purposes but for the promotion of the sector more broadly.

The dearth of high-quality research in CPC has two primary effects: first, it hinders the ability of providers to advocate for the importance of CPC, as they don't have the evidence base on the effectiveness or coverage of their services. Secondly, it constrains the CPC provider's ability to monitor their own service and make informed adjustments and improvements.

Organisational capacity is also a major constraint to CPC providers getting more involved in research, but if scaled to a sufficient size and with the right academic partners, many healthcare providers in other fields find that research funding can be a significant source of revenue, through grants. CPC providers embedded in tertiary hospitals likely have a head start, but there is no reason that a standalone provider cannot position itself as an academic health science centre in CPC as well, one example being the Martin House Research Centre in the UK, which is a collaboration of two universities and a children's hospice.

but if scaled to a sufficient size and with the right academic partners, many healthcare providers in other fields find that research funding can be a significant source of revenue

Many CPC programs, often without realising it, are sitting on treasure troves of qualitative information that could be harnessed to power research efforts and attract academic partners. While in many cases this data is not collected or organised in any systematic or easily shareable way, efforts to extract and clean this data from CPC programs serving a wide array of patients could generate a much-needed body of evidence for the sector. Furthermore, such studies could be used as a means of setting up ongoing, quantitative systems of real-time monitoring of outcomes, experience and service performance.

Future best practice for CPC providers in this area may include sharing their data with other organisations including governmental bodies (though CPC patient data can be difficult to anonymise due to rare conditions and other characteristics), and publishing their organisation's performance, best practices and lessons learned. A few CPC providers are now beginning to employ dedicated staff for the collection and management of their data (See Box 11), and the ideal would be to secure funding which can free up meaningful time of staff to conduct research. Even if the organisation itself lacks the capacity for data analysis or further research efforts, simply submitting this information to a national database or otherwise sharing it with researchers will go a long way to bettering the overall sector.

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## Sectoral Recommendations

Specific recommendations for CPC providers are not given in this report – largely because the blueprint itself is offered as a tool for their consideration and response. The insights it contains were largely gathered through listening to providers talk about their current best practice and hopes for the future, with the key themes brought together into this report. Far from being a 'recommendation' of what they should do next, providers are instead invited to consider this blueprint against their own visions for the future, and take what ideas and inspiration it offers.

At a cross-sector level, however, a number of specific recommendations stand out from this blueprint where which actions by other key players are needed to support this shift this blueprint outlines:

### **For global health institutions**

There is a need for an accessible, engaging and popular global platform on which CPC providers can share their innovations, collaborate on projects of common interest, and support scale up.

As this report shows, the CPC sector is rich in innovations but these are often not being widely or systematically shared. There are many examples in the wider global health sector of platforms designed to do this<sup>66,67,68,69,70</sup>, and a dedicated community where CPC providers could exhibit leading practice, share lessons and collaborate on innovation projects that would benefit from multiple providers working together would help to accelerate the pace, scale and uptake of some of ideas and opportunities described in this report.

## **For technology and digital partners:**

Explore partnerships with CPC providers as a means of applying technical knowledge and skills towards social good.

There is tremendous potential for technology developers of all kinds and all sizes to transform the lives of children with LLCs and LTCs and their families. While the CPC market is unlikely to ever be a major innovation draw from a commercial standpoint, the social good that can be created is a valuable asset for firms looking to motivate their workforce and contribute to society. To date, CPC technology partnerships have largely been between small scale technology developers and one or just a few CPC providers. Larger scale partnerships, with better-resourced technology partners and consortia of providers should be explored as a means of accelerating the potential of technology in CPC.

## **For donors**

Recognise the untapped potential for scalable innovations in CPC, and seek to catalyse their invention and adoption through product development partnership grants and challenge funds.

The donor funding landscape for CPC has been inconsistent, with significant peaks and troughs in national and international funding over the years. This variation has been unhelpful, as many promising initiatives have had to be closed or curtailed as financing runs out or is not renewed. CPC needs donors to come forward with more sustained commitments to the sector, and also to innovate themselves by proposing additional, more catalytic funding models that can attract further donor and non-donor funding (e.g. challenge funds with governments), develop solutions that will be more rapidly scalable (e.g. product development partnerships), and encourage the CPC sector to build up an evidence base of impact that will support future advocacy (as opposed to measuring what matters to the donor).

## **For payers**

Include CPC services as an essential dimension within national benefit packages and universal coverage, and look to where CPC providers can be funded or contracted to expand and improve their services.

No country can claim to have achieved universal health coverage if children in need of palliative care are not able to receive it. Healthcare payers – be that governments or insurers – need to have the full scope of CPC services included in their entitlements for citizens and beneficiaries. The gaps in CPC provision globally demonstrate that this is not currently the case, and that to expand capacity a more ‘activist’ approach is often needed in which payers proactively grow this market through grants and other financial and non-financial support measures.

## **For researchers**

Increase the quantity and diversity of cross-sector, inter-disciplinary and multi-stakeholder cooperation around CPC innovation and improvement.

As noted throughout this report, there is an urgent need for more direct funds to support improvement and research in children’s palliative care. In addition to this – and perhaps as an interim solution – is the need for broader and more systematic involvement of researchers from sectors and disciplines not currently engaged in CPC innovation and improvement research, whether health, education, technology, social science, data science, organisational research or other fields. CPC providers and service delivery represent a rich and under-exploited field for these researchers from other sectors to contribute their expertise, as well as their own particular funding streams, to focus on. More systematic means are needed to encourage these kinds of cross-sector research collaborations between and within countries

# Research Methods

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To develop this report, the research team followed a three-phase approach that aimed to collect a broad range of ideas and examples around current and future innovation in children's palliative care, and then refine these into a discrete number of themes and trends – an analytical framework that formed the basis of the blueprint.

The first phase involved a broad but targeted literature of key written resources focused around three key areas: the current state of and global unmet need for children's palliative care globally; current best practice and trends among children's palliative care providers to address these needs; and reports on the wider future of healthcare service delivery and health innovation globally that might have relevance to the CPC sector. Using this initial literature search, the key domains to explore during semi-structured interviews were developed, including: recent changes to CPC care delivery over the last decade, the impact of the COVID-19 pandemic, shifts in access, quality and service scope, technology, physical infrastructure, person-centred care, care settings, staff training and deployment, financing, organisational management practices, and others.

The second phase involved semi-structured interviews over video-conferencing software with 50 individuals selected primarily on the basis of being CPC service leaders with a broad global distribution, working in services or organisations that were regarded as in some way innovative. These individuals were identified through a purposive sampling strategy using recommendations by global sector leaders and subject matter experts, as well as the research team's own networks. Additional interviews were carried out to focus on particular issues in need of further expertise from outside of CPC provider organisations, such as technology developers and service design and innovation experts. Interviews were recorded and coded thematically against the key domains identified during the literature review, with some adaptation of the topic guide as the interviews progressed.

The third phase involved thematic analysis of the interviews to find common themes and key messages underneath the key domains explored in the interview, and triangulating this with findings from the literature review. Through a retroductive approach, the research team refined this thematic data into a framework of the most promising areas for innovation in the CPC sector. This framework was subjected to internal discussion and review by the research team, and then populated with the detailed insights from the literature and interviews. The drafted report was then sent to selected global subject matter experts for peer review, in addition to all organisations featured in case studies to validate the information contained within them.

The topic of innovation in children's palliative care is not well researched, and nor are most CPC provider organisations resourced in such a way as to have conducted their own systematic research on the topic. As a result, the blueprint contained in this report is new and there is relatively little wider literature to compare it against. It is thus presented in this report as a tool to aide discussion and reflection among CPC providers and other health system actors, rather than a definitive prescription for the future. Further work to test it with providers and other CPC experts would help to further refine it – a process which is actively planned following its publication.

# Interviewees and Contributors

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The authors extend their sincere thanks to the following individuals who were interviewed for this study, whose passion and expertise made an essential contribution to its findings. Particular thanks go to Julia Downing, Chief Executive, ICPCN for her advice, support and challenge throughout the project.

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